5-2018

Culture Care Needs of Puerto Rican Women Receiving HIV Care from Nurse Practitioners in New York City

Michele Crespo-Fierro

The Graduate Center, City University of New York

How does access to this work benefit you? Let us know!

Follow this and additional works at: https://academicworks.cuny.edu/gc_etds

Part of the Latina/o Studies Commons, Medical Humanities Commons, Other Nursing Commons, Public Health and Community Nursing Commons, and the Women's Health Commons

Recommended Citation

Crespo-Fierro, Michele, "Culture Care Needs of Puerto Rican Women Receiving HIV Care from Nurse Practitioners in New York City" (2018). CUNY Academic Works.
https://academicworks.cuny.edu/gc_etds/2596

This Dissertation is brought to you by CUNY Academic Works. It has been accepted for inclusion in All Dissertations, Theses, and Capstone Projects by an authorized administrator of CUNY Academic Works. For more information, please contact deposit@gc.cuny.edu.
Culture Care Needs of Puerto Rican Women Receiving HIV Care
from Nurse Practitioners in New York City

by

Michele Crespo-Fierro

A dissertation submitted to the Graduate Faculty in Nursing
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy, the City University of New York

2018
Culture Care Needs of Puerto Rican Women Receiving HIV Care from Nurse Practitioners in New York City

By

Michele Crespo-Fierro

This manuscript has been read and accepted for the Graduate Faculty in Nursing to satisfy the dissertation requirement for the degree of Doctor of Philosophy.

Marianne Jeffreys
Committee Chair

Donna M. Nickitas
Executive Officer

Supervisory Committee:
Marianne Jeffreys
Carol Roye
Marilyn Aguirre-Molina
Hiba Wehbe-Alamah
Keville Frederickson

THE CITY UNIVERSITY OF NEW YORK
The purpose of this mini-ethnonursing research study was to discover, describe, and interpret culture care values, beliefs, expressions, practices and needs of Puerto Rican women receiving HIV care from nurse practitioners (NPs) and other providers in New York City. The emic, or insider, perspective of Puerto Rican women living with HIV was the focus of this study and Leininger’s Culture Care Theory (CCT) provided the theoretical framework. Various enablers of the CCT, including Leininger’s Sunrise Enabler to Discover Culture Care, guided the design and implementation of the study. Six key and twelve general informants were interviewed and data from the interviews were coded using the QSR NVIVO10 software. Categories of data discovered through analysis included Puerto Rican female identity; self-care; caring for others; family and familismo; culture; personalismo and professional care; and, living with HIV. Other important data focused on experiences of various forms of discrimination; substance use; and, intimate partner violence. Sixteen patterns; and, five universal and one diverse theme emerged through analysis. Culture care decision and action modes were identified to assist providers to preserve and/or maintain, accommodate and/or negotiate, and repattern and/or restructure culture care practices, patterns, and experiences of Puerto Rican women receiving HIV care. Current HIV care practice emphasizes engaging patients in the HIV continuum of care and the culture care decision and action modes can enhance desired engagement. Implications for theory, research, practice, education, healthcare administration and healthcare policy were made based on the findings and analysis. These recommendations can improve delivery of care for diverse communities living with HIV.
Dedication

This dissertation study is dedicated to the participants who so freely shared their personal stories with me. Their determination to care for others by disclosing their life stories and serving as role models for self-care is an inspiration. They represent the experiences of many Puerto Rican women living in Puerto Rico, New York City and throughout the US Mainland. It is my hope and theirs to effect change and improve care for all Latinas at risk for and living with HIV. To these women and the other strong Puerto Rican women in my personal and professional lives, I remain forever indebted.

This dissertation study is also dedicated to my husband, Anthony Fierro, and our children Regina Luz Fierro and Luca Antonio Fierro. You are my inspiration and motivation in all that I do. You have sacrificed so much for our achievement in these pages. None of this would have been possible without your commitment and forgiveness. Being your life partner and mother is an honor.

Lastly, I dedicate this work to my mother, Carmen Luz Navarro Crespo, who taught me by word and example that I could do anything.
Acknowledgements

I wish to acknowledge the following for their support during my doctoral studies:

- The faculty and staff of the Nursing Department of the Graduate Center, CUNY, especially Keville Frederickson, EdD, RN, FAAN & Donna Nickitas, PhD, RN, FAAN, for championing doctoral study in nursing research at a public university in NYC.
- The Dissertation Cohort 4, for company and cheerleading on Fridays and beyond.
- The dissertation chair, Marianne Jeffreys, EdD, RN, for walking this journey with me.
- The ethnonursing research method mentor, Hiba Wehbe-Alamah, PhD, RN, FNP-BC, CTN-A for keeping this study true to the vision of Madeleine Leininger, PhD, RN, CTN-A, FAAN.
- The dissertation committee members, Carol Roye, EdD, RN, Keville Frederickson, EdD, RN, FAAN & Marilyn Aguirre-Molina, EdD for your important insights on this study.
- The faculty, administration, and staff of New York University Rory Meyers College of Nursing, especially my mentors: Emerson E. Ea, PhD, DNP, RN; Madeline Nagle, PhD, RN, FAAN; James Pace, PhD, RN, FAAN; Allison Squires, PhD, RN, FAAN & Michele Shedlin, PhD.
- ANAC colleagues & mentors, especially Peter Ungvarski, RN, MS, FAAN; F. Patrick Robinson, PhD, RN, FAAN; J. Craig Phillips, PhD, RN, FAAN; Suzanne Willard, PhD, RN, FAAN; Inge Corless, PhD, RN, FAAN; Anne Hughes, PhD, RN, FAAN; Ann E. Kurth, PhD, CNM, FAAN; & Lucy Bradley-Springer, PhD, RN, FAAN.
- Research Partners: Marya Gwadz, PhD, Sherry Deren, PhD; Noelle Leonard, PhD & Holly Hagan, PhD, RN & the Center for Drug Use and HIV & Hep-C Research (CDUHR) & The ACT-2 Study Group.
- My family and friends for keeping me grounded.
- External Financial Support:
  - STTI, Upsilon Chapter Research Grant, 2014
  - Centro por Estudios Puertorriqueños, Summer Doctoral Student Fellowship, 2012
  - Graduate Center, CUNY Doctoral Student Grant, 2012
  - National Hispanic Health Student Scholarship, 2011
  - New York University College of Nursing, Dean’s Award, 2010
# Table of Contents

List of Tables                                      xvii
List of Appendices                                  xviii

I. Introduction                                     1
   A. Background of the Study                      1
   B. Latinos and HIV Disease in the US            1
   C. Puerto Ricans and HIV Disease                1
   D. Puerto Rican Women and HIV Disease           2
   E. Purpose and Goal of the Study                3
   F. Domain of Inquiry and Method                 4
   G. Rationale                                     6
       1. Demographic                               6
       2. Treatment cascade/HIV care continuum      8
       3. Culturally congruent care                 8
       5. Healthy People 2020 and the Office of Minority Health objectives 11
       6. Sustainable Development Goals             13
   H. Culture Care Theory (CCT) and the Ethnonursing Research Method 14
   I. Research Questions                           15
   J. Orientational Definitions                    16
   K. Assumptions                                   19
   L. Significance to Nursing and other Health Care Professions 19
   M. Limitations and Facilitators                  20
N. Organization of the Study 21

II. Review of the Literature 23
   A. Chapter Introduction 23
   B. Leininger’s Sunrise Enabler to Discover Culture Care 23
   C. Ethnohistory of the island of Puerto Rico 24
      1. Taíno Indians 24
      2. From Spanish conquest to the Spanish American War 26
   D. Political and legal factors 29
      1. American occupation 29
      2. Current political status of Puerto Rico 30
   E. Economic Factors 32
      1. Operation Bootstrap and the Commonwealth 32
      2. “The Puerto Rican Problem” 36
      3. The Diaspora continues 38
   F. Spiritual and religious factors 39
      1. Christianity 39
      2. Santería 41
      3. Espiritismo 42
   G. Cultural Values, Beliefs, Kinship and Lifeways 44
      1. Marianismo & Machismo 44
      2. Familismo 45
      3. Personalismo/Respeto 47
      4. Curanderos/Espiritistas 47
H. Kinship and Social Factors Influence by the Post-Colonial Experience 49
   1. Puerto Rican identity and citizenship 49
   2. Puerto Rican identity on the mainland 50
   3. Roles responsibilities and reproductive health choices 51
   4. Female-headed households 53
   5. Substance use 55
I. Language 56
J. Biological Factors 58
K. Educational Factors 59
L. Technological Factors 61
M. Environmental Context 62
   1. Health care in Puerto Rico and New York 62
   2. Substance use treatment in Puerto Rico and New York 64
   3. Pharmaceutical industry in Puerto Rico. 66
N. Summary of Cultural and Social Structural Dimensions of Puerto Ricans 66
O. HIV Epidemic in the Puerto Rican Community 68
   1. The air bridge 68
   2. Disparities in HIV for Hispanics/Latinos 70
   3. Latino Commission on AIDS and other CBOs 74
P. HIV Treatment Cascade and the Continuum of Care 75
Q. Current State of the Art in HIV Care in Puerto Rico and the Mainland 78
R. Important concepts regarding health research in Latinos 80
   1. Identity: Hispanic vs. Latino 80
2. Consolidating data 81
3. Acculturation 82
4. Trust 85

S. Summary of concepts regarding health research in Latinos 88

T. Select Studies on HIV focused on Puerto Ricans and Latinas 88
1. Risk and prevention 88
2. Acculturation as risk and prevention 95
3. Living with HIV and medication adherence 99
   a. Stress and coping 99
   b. Symptoms and quality of life 100
   c. Adherence 102
   d. Changing relationships 103
4. Familial care 105

U. Summary of HIV-related Studies on Latinos and Puerto Ricans 107

V. Ethnonursing and Ethnography Studies using the CCT with Puerto Rican Communities 107

W. Ethnonursing and Ethnographic Studies using the CCT with HIV Care 112

X. Chapter Summary 115

III. Methodology 116

A. Chapter Introduction 116
B. Ethnonursing Research Method 116
C. Ethnonursing Research Process 118
   1. Ethnonursing research mentor 119
D. Research Site, Setting and Access to Informants 120

E. Human Subjects and Ethical Considerations 123

F. Enablers 124

1. Leininger’s Stranger-to-Trusted-Friend Enabler 124

2. Leininger’s Observation-Participation-Reflexion Enabler 126

3. Leininger’s Semi-Structured Inquiry Guide Enabler to Assess Culture Care and Health 128

4. The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler 128

G. Selection of Key and General Informants 129

H. Data Collection Plan 131

I. Leininger’s Phases of Ethnonursing Data Analysis Enabler for Qualitative Data 134

J. Evaluation Criteria for Ethnonursing Research Findings 135

K. Chapter Summary 137

IV. Results and Presentation of Findings 139

A. Chapter Introduction 139

B. Study Organization 139

C. Study Participants/Informants 140

1. General comparison of key and general informants 146

D. Presentation of Categories 147

E. Presentation of Findings 148

1. Worldview 148

2. Environmental context 150
a. New York City 150
b. Neighborhoods and housing 151

3. Ethnohistory 153
   a. Air bridge 153

4. Language 155

5. Biological factors 156

6. Technology factors 156

7. Religious, spiritual and philosophical factors 157

6. Kinship and social factors 160
   a. Parents 161
   b. Siblings 164
   c. Spouses/Partners 166
   d. Children 169

7. Cultural values beliefs and lifeways 171
   a. Familismo 172
   b. Personalismo 174
   c. Machismo, marianismo and intimate partner violence 175
   d. Food 179
   e. Celebrations 180
   f. Music and dancing 181

8. Political and legal factors 183

9. Economic factors 185

10. Educational factors 188
F. Folk Care Maintenance and Illness Prevention 189
   1. General health practices 189
   2. Herbs, teas and other home remedies 190
G. Comparison of Health Care Systems of Puerto Rico and the United States 191
H. Care Beliefs, Expressions, Patterns and Practices 193
   1. Caring behaviors 195
   2. Protection 197
   3. Caring during illness 199
   4. Folk beliefs on death and dying 200
   5. Care for the dying 201
   6. Caring for the dead and those in mourning 204
I. Diagnosis with HIV 204
J. Folk Beliefs of HIV and Expectations of Care 205
   1. Stigma 208
   2. Confidentiality and privacy 209
   3. Communication 210
K. Barriers to HIV Care 211
   1. Language 211
   2. Delays in care 212
L. Caring Attributes and Actions related to HIV 213
M. Non-caring Attributes and Actions related to HIV 214
N. Professional Caring Attributes and Actions 215
O. Professional Non-caring Attributes and Actions 221
P. Living with HIV through Caring 224

1. Self-care 226
2. Nutrition 226
3. Personal care 227
4. Safer sex practices 228
5. Disclosure as self-care and protection 230
6. Care from others and care for others 231

Q. Patterns and Themes 233

R. Chapter Summary 234

V. Discussion 235

A. Introduction 235

B. Summary Review and Key Findings of the Study 235

C. Universal Theme I: For Puerto Rican Women Living with HIV, The Diagnosis is Life Changing and Empowering 239

D. Universal Theme II: Puerto Rican Women Living with HIV Experience a Myriad Range of Emotions 243

E. Universal Theme III: Puerto Rican Women Living with HIV Experience and Desire Care and Caring Practices Towards Self and Others 254

F. Universal Theme IV: Caring expressions and Practices of Puerto Rican Women Living with HIV are Deeply Influenced by Kinship, Social, and Cultural Factors 259

G. Universal Theme V: Spiritual and Religious Factors Play a Significant Role in the Care of Puerto Rican Women Living with HIV 265
H. Diverse Theme I: Puerto Rican Living with HIV Reported Difference and Similarities in Professional Care in New York City and Puerto Rico

I. Cultural Care Decision and Action Modes

1. Cultural care preservation and/or maintenance
2. Cultural care accommodation and/or negotiation
3. Cultural care repatterning and/or restructuring

J. HIV Continuum of Care

K. Theoretical Formulations

L. Implications

1. Theory
2. Research
3. Practice
4. Education
   1. Higher education (academic setting)
   2. Professional education
   3. Continuing professional education

5. Administration
6. Policy

K. Limitations of the Study

1. Study design
2. Study participants
3. Researcher

L. Strengths of the Study
1. Study design
2. Study population
3. Researcher
4. HIV Care and the CCT

M. Reflections on this Study
N. Conclusions

VI. Appendices
VII. References
List of Tables

Table 4.1 Select Demographic Characteristics of Key Informants 141
Table 4.2 Select Demographic Characteristics of General Informants 142
Table 4.3 Select Study and HIV Care Indicators for all Informants 143
Table 4.4 Culture Care Themes and Patterns for Puerto Rican Women Living with HIV in NYC 233
Table 5.1 Universal and Diverse Themes and Patterns for Puerto Rican Women Living with HIV in NYC 238
Table 5.2 Examples of fears of Puerto Rican women living with HIV 243
Table 5.3 Culture Care Decision and Action Modes for Use in the HIV Continuum of Care 292
List of Appendices

Appendix A  Table 1: Conceptualization of the Ethnonursing Research Plan  332
Appendix B  Table 2: Node Names (as coded in NVIVO10) and Corresponding
Culture Care Theory Category, Domain and Code Number (using The
Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler)
Appendix C  Figure 1: Leininger’s Sunrise Enabler to Discover Culture Care  339
Appendix D  Figure 2: Map of Puerto Rico  340
Appendix E  Figure 3: Map of Sea and Air Route from San Juan, PR to New York City 341
Appendix F  Figure 4: Visual representation of the “Three Races, One Culture” of
Puerto Rico
Appendix G  Figure 5: Leininger’s Phases of Ethnonursing Research Process  343
Appendix H  Figure 6: Leininger’s Stranger-to-Trusted-Friend Enabler  344
Appendix I  Figure 7: Leininger’s Observation-Participation-Reflection Enabler  345
Appendix J  Figure 8: Leininger’s Phases of Ethnonursing Data Analysis for Enabler
for Qualitative Data
Appendix K  Study Consent Form in English  347
Appendix L  Study Consent Form in Spanish  350
Appendix M  Study Consent Short Form in English  353
Appendix N  Study Consent Short Form in Spanish  356
Appendix O  Study Semi-Structured Inquiry Guide in English  359
Appendix P  Study Semi-Structured Inquiry Guide in Spanish  363
Appendix Q  Reprint Permissions  367
Chapter I

Introduction

Background of the study

Latinos and HIV Disease in the US

The HIV epidemic disproportionately affects Latinos living in the US and its territories, with 20% of people living with HIV (1.2 million) being of Latino descent and 21% of new infections in 2013 occurring among Latinos (Gray, Valverde, Tang, Siddiqi & Hall, 2015); however, Latinos only comprise 17% of the US population. At the end of 2012, the prevalence rate of HIV in the Latino population was 458.8 cases per 100,000 people (Gray, et al, 2015). Latinas at risk for HIV disease are more likely to be economically disadvantaged, or culturally stigmatized by behavioral practices regarding sexuality or drug use (Collins, von Unger & Armbrister, 2008; Chase, 2011; Zambrana, Cornelius, Boykin & López, 2004). These factors in combination with immigration/migration status issues can present significant barriers to engaging in healthcare, contributing to disparities in health and healthcare of Latinos. For Latinos with HIV, the added components of culture and language have been found to complicate access to healthcare services (Chase, 2011; Zambrana, et al, 2004), resulting in Latinos experiencing health and healthcare disparities in HIV disease, demonstrated as delayed entry into care and twice the death rate of Whites (Office of National AIDS Policy (ONAP), 2015, July).

Puerto Ricans and HIV Disease

Within the Latino community, the Puerto Rican community has been particularly hard hit by the HIV epidemic. New York ranked first, and Puerto Rico ranked twelfth out of 56 US states and territories for the number of people living with AIDS through December 2013 (Center for Disease Control & Prevention (CDC), December 2015). It should be noted that Puerto Rico
continues to experience an outflow of residents to the mainland US, which has recently been exacerbated in the wake of Hurricane Maria in 2017. Puerto Ricans both on the US mainland and the island of Puerto Rico consistently had a significantly higher rate of HIV infection than other Latino groups (Selik, Castro, Pappaioanou & Buehler, 1989) and this trend continues (CDC, 2012, October). When the AIDS epidemic began in the late 1970s, most cases were situated in large cities, like New York, where initial cases were among injecting drug users and men who have sex with men. Injecting drug use is the predominant documented risk factor for more Puerto Ricans than other Latino groups. While men having sex with men without barrier protection, exclusively or in addition to maintaining heterosexual relationships, is a significant risk factor for all populations, this has not mitigated the effect of injecting drug use for Puerto Ricans. Puerto Rican women, who have HIV, were more likely to be at risk due to either their own injecting drug use or that of their partner (Barron, 1992; CDC, 2012, October). A continuing issue in the analysis of HIV/AIDS statistics is the failure to identify Latinos born in the United States by their country(ies) of origin. Besides creating a distortion of the statistics in these communities, it also fails to fully appreciate the effects of acculturation on HIV risk for these Latino communities (Deren, Gelpi-Acosta, Albizu-García, González, Des Jarlais & Santiago-Negrón, 2014).

**Puerto Rican Women and HIV Disease**

Much of the literature on Puerto Rican women with HIV, as with other Latinas, has focused on explorations of their risk factors and the cultural rationales behind them, as well as, the development of culturally congruent HIV risk prevention interventions (Díaz, Vlahov, Greenberg, Cuevas & Garfein, 2001; Zambrana, et al, 2004; González-Guarda, Vásquez, Urrutia, Villarruel & Peragallo, 2011; Loue, Sajatovic & Méndez, 2011). The literature on HIV care,
dominated by issues regarding adherence to antiretroviral medications, focuses mostly on general influencing factors which are potentially applicable to anyone: mental status, pill burden, side effects of medications, and interactions with other medications or exacerbation of other symptoms (Raper, 2010; Ridgeway, et al, 2014). For people who experience health and healthcare disparities, the emphasis is on socioeconomic issues, such as, being employed, having health insurance, and having a steady residence; or personal factors, such as, being health literate, having support systems, and being ready for behavior change. Added factors for racial and ethnic minorities are trust of the provider and, specific to culture, the use of folk and other caring practices (Acevedo, 2008). Only one exploration of the experience of Puerto Rican women living with HIV disease in the northeast US was found (Chase, 2011) but it was focused on the women’s ability to activate social capital to survive. Whereas no specific studies on client-provider trust and folk beliefs and practices for Puerto Rican women in treatment for HIV disease were revealed following an extensive review of the nursing, medical, and social science literature. In general, most studies that explicitly included Puerto Rican women, either compared them to Mexican women, the largest US resident Latina group and now the largest group of HIV infected Latinas (Gray, et al, 2015), or consolidated their data with other Latinas. This practice of pooling data of large and diverse ethnic and racial groups fails to identify the specific needs of the smaller communities and subsequently the individual person.

**Purpose and Goal of the Study**

The purpose of this ethnonursing research study was to discover, describe, and interpret the culture care values, beliefs, expressions, practices and needs of Puerto Rican women receiving HIV care from nurse practitioners (NPs) and other providers in the outpatient setting. The emphasis was on identifying and describing emic (the Puerto Rican woman living with HIV)
versus the etic (nurse practitioner/provider) perspective. The goal of this ethnonursing research study was the discovery of culture care decision and action modes that would assist NPs and other providers to preserve and/or maintain, accommodate and/or negotiate, and repattern and/or restructure culture care practices, patterns, and experiences of Puerto Rican women receiving HIV care from NPs and other providers in the outpatient setting.

Domain of Inquiry and Method

The domain of inquiry (DOI) for this study was the culture care beliefs, values, expressions, practices, and needs of Puerto Rican women receiving care for HIV disease in clinic settings. The emic, or insider, perspective of Puerto Rican women receiving care was the focus of this study, to discover the depth of understanding desired. The body of knowledge generated by researchers using the ethnonursing research method (ERM) for over fifty years regarding the phenomena of culture and care, provided empirical support for Leininger’s Culture Care Theory (CCT), (1991, 2002b & 2006a; McFarland & Wehbe-Alamah, 2015) as the guiding framework of choice. The ERM was determined to be the best fit for this study’s purpose of discovering the culturally congruent HIV care needs of Puerto Rican women in New York City and the goal of applying this discovery to practice.

According to the CCT, the care that people need, and desire is grounded in their culture. Even nursing care is grounded in culture. The ERM is focused on discovering generic (folk or lay) and professional care (nursing) practices that support people in culturally appropriate ways throughout their life journeys (Leininger, 2006b; Wehbe-Alamah & McFarland, 2015b). The ERM places importance on the culture care needs expressed by clients, themselves, rather than indirect, etic, measures or other voices (the nurse or healthcare provider). For this researcher, it is vital that this depth of understanding be achieved, and this can only occur by using the CCT and the ERM.
Nurses and NPs provide holistic care that “assists, supports, facilitates or enables maintaining or regaining wellbeing in culturally meaningful ways,” (Leininger, 1991, p. 47). The nurse-client relationship is central to the CCT, and nursing care is considered through the presentation of findings from the data collected using the ERM. In a study comparing the cultural competence perspectives of different healthcare providers in clinic settings, NPs were found to include attitudes and behaviors in their practice that enhanced the delivery of culturally congruent care (Mattelliano & Street, 2012). McFarland and Eipperle (2008) have proposed the CCT as an ideal framework for nurse practitioner practice because it can assist NPs and other providers as they “sensitively and competently integrate culture care into contextual routines, clinical ways, and approaches to primary care practice” (p. 49). Furthermore, Eipperle (2015) has provided more detailed guidance for the application of the three modes of culture care decision and action modes in the primary care setting. In HIV care, NPs are among the care providers who may prescribe medications and work directly with the client as they plan for, implement and evaluate the care plan. While the CCT and other transcultural theories have become increasingly popular with other disciplines to frame culture care practice, the theories were initially developed for use with nursing practice, focusing on the holistic perspectives that nursing embraces. Therefore, in keeping with this line of thinking, this researcher seeks first to explore culture care of Puerto Rican women receiving HIV care from NPs and then, other providers.

Empirical evidence indicates NPs are equally as effective as physicians in providing guideline-based care to people living with HIV (Wilson, et al, 2005). These findings have been further bolstered by the recommendations of the Health and Medicine Division of the National Academies of Science formerly known as the Institute of Medicine (IOM, 2011) and the Patient
Protection and Affordable Care Act (2010) encouraging the use of nurse practitioners to the “full extent of their training” to deliver culturally congruent and safe nursing and primary care. Eipperle (2015) in a review of the literature on nurse practitioner roles and functions, also emphasized their ability to engage with clients more holistically while providing care. There are other care providers (e.g. social workers, patient care navigators/care coordinators, and peer educators) in the clinic setting who may work in a supportive way with clients as they undertake medication regimens and collaborative plans of care. Yet, it is the unique twofold relationship with their patients (providing nursing and primary care), that enables NPs to build a holistic, trusting, and collaborative relationship in which clients play an active role in formulating a plan of care that fosters medication adherence and behavioral change. Therefore, the Puerto Rican women receiving professional nursing care and HIV care from the nurse, NP in this case, were of interest in this study. The complexity of the health care delivery system requires the inclusion of other healthcare providers as well. The discovery of the folk care practices and culture care needs of these women will facilitate integrative care including folk/traditional and professional care practices into patient-centered care leading to the provision of culturally congruent and collaborative care.

**Rationale**

**Demographic.** While there have been more recent census data analyses since 2010, there has not been a detailed analysis of Latino statistics performed since 2011. Therefore, the following section is based on the 2010 preliminary data and the 2011 analysis of the US Latino population. In 2010, the US population was 308,745,538; the New York State (NYS) population was 19,378,102. Data on the Hispanic/Latino population documents 50,477,594 Hispanics/Latinos in the US of which 4,623,716 or 9.2% are of Puerto Rican origin (Ennis, Ríos-
Vargas & Albert, 2011). In NYS, there are 3,416,922 Hispanic/Latino people, of which 1,070,558 or 31% are of Puerto Rican origin (Ennis, et al, 2011). The 2010 US Census (2011, December) lists Puerto Rico’s population as 3,725,789 people and 96% are of Puerto Rican origin (Ennis, et al, 2011). Collazo, Ryan and Bauman (2010) presented an analysis of the Puerto Rican island and mainland communities and found that the mainland US population has surpassed the island population. The total number of people of Puerto Rican origin residing in the US mainland in 2010 is 4,623,716, making it the second largest Hispanic/Latino population in the US after Mexicans (Ennis, et al, 2011).

As of the end of 2014, the cumulative number of all persons diagnosed with AIDS in New York State and the New York City area totaled 206,260 and 163,927, respectively (CDC, 2015, December; New York State Department of Health (NYSDOH), 2016, August). In 2014, 24% of the newly diagnosed cases of HIV were of Hispanic/Latino origin (CDC, 2016, October). The high concentration of AIDS cases within NYS and NYC has spurred the development of a wealth of services to promote the health and wellbeing of those living with and affected by HIV disease. The most well-known social services agency, Gay Men’s Health Crisis (GMHC) and political activist group, AIDS Coalition To Unleash Power (ACT-UP), were founded in NYC in the mid-1980s and lead the way in demanding that people with HIV/AIDS receive high quality healthcare.

The growing rate of Latinos diagnosed with AIDS resulted in the founding of the Latino Commission on AIDS in NYC in 1990. The mission was to address the unmet HIV-related needs of the Latino communities throughout the mainland US and Puerto Rico. Specifically, as of 2014, Latinos account for 252,778 cumulative AIDS diagnoses in the mainland US, while there were 35,245 cumulative AIDS diagnoses in Puerto Rico (CDC, 2015, November).
Homecare nursing services, such as, the AIDS Project at the Visiting Nurse Service of New York, provided interdisciplinary care guided by nurses to people living with AIDS. With the lack of state of the art healthcare available in Puerto Rico early in the epidemic, and with relatives willing to help, many islanders came to NYC to receive care (Maldonado, 1992) making it a center of healthcare for many Puerto Ricans with HIV.

**Treatment cascade/HIV continuum of care.** The Treatment Cascade has demonstrated striking disparities in the numbers of persons with HIV (1,106,400); who are aware of their HIV diagnosis (874,056); linked to (655,542) and retained (437,028) in care; prescribed antiretrovirals (262,217); and have achieved viral suppression (209,773) across the US (Gardner, McLees, Steiner, del Rio & Burman, 2011). The Medical Monitoring Project (MMP), the data source for the Treatment Cascade, demonstrated similar disparities across racial/ethnic and risk behavior categories although there are greater differences (lower rates of retention in care (54.4%) and viral suppression (36.9%)) in Latinos (Gant, Bradley, Hu, Skarbinski, Hall & Lansky, 2014). To reduce the effects of HIV/AIDS in the US, research efforts are exploring methods that will increase the number of people living with HIV who are retained in care; prescribed antiretrovirals; and virally suppressed and will also address the demonstrated disparities across race and ethnicity (Gardner, et al, 2011). The treatment cascade has come to be referred to as the HIV continuum of care.

**Culturally congruent care.** The provision of culturally congruent care, first promoted by Leininger, has been proposed by transcultural nursing experts as a method to address, on multiple interprofessional levels, healthcare disparities among the racially/ethnically diverse (Giger, Davidhizar, Purnell, Harden, Phillips & Strickland, 2007). Saha and associates (2013) conducted a study which demonstrated an association between the cultural competence of
providers and quality of HIV care. Data on Latinos’ trust or distrust of healthcare providers varies (Armstrong, Ravenell, McMurphy & Putt, 2007; Boyas & Valera, 2011; Earl, et al 2013). When there are issues of trust, Latinas have been shown to restrict what they discuss with their providers, or doctors (Julliard, et al, 2008). Latinos reported being satisfied with care received from providers of similar cultural background when that is their preference (Blanchard, Nayar & Lurie, 2007). A more recent study of nurses, over half of which were master’s prepared, documented their desire to deliver culturally congruent care and eagerness to participate in learning opportunities to prepare them accordingly (Hart & Mareno, 2013). The increased interest in understanding the cultural sensitivity of providers has led to extensive instrument development to measure this construct (Nápoles, et al, 2011). The effects of the cultural competence of nurse practitioners on Latina patient satisfaction has also been explored (Castro & Ruiz, 2009). These studies focused on quantitative measures and any qualitative efforts were intended for further item development for the surveys. These studies did not look at what culture care practices these client groups wanted or needed from their care providers.

Cultural meanings of living with HIV and caring for others with HIV were explored using Leininger’s CCT (Leininger, 2006a; 2006b; McFarland & Wehbe-Alamah, 2015) and ERM (Schumacher, 1995; MacNeil, 1994, 1996 & 2002; Aga, Kylmä & Nikkonen, 2009a). However, these studies focused on the generic or folk care in those cultures, and none focused on the Puerto Rican culture. Schumacher (1995) studied the culture care needs of a small rural village in the Dominican Republic that was just beginning to be affected by HIV. MacNeil (1994 & 1996) discovered the culture care needs of Baganda women caregivers in Uganda, many of whom were HIV positive themselves. She also explored culture care needs for HIV disease in the US, with no specific discussions of differing cultural groups (MacNeil, 2002). Lastly, Aga,
and associates (2009a; 2009b) centered their study on HIV-related culture care needs in Ethiopia. These studies explored a small fraction of the cultures and peoples affected by HIV disease, yet none focused on nursing care by NPs. More data were needed on the professional culturally based care that nurses and NPs and other providers give to their clients.

Most nurses and nurse practitioners are not of Latino heritage, and not of Puerto Rican descent. While 17% of the US population is Latino, only 4.8% of the nursing workforce is Latino; no data on race/ethnicity has been collected on the nurse practitioner population (Health Resources and Services Administration (HRSA), 2013, October; A. Millan, personal communication, December 1, 2011). Providing care that is culturally congruent and considers the culture care needs of Puerto Rican women with HIV may be difficult for providers because data is not readily available to them. While there have been publications that address the culture care needs of the Puerto Rican community (Purnell, 2013), these resources are not specific to the needs of Puerto Rican women with HIV disease nor do they fully reflect the acculturation of Puerto Rican communities both in the mainland US and in Puerto Rico. The folk care practices of Puerto Ricans, including spiritual belief practices that incorporate healing modalities, must also be understood as they play a vital role in HIV care. Researchers have utilized the CCT to guide their work studying Puerto Rican communities in Philadelphia (Martin-Plank, 2008); Western NYS (Higgins, 2000); and Western Pennsylvania (Fliszar, 2003). They made important discoveries in the use of spiritualist care (addressing physical and emotional maladies by caring for the spiritual aspect of the concern), feeding practices and familial care, but were not focused on Puerto Rican women with HIV in NYC. More data are needed in this specific domain.

**National HIV/AIDS Strategy.** The Office of the National AIDS Policy, formed by President Obama in 2008, initially released the National HIV/AIDS Strategy for the United
States in 2010. The intervening years had seen significant developments in HIV prevention and treatment; and, health care funding and programs at the federal and state levels. Therefore, the office subsequently updated the plan looking towards the year 2020 (ONAP, 2015). The four broad goals are further defined by steps to operationalize them and ten quantifiable indicators as measures of the effectiveness of the steps. The following revised goals supported this ethnonursing research study:

**Goal 2:** Increasing access to care and improving health outcomes for people living with HIV

**Step 2.A:** Establish seamless systems to link people to care immediately after diagnosis, and support retention in care to achieve viral suppression that can maximize the benefits of early treatment and reduce transmission risk

2.A.3: Support and strengthen capacity to implement innovative and culturally appropriate models to more effectively deliver care along the care continuum.

2.A.4: Prioritize and support research to fill gaps in knowledge along the care continuum.

**Goal 3:** Reducing HIV-related disparities and health inequities

**Step 3.C:** Reduce stigma and eliminate discrimination associated with HIV status.

3.C.3: Mobilize communities to reduce HIV-related stigma.

These broad goals were developed with a specific emphasis on reducing the disparities, health inequities, and stigma experienced by African-Americans and Latinos living with HIV/AIDS. While this ethnonursing research study focused only on Puerto Rican women living with HIV/AIDS in New York City, the anticipated data could support those steps outlined by the strategy.

**Healthy People 2020 and the Office of Minority Health objectives.** The Healthy People initiatives also provided support for this study. By seeking to improve the health of US residents, they have consistently had the goal of achieving health equity, eliminating disparities and improving health for all groups (Healthy People 2020, n.d.). This ethnonursing study targeted the following two Healthy People 2020 objectives on HIV care:
HC/HIT-3 Increase the proportion of persons who report that their health care providers always involved them in decisions about their health care as much as they wanted;

HIV-10 Increase the proportion of HIV-infected adolescents and adults who receive HIV care and treatment consistent with current standards;

one objective emphasizing access to care:

AHS-7 Increase the proportion of persons who receive appropriate evidence-based; clinical prevention services

and one objective focused on health-related quality of life and well-being:

HRQOL/WB-1 Increase the proportion of adults who self-report good or better health.

While the baseline data available in the document do not report racial/ethnic nor gender specific information, outcomes will be monitored using demographic criteria. This ethnonursing research study sought to understand how Puerto Rican women receiving HIV care want to be involved in decisions about their health care.

The Office of Minority Health (OMH) provided more specific analysis and objectives to address the health and healthcare disparities experienced by minority groups in the US. Disparities originate in the following areas: health care access; human services workforce and infrastructure; health, safety and wellbeing in minority communities; scientific knowledge and innovation specific to minority groups (United States Department of Health and Human Services (USDHHS), April 2011). This study addressed the following goals, strategies and actions of the HHS Action Plan to Reduce Racial and Ethnic Health Disparities in its efforts to achieve a “nation free of disparities in health and healthcare”:

Goal IV: Advance Scientific Knowledge and Innovation
Strategy IVB: Conduct and support research to inform disparities reduction initiatives
Action IVB2: Develop, implement and test strategies to increase the adoption and dissemination of interventions based on patient-centered outcomes research among racial and ethnic minority populations
Action IVB4: Expand research capacity for health disparities research.
While these goals, strategies and actions are not specific to HIV care or the care of Puerto Rican women, the data collected by this study will add to the body of holding knowledge of primary care providers delivering culturally congruent care to racial and ethnic minority populations.

**Sustainable Development Goals.** This study also corresponded with global goals, such as those identified in the United Nations (UN) Sustainable Development Goals (SDG) (2016). The SDGs are the update of the Millennium Development Goals (MDGs) which were a product of the Millennium Summit held by the United Nations in 2006, where the largest gathering of world leaders was tasked to develop quantifiable objectives to address extreme poverty and its manifestations, including hunger, disease, lack of adequate shelter, human rights issues, lack of education, and environmental concerns (UN, 2006). The goals were evaluated during 2015, the targeted year, and the eight goals that sought to improve the health and wellbeing of this planet and the people inhabiting it were expanded to seventeen (UN, 2016). Goal 6 of the MDGs was explicitly focused on infectious diseases that are devastating the world’s population, with HIV/AIDS being one of them. The new target regarding HIV/AIDS are part of SDG Goal 3, listed below, is applicable throughout the world, even though the greatest impact will be experienced in resource-poor countries.

**GOAL 3:** Ensure healthy lives and promote well-being for all at all ages  
**Target:** By 2030, end the epidemics of AIDS, tuberculosis and malaria and neglected tropical diseases, and combat hepatitis, water-borne diseases and other communicable diseases.

For all peoples, understanding culture care needs and using that data to provide culturally congruent care encourages continued engagement in care and adherence to medication regimens. By remaining active in care and adherent to antiretroviral (ARV) medications people can achieve and maintain undetectable viral loads; and, reduce transmission of HIV to others, including sex partners and children during the perinatal period. Goal 3 of the SDG was explored during the
implementation of this study. Giving NPs, other nurses and other providers the culture care information they need to engage Puerto Rican women in NYC in care, increases the probability of adherence to ARVs; consequently, reduces viral loads to improve health and wellbeing of women; and, reduces transmission to sexual or drug use partners and unborn children.

**Culture Care Theory (CCT) and the Ethnonursing Research Method (ERM)**

Dr. Madeleine Leininger (1991, 2002b, 2006; McFarland & Wehbe-Alamah, 2015) developed the CCT and the ERM to discover, explain and predict the phenomenon of care, the essence of nursing, through a cultural perspective. In her work, she noted that differences and similarities in how people responded to illness and the nursing care they received were grounded in their cultures. She maintained that by exploring the worldview, lifeways, social structure, cultural values, language, and ethnohistory of different cultures nurses can provide culturally congruent nursing care. When providing culturally congruent nursing care, the three modes of culture care decision and action modes incorporate both emic (client/insider) and etic (professional nurse/outsider) perspectives (Leininger, 2006a; McFarland & Wehbe-Alamah, 2015). By integrating the CCT, the nurse co-participates with the client (individual, family, group, community and/or institution) to create a plan of care that is preferred by the client for health and wellbeing.

The discovery of the culture care practices and needs of any cultural group can be achieved using the ERM, a people-centered, inductive, open inquiry qualitative research method utilizing interviews, participant experiences, direct naturalistic observations, reflection, on-going data analysis and confirmability of findings with the informants. The use of enablers, or research guides, to assist the researcher in the collection of data and ground its interpretation in emic perspectives, is a technique specific to the ERM and necessary for the discovery of the cultural information. Dr. Leininger developed the enablers for use by researchers seeking knowledge
about various cultures. The researcher can adapt the enablers to focus more specifically on the DOI (Leininger, 2006b; Wehbe-Alamah & McFarland, 2015a). Integrated use of the enablers and the steps of the method promote revelation through people’s stories of their perceptions and experiences of care, wellbeing, health, and illness that are embedded in the worldview, social structures, cultural values, ethnohistory and language of cultures (Leininger, 1991; Wehbe-Alamah & McFarland, 2015b).

The disparities in HIV and AIDS in the Puerto Rican community required further research and the impact of this disease on women was and continues to be particularly salient. The CCT and the ERM provided a paradigm that permitted a full exploration of the cultural aspects of this health condition. Having this information will assist in the provision of culturally congruent nursing care resulting in a plan of care that incorporates culture care preservation and/or maintenance, culture care accommodation and/or negotiation and culture care repatterning and/or restructuring (Eipperle, 2015). The ultimate goal of the study was to integrate both generic (folk, lay, or traditional) emic caring practices of the culture, and professional etic caring practices of HIV care, as best meets the needs of the Puerto Rican woman with HIV to enhance wellbeing in health, disability, illness, dying and death through the delivery of culturally congruent care.

**Research Questions**

The following research questions guided this ethnonursing research study conceptualized within the CCT:

1. What are the culture care beliefs, values, expressions, practices, and needs of Puerto Rican women with HIV receiving care from NPs and other providers?
2. In what ways do social structure factors, environmental context, ethnohistorical dimensions, and language influence health and wellbeing for Puerto Rican women with HIV?

3. What are the cultural perceptions of care of Puerto Rican women receiving HIV care from NPs and other providers?

4. What are the generic care beliefs and practices of Puerto Rican women living with HIV and how do they compare to the professional care they receive from NPs and other providers?

5. In what ways can nurses, nurse practitioners and other providers use Leininger’s three culture care decision and action modes to offer care that is meaningful and congruent with the culture care needs of Puerto Rican women with HIV?

**Orientational Definitions**

Consistent with the CCT and the ERM, orientational definitions were used instead of operational definitions to facilitate discovery of data of a more qualitative nature (Leininger, 2006a; Wehbe-Alamah & McFarland, 2015b). The following orientational definitions guided this qualitative inquiry:

1. **Culture** – “the learned and shared beliefs, values, and lifeways of a designated or particular group that are generally transmitted intergenerationally and influence one’s thinking and actions” (Leininger, 2006a, p. 13).

2. **Culture care** – “cognitively learned and transmitted professional and indigenous folk values, beliefs and patterned lifeways that are used to assist, facilitate, or enable another individual or group to maintain their wellbeing or health to improve a human condition or lifeway” (Leininger, 2002a, p. 57).

3. **Culturally congruent care** – “culturally based care knowledge, acts and decisions used in sensitive and knowledgeable ways to appropriately and meaningfully fit the cultural values,
beliefs, and lifeways of clients for their health and wellbeing or to prevent illness, disabilities, or death” (Leininger, 2006a, p. 15; McFarland & Wehbe-Alamah, 2015, p.14).

4. Culture care preservation and/or maintenance – “assistive, supporting, facilitative, or enabling professional decisions and actions that help people of a particular culture to retain and/or preserve relevant care values so that they can maintain their wellbeing, recover from illness, or face handicaps and/or death” (Wehbe-Alamah & McFarland, October 31, 2015).

5. Culture care accommodation and/or negotiation – “assistive, supporting, facilitative, or enabling creative professional decisions and actions that help people of a designated culture to adapt to, or to negotiate with others for a beneficial or satisfying health outcome with professional care providers” (Wehbe-Alamah & McFarland, October 31, 2015).

6. Culture care repatterning and/or restructuring – “assistive, supporting, facilitative, or enabling professional decisions and actions that help a client(s) reorder, change, or greatly modify their lifeways for new, different, and beneficial health care patterns while respecting the client(s) cultural views and beliefs and still providing a beneficial or healthier lifeway before the changes were coestablished with the client(s)” (Wehbe-Alamah & McFarland, October 31, 2015).

7. Acculturation – “process by which an individual or group from one culture learns how to take on many, but not all, of the values, behaviors, norms and lifeways of another culture” (Leininger, 2002a, p. 56).

8. Emic – “the local, indigenous, or insider’s cultural knowledge and view of specific phenomena” (Leininger, 2006a, p. 13-14; McFarland & Wehbe-Alamah, 2015, p. 14).
9. Etic – “outsider’s or stranger’s views and often health professional views and institutional knowledge of phenomena” (Leininger, 2006a, p. 14; McFarland & Wehbe-Alamah, 2015, p. 14).

10. HIV infection – laboratory confirmed HIV infection either by positive result of an HIV antibody test, or detection of HIV particles by nucleic acid detection, p24 antigen, or viral culture. Case classification includes a combination of CD4+ T-lymphocyte count or percentage and documentation of an AIDS defining condition. [Stage 1: CD4 T-lymphocyte ≥500 cells/μl or ≥29%; Stage 2: CD4 T-lymphocyte 200-499 cells/μl or 14-28%; Stage 3: CD4 T-lymphocyte <200 cells/μl or <14% or documentation of an AIDS defining condition; Stage Unknown: no documentation of CD4 T-lymphocyte count or percentage and no documentation of an AIDS defining condition] (CDC, 2008).

11. Antiretrovirals (ARVs) – medications used to treat retroviral infections, specifically for the purposes of this study, the human immunodeficiency virus. These medications are classified according to their action to disrupt the life cycle of the virus and are prescribed in combinations to act on the virus in multiple ways thereby reducing viral load in blood and body fluids.

12. Adherence – “the persistence in practice and maintenance of desired health behaviors and is the result of active participation and agreement” (Cohen, 2009, p.33). Regarding HIV, adherence is measured quantitatively by self-report of taking each prescribed dose. It is recommended that 95% adherence is necessary to achieve viral suppression in HIV infection (Patterson, et al, 2000, Lima, et al, 2009).

13. Nurse practitioner – nurse practitioners (NPs) are registered nurses who are prepared, through advanced education and clinical training, to provide a wide range of preventive and
acute health care services to individuals of all ages (American College of Nurse Practitioners, n.d.). Nurse practitioners may diagnose, treat, and prescribe for a patient’s condition that falls within their specialty area of practice (Office of the Professions, New York State Education Department, 2014, August 13).

14. Puerto Rican – an individual who self-identifies as being of Puerto Rican origin (background) and as being a member of the Puerto Rican culture.


Assumptions

There were several assumptions underlying this study.

1. Puerto Rican women living with HIV and currently receiving HIV care would be willing to candidly share their perceptions of the care patterns of their NP and other providers.

2. Applying Leininger’s CCT and the ERM was the most appropriate approach to understand and explain the desired nursing and culture care of Puerto Rican women receiving HIV care.

3. HIV care is a process that is affected by the care patterns that exist between the NP and other providers and client.

4. Puerto Rican women have culture-specific preferences for the professional nursing care that they receive from NP and other providers.

Significance to Nursing and other Health Care Professions

The findings of this study provided data on the culture care needs of Puerto Rican women receiving HIV care. Many studies aggregate quantitative and sometimes qualitative data collected on Latino communities (Zambrana, 2011). Latinos are people from over twenty
countries of origin. There are many, and varied differences amongst them, including language, customs, religious beliefs, economic experiences and culture care needs. While many researchers may wish to consolidate the data, they have collected on the varied Latino communities to achieve statistical levels of significance; they lose the richness of the data and its full applicability to specific groups. The experience of Puerto Rican women with HIV is unique and needed to be understood to provide culturally congruent, patient-centered nursing, and primary care, by NPs and other providers. This ethnonursing study also supported the use of a qualitative research method to discover culturally congruent ways to address health disparities as directed by the National HIV/AIDS Strategy for the United States, the Healthy People 2020 goals and objectives, and the Department of Health and Human Services Action Plan strategies; and the UN’s Sustainable Development Goals regarding HIV disease.

**Limitations and Facilitators**

This study was centered on Puerto Rican women living in NYC who were engaged in HIV care from NPs and other providers in NYC. Limitations of this study were focused on the methods of data collection and the specific emphasis on a small subset of the population of interest. The data was gathered through interviews and self-reported information (laboratory values; dates of HIV or AIDS diagnosis) were not confirmable by the researcher through other means, such as chart review. The interactions with the informants were confined to the interview setting, limiting opportunities for other data gathering opportunities. The Puerto Rican women participating in this ERM study were current or former clients of an AIDS service organization which could limit the diversity of the data collected, potentially limiting the breadth of the findings and the potential applicability to other populations.
Facilitators of this study included unique attributes of the researcher. The researcher is a bilingual second-generation Puerto Rican, born and raised in NYC, with limited ties to the island of Puerto Rico. The researcher worked with an ethnonursing research mentor and an expert on the CCT and ERM and used other recommended methods to address the potential for bias, bracketing and journaling (Leininger, 2006b; Wehbe-Alamah & McFarland, 2015b). The researcher conducted the interviews in English and/or Spanish, using code-switching, as the informants so desired. It was expected that this flexibility in language would open the study to more informants, and the nuances of the perceptions of care, and therefore provide richer data.

It was expected that the findings would inspire similar studies to explore culturally congruent care in other groups further developing beginning data sources about vulnerable populations living with chronic illness; and this study would bridge significant gaps in knowledge about the experiences of living with HIV and receiving care for HIV in these vulnerable populations, building nursing and inter-professional knowledge bases in theory, research, practice, education and collaboration, as well as healthcare administration and healthcare policy.

**Organization of the Study**

This research study is presented in five chapters. The first chapter introduced the HIV epidemic in the US Latino population in general and the Puerto Rican community more specifically. Statistical data; select ethnohistorical and cultural data; HIV care, nursing care and research concerns; and, national and international goals to reduce health disparities further supported the rationale for a study focused on Puerto Rican women receiving HIV care from NPs and other providers. The purpose, DOI, goals and research questions framing the study and the orientational definitions for this study were presented. Leininger’s (2006a; 2006b) CCT
(McFarland & Wehbe-Alamah, 2015) and the ERM (Wehbe-Alamah & McFarland, 2015b) were introduced as the theoretical framework and research methodology guiding the study. The assumptions of the researcher, the limitations and the significance of this ethnonursing study to nursing and HIV care were also discussed. The second chapter further describes the theoretical framework of this study and the review of literature supporting the need for this study. This literature review is specific to the ethnohistory and culture of Puerto Rico; the literature on HIV care and HIV research focused on Puerto Ricans and Latinos; and ethnonursing research focused on Puerto Ricans and ethnonursing research exploring transcultural care needs of people living with HIV disease. The third chapter provides the details on the implementation of the study using the ERM, including study inclusion criteria; human subject considerations; use of enablers; and, data collection, data storage and data analysis methods. The fourth chapter presents the findings of this study with supporting quotations from the informants and the identification of culture care patterns and themes. The final chapter includes a discussion of the findings and culture care patterns and themes with supporting quotations; corresponding culture care decision and action modes for NPs and other providers to use when delivering HIV care across continuum to Puerto Rican women living with HIV; the implications for this study for CCT theory, research, HIV care practice, nursing and interprofessional education, healthcare administration and policy development; and, the limitations and strengths of this study.
Chapter II

Review of the Literature

Chapter Introduction

This chapter provides a discussion of the Puerto Rican experience of the global HIV epidemic. This discussion is framed by Leininger’s Culture Care Theory (CCT) (McFarland & Wehbe-Alamah, 2015). The Puerto Rican culture is presented using Leininger’s Sunrise Enabler to Discover Culture Care (Leininger, 1991, 2002b & 2006a; Wehbe-Alamah & McFarland, 2015a; Wehbe-Alamah & McFarland, 2015, October 31) to review the ethnohistory of Puerto Rico; political and legal factors; economic factors; spiritual, and religious factors; cultural values, beliefs, and lifeways; kinship and social factors; language of Puerto Ricans; biological factors; educational factors; technological factors; and, environmental contexts. Next, the history of the HIV epidemic in the Puerto Rican community is explored; followed by a presentation of health research issues regarding the Hispanic community in the US. A brief synopsis of select HIV-related research that has included Puerto Rican women is offered. Previous research using the CCT to discover the culture care needs of Puerto Ricans and culture care related to HIV disease are discussed. A summary of the literature review concludes the chapter.

Leininger’s Sunrise Enabler to Discover Culture Care

Leininger’s Sunrise Enabler to Discover Culture Care is a guide to any study grounded in the CCT. It represents the comprehensive nature of culture and need for ethnonursing researchers to explore various dimensions to discover the foundations of culture care beliefs, values, expressions, practices, and needs regarding a domain of inquiry. In this study, the domain of inquiry is Puerto Rican women receiving HIV care from nurse practitioners and other providers in New York City (NYC). The Puerto Rican history and culture are rich and complex
and Leininger’s Sunrise Enabler to Discover Culture Care, Figure 1 (Appendix C) has been used to organize the collection and presentation of the data discovered by this researcher. The enabler depicts the inter-connected nature of various factors that represent the worldview and cultural and social structure dimensions of culture. No factor is considered to have a greater weight than any of the others, and together, they are meant to be studied as a whole. The rising sun metaphor represents the light shining on all aspects of culture yet also implies that not everything can be known at once (Leininger, 2002b; Wehbe-Alamah & McFarland, 2015, October 31); consequently, reminding ethnonursing researchers that there will always be something new to discover. The organization of the order used to present the factors for this study is intended to support the data shared in subsequent sections, building understanding of the unique experiences of the Puerto Rican community.

**Ethnohistory of the island of Puerto Rico**

**Taino Indians.** The island of Puerto Rico (Figure 2, Appendix D), the smallest of the four Greater Antilles Islands in the Caribbean Sea, had been inhabited by three groups of indigenous peoples by the end of the 15th century, when Christopher Columbus and his crew first ventured into the area. Like all indigenous peoples of the Americas, current theory proposes that they migrated from Asia by crossing on foot over land that once existed in what is now the Bering Straits between the most Eastern point of Asia and the most Western point of North America.

The Archaics were the first group to reach Puerto Rico, arriving in the Antilles via boat from South America circa 5,000 BCE. These people were hunter-gatherers, mostly of fish, and they lived in caves. The next known indigenous group, the Igneri, also came via boat from the northeastern areas of South America around 500 BCE. The Igneri, in contrast, were an
agricultural community, who settled in areas near rivers, produced ceramics and jewelry, and had a well-developed religious and cultural tradition. The Archaics and Igneri coexisted on the island and historians believe that the mingling of their people resulted in the Taíno culture (González Muñiz, 2010).

The Taíno named the island, now known as Puerto Rico, *Borinquén* (Borikén), meaning “Land of the Valiant and Noble Lord” (Santiago, 1995). The people of *Borinquén* were called *Boricua* and this name is still used to refer to people of Puerto Rican origin. The Taíno people created written symbols to represent items of cultural importance and had a well-developed spiritual belief system. Their traditions included a supreme deity, called *Yocahú Baguo* Maracotí, and *cemís*, lesser gods represented by idols, who controlled daily and meteorological events (González Muñiz, 2010). The Taíno believed in an after-life called *Coaibay*. Elaborate funerals were celebrated in which people were buried with personal items and food for their journey to *Coaibay*, conceived as similar to their current existence. Important tribal members could become *cemís* upon their death. Religious rituals included the inhaling of burned herbs to induce a trance-like state to facilitate communication with the *cemís* (González Muñiz, 2010).

The Taíno had a matrilineal society (Acosta-Belén, 1979) which was organized into two main groups: the *nitainos* (nobles) and *naborías* (common people) (González Muñiz, 2010). The *bohiques* were the local healers, whose lore was mostly based on the use of herbs and idols to treat physical and spiritual illness. The communities were called *yucayeques* and the leader was a *cacique*. The cacique was usually a man, but succession was through the eldest sister’s eldest son. One *cacique*, the *guamiquina*, was selected to lead all the caciques. The *guamiquina* was consulted during times of trouble and would provide leadership during conflicts (González Muñiz, 2010). The Taíno women enjoyed equal rights, freedom and respect in their society.
They participated in all ritual activities of the *yucayeques*. They were responsible for creating their pottery, making traditional bread and weaving hammocks used for sleep. During pregnancy, women remained active throughout the prenatal and postnatal periods (González Muñiz, 2010).

**From Spanish conquest to the Spanish American War.** During the 1493 sailing to the New World, Columbus saw *Borinquén* and named the island for *San Juan Bautista* (St. John the Baptist) when he claimed it for Spain. The island was not settled by the Spanish until Juan Ponce de León arrived in 1508 with his crew in search of the Fountain of Youth. The city they established in the north was named *Puerto Rico*, meaning “rich port” (Santiago, 1995). The names of the city and island were eventually switched as we know them today. At the time, the Taínos had been fighting the Carib of Northern South America, a warring people who had been arriving by boat to attack the *yucayeques*, stealing food and other valuables, over many years. The Taíno believed the Spanish conquistadors would be allies and assist them in defeating the Carib. It soon became clear that the intention of the Spaniards was to look for gold, which they found, and establish *encomiendas*, settlements for raising cattle and growing crops, like sugar cane.

The Taíno were enslaved by the Spaniards and forced to work the *encomiendas*. Over the next 50 years many of the Taíno were killed either by infectious diseases brought by the Spaniards or the harsh physical conditions they endured (Castanha, 2011). Taíno women intermarried with the Spaniards, from a patriarchal society; and, their children were identified with their fathers’ heritage. Later in the century, a census of the Spanish Empire in the Caribbean recorded very few Taíno. Subsequent censuses counted fewer and fewer Taíno leading some historians to believe that they were eventually eliminated by the 18th century
(Dávila, 2001). It is believed that some Taíno sought refuge in the dense forest to escape the Spaniards and it is through these individuals that the Taíno culture survived.

Evidence of the endurance of Taíno culture is in words that became part of the Spanish and English languages: hammocks (hamacas), canoes (canoas), hurricane (huracán) (González Muñiz, 2010). Many of the musical instruments created by the Taíno continue to be used in Puerto Rican music today (Castanha, 2011). The present day Taíno movement claims the physical characteristics, visible in Puerto Ricans, of “straight hair, a narrow forehead, elongated eyes…short nose, pronounced cheekbones, copper coloring and lack of body hair” (Dávila, 2001, p. 45), as proof that the Taíno people have survived.

To replenish workers for the encomiendas, as the Taíno diminished, the Spaniards traveled to the Western coast of the African continent and enslaved Africans, many from the Yoruba peoples, transporting them to Puerto Rico and other Caribbean islands. These areas of Africa had their own variations of slavery within the ethnic groups to work in an agricultural society. After a harrowing journey to the New World, which many did not survive, the Africans were then auctioned as property to work the encomiendas. In the more rural society of Puerto Rico, Africans easily intermingled with the remaining Taíno and the Spaniards bringing their culture and genes, as well into the mix.

The Spaniards enforced the practice of Roman Catholicism on both the Taíno and African peoples. To maintain their own sense of self while at the same time complying with the Spaniards, the Taíno and the Africans blended their own spirituality with the Catholic religion. The resulting practices and beliefs continue today. Another result in the intermingling of these people is the variation in phenotype within families. Full siblings can differ by having a more
European, Taino, or African appearance. As with most blended cultures in the higher socioeconomic groups, the children with more European features were favored within the family. The Spanish ruled the Latin American colonies with varying success through the 16th through 19th centuries. During the 19th century, Spain continued to lose major parcels of land through fights for independence by the inhabitants, and the expansionist agenda of the newly formed country, the United States of America (US). The middle-class farmers and merchants of Puerto Rico were also eager to create a free society, without slavery, censorship or restrictions on trade. Similar sentiments were building in Cuba at the same time, and with the similarities between the two countries, such as, an agrarian economic base; a significant African population; and, a desire to build trade with the US, the Puerto Rican and Cuban rebels supported each other’s efforts. Both countries abolished slavery in 1875. Puerto Rican poet, Lola Rodriguez de Tío, described the connection between Cuba and Puerto Rico as “of one bird, the two wings” (Fox, 1996). The most obvious remnant of this partnership is the similarities in the countries’ flags.

Even though Spain attempted to appease the rebel factions in both Puerto Rico and Cuba by granting autonomous rule in 1897 (Fox, 1996), too many losses were incurred by the rebel leaders to establish independent countries. They reached out to the US for assistance, which had great interest in removing Spanish influence in the Caribbean and increasing their own access to the sugar and coffee crops in Puerto Rico and Cuba. A questionable explosion on the USS Maine stationed in Havana Harbor in 1898 started the Spanish American War (Benson, 2003). Over, before it had a chance to begin; the end of this war resulted in the Treaty of Paris, which led to the transfer of Puerto Rico, Cuba, the Philippines and Guam to the US.
Political and legal factors

**American occupation.** After the transfer of Puerto Rico, the US military governed the island for the next 2 years until the passing of the Foraker Act in 1900 which granted Puerto Rico self-governance under US control and provided Puerto Rico with a non-voting representative in the US House of Representatives. In 1901, the US Supreme Court declared that Puerto Rico was “an unincorporated territory” that belonged to but was not part of the US (Benson, 2003; Duany, 2009, February 13; Meléndez, Edgardo, 1993). Puerto Rico became subject to the US Constitution but would not be eligible to become a state (Meléndez, Edgardo, 1993). The government in Puerto Rico was led by Americans appointed by the US government at the higher-level offices and Puerto Ricans elected Puerto Ricans at the local level.

During this time, the US military established Puerto Rico as a strategic base to protect US interests in the Caribbean and Latin America, while US economic interests took hold in agriculture. Large tracts of land were consolidated into sugar plantations. The sugar industry usurped the land of small subsistence farmers and even many of the coffee plantations, which had provided a consistent living for many farmers, known as *jíbaros*. In addition, the import of goods manufactured in the US, priced to the advantage of American manufacturers (Fox, 1996), affected the livelihoods of local business people, including, carpenters, clothing and shoemakers. People who were previously able to support their families, found themselves with diminishing work opportunities, and salaries. Former farmers were displaced to the cities as they looked for work (Meléndez, Edwin, 1993).

While Puerto Rico became a colony of the US, the people were still fighting for their independence. To weaken the rebels, the Jones Act was passed in 1917, inaugurating significant changes for Puerto Rico. The Puerto Rican government was modified to include two houses
allowing for more self-governance (Benson, 2003). However, the governor was still an appointed American or non-Puerto Rican. The act granted US citizenship to the residents of Puerto Rico, while the island maintained its designation as not a part of the US. The timing of this legislation is curious as it created unique colonial benefits for the US. First, as US citizens Puerto Rican men were required to join the armed forces to supplement the US troops during World War I (Sánchez Korrol, 1983). Second, US citizenship facilitated the migration of low skilled workers, thereby avoiding the immigration quotas imposed on Asia and Southern Europe during the same period, by the Johnson Acts of 1921, 1924 and 1929 (Sánchez Korrol, 1983). The migration of former farmers and shopkeepers, displaced by the sugar plantations and imported goods, helped to establish communities in New York, New Orleans, San Francisco, Arizona and even Hawaii. The majority of migrating Puerto Ricans, though, have relocated to the northeastern US states, while recent trends demonstrate a shift to Florida.

**Current political status of Puerto Rico.** Puerto Rico and Puerto Ricans have a complex political and legal relationship with the US. While all Puerto Ricans are US citizens, they are not able to fully exercise those rights until they reside in one of the fifty US states (Fox, 1996). Then they are permitted to vote, and they are also required to pay income taxes. All residents of Puerto Rico are unable to vote in national elections, even though they do hold presidential primaries every four years. The duly elected representative from Puerto Rico only has observer status within the US legislature and is unable to vote on any laws including those directly affecting Puerto Rico. However, this representative can introduce bills for consideration. Bills introduced in the 113th - 115th Congresses include amendments to federal laws governing entitlement programs, such as Social Security, Medicare and Temporary Assistance to Needy Families (TANF). These amendments seek equal consideration of Puerto Rico and the three
other US territories (US Virgin Islands, Guam and American Samoa) as the District of Columbia for the allocation of funds. It is not expected that these bills will move past committee (govtrack.us, n.d.).

There have been multiple attempts over the years to clarify and enhance the political status of Puerto Rico in relation to the US. Every few years there is a proposal for a plebiscite and there have been two elections held in the 1990s and most recently in 2012. The options provided to the electorate include independence, statehood or the status quo. According to the Foraker and Jones Acts, Puerto Rico is not eligible for statehood, meaning the Puerto Rican people cannot decide their status on their own (Benson, 2003; Fox, 1996). Consequently, the US Congress would need to vote to approve any change in Puerto Rico’s status. While various US legislators have weighed in and stated that the will of the Puerto Rican people will be/should be honored, nothing has changed. A consistent obstacle to change in Puerto Rico’s political and legal status has been the lack of a clear delineation of what changes would occur with each option. Another factor that has been considered during the plebiscites, particularly in 1993, was the question of the inclusion of Puerto Ricans residing on the mainland in the vote (Falcón, 1993). The options offered were either to include only first-generation Puerto Ricans, or second and subsequent generations, as well. In the end, only those living on the island voted, and no majority was achieved for any of the options.

The 2012 plebiscite, held in conjunction with the national election, included a two-part question. Part one: do you want to maintain the status quo or not? Part two: if not, do you want statehood, independence or enhanced commonwealth (sovereign free-associated state)? The result revealed that a majority, 54%, did not want to maintain the current commonwealth relationship. Of those who did want change, the second ballot results were statehood (45.1%),
independence (5.5%), and sovereign free-associated state (33.3%). Over 17% of voters skipped the second question, as instructed by the pro-commonwealth party in protest of the ballot format (Royston Patterson, 2012, November 24) and no change was implemented. In 2016, as happens every four years, as part of the presidential election, candidates weighed in on the fate of Puerto Rico to garner primary votes, yet no questions were placed on the ballot to determine the will of the Puerto Rican people.

Puerto Rican academia refers to the movement of Puerto Ricans out of Puerto Rico to various US states as the Puerto Rican Diaspora. There is an overwhelming sentiment that Puerto Ricans were forced from their homeland. The forces were mostly economic, and included promises of full citizenship, jobs and educational opportunities, inducing families to leave Puerto Rico willingly. Those who migrated to the US in the mid-20th century believed their presence was desired and would be a beneficial arrangement for all parties (Duany, 2009, February 13). However, they soon came to realize that they would be subject to discrimination unlike anything they had experienced. Even so, the flow of migration continued and there are now more Puerto Ricans residing within the US mainland, 4,623,716, than live in Puerto Rico, 3,808,610 (Ennis, et al, 2011). In September 2017, Hurricane Maria devastated Puerto Rico, including destroying the power grid, disrupting access to clean water. Consequently, residents began to migrate to the US to live with their families in New York and other locations on the east coast of the US, especially Florida (Alvarez, 2017, November 17). It is unclear if they will remain on the Mainland once Puerto Rico has recovered.

**Economic Factors**

**Operation Bootstrap and the Commonwealth.** The US government created an economic scenario in Puerto Rico which requires the use of US funds to address the social and
economic instability that resulted from policies that served to benefit US business and military
ingterests. These funds were not enough to quell the renewed unrest, so in 1948 the US
government permitted Puerto Ricans to vote for their own governor (Benson, 2003). Luis
Muñoz-Marín, the first elected governor and son of the leader during Puerto Rico’s brief time of
independence in 1897, was expected to bring Puerto Rico closer to sovereignty (Fox, 1996). He
envisioned a relationship with the US that would mirror the one between Great Britain and
Canada and Australia, recognizing the sovereignty of both countries yet maintaining a
connection. However, insurgent acts by those seeking full independence instead of
commonwealth status, resulted in the Estado Libre Asociado de Puerto Rico which had much
less autonomy than originally desired (Fox, 1996).

Muñoz-Marín also sought more public funding for investments in Puerto Rico for job
development, called “Manos a la Obra” or “Operation Bootstrap”, but instead the US Congress
provided tax incentives to American companies to invest private funds in Puerto Rico. The
companies that moved their factories to Puerto Rico, in search of cheaper labor than in the US,
were mostly manufacturing industries that traditionally employed women more than men (Ríos,
1993). These jobs in the garment industry, for example lace making, often paid lower wages
than other industries. The women found steady employment while their husbands continued to
work in seasonal jobs, on farms or in construction (Rivera Quintero, 1979). Meanwhile the hotel
industry was establishing itself, creating new employment options. In some households, the
marital balance was upset, as more women worked outside of the home (Muñoz Vázquez, 1979;

At the same time, Commonwealth status was granted, and Operation Bootstrap was
initiated, Muñoz-Marín also established an office of the Puerto Rican government in NYC. The
purpose of this office was to assist Puerto Ricans arriving in NYC, and the surrounding areas to settle into their new lives in the metropole. With the advent of commercial airplane use and development of routes with inexpensive fares between the US, especially NYC, and San Juan, more and more Puerto Rican families migrated to escape the dismal job prospects in Puerto Rico, and in search of a better life in the US. Please see Figure 3 (Appendix E) for a map of the sea and air route between San Juan and NYC.

Even with steady migration of Puerto Ricans from the island (more than 50,000 people in 1930 (Benson, 2003), there were still reports of excessive population and poverty on the island. US corporate investment in Puerto Rico was not able to create the types and numbers of jobs necessary to reduce the employment and poverty problems in Puerto Rico (Ríos, 1995). The continued displacement of the people from rural areas and smaller towns to the larger cities of San Juan, Ponce and Mayagüez, exaggerated the problem (López, 2008). The large farming families living in squalid conditions in the cities and on farms, was documented by photographers and journalists and circulated around the world (Kantzman & Brannan, 2011).

In the 1970s, after some years of economic growth in Puerto Rico, the industries that had benefitted from the Operation Bootstrap strategies had changed. They either became increasingly automated or required cheaper labor to maintain low costs, and Puerto Rican workers were displaced once again. The US government issued a new tax incentive program in 1976 called Section 936 after its section in the US Internal Revenue tax code (Meléndez, Edwin, 1993). This program attracted petrochemical firms, pharmaceutical companies and banks to the island. The programs also made Puerto Rico a location for the headquarters of US businesses with interests in Latin America. So long as their profits were reinvested in Puerto Rico through
the banks, the companies would be taxed at a much lower rate (Dietz & Pantojas-García, 1993). This program was phased out completely by 2005.

The dependence of Puerto Rico on the US as a result of the commonwealth status has been described as a neocolonial relationship, dominated by economic and military control of Puerto Rico by the US (Cabán, 1993). One aspect of the presence of the military has been the steady recruitment of Puerto Ricans to join the military. For many Puerto Ricans, as with other disadvantaged US citizens, joining the military was the best route to economic security through job training and an education. Some chose to make a career out of military service and others retired when eligible. Having a military background provided opportunities for employment, higher education or starting one’s own business through the GI bills.

Another aspect of military control was the establishment of military bases on the smaller islands of Vieques and Culebra just to the east of the main island (García Muñiz, 1993). The people living there were displaced, when the US military built the bases for practicing military maneuvers and shelling. For the people who remained, there have been reports of illness, including cancer, over the years. In the later 20th century there were increasing protests to close the bases (García Muñiz, 1993). In 2001 the US Navy ceased training maneuvers there and left the island officially in 2003 (Duany, 2009, February 13). Community leaders have expressed environmental concerns regarding the clean-up of the sites after decades of bombing.

In 2015, the government of Puerto Rico announced their inability to make lump payments on the debt owed to US banks, ten years after all financial benefits from Section 936 ceased. Federal laws permitting any local municipality or state to declare bankruptcy are not applicable to Puerto Rico, due to its commonwealth status. Negotiations to restructure the debt, reduce spending on special programs; and, increase taxes by the Puerto Rican government were
begun to start the debt repayment but the diminishing island population has eroded the tax base further exacerbating the crisis (New York Times Editorial Board, December 26, 2015). In May 2016, Puerto Rico began to default on debt payments. Both houses of the US government moved slowly to provide a solution, eventually deciding to appoint a panel to supervise the debt restructuring rather than permit a bankruptcy declaration as desired by the Puerto Rican people. Even the US Supreme Court has maintained the weight of the financial debt by not allowing the public utilities to restructure their own debt (Walsh, 2016, July 1).

“The Puerto Rican Problem.” In the early 20th century, Puerto Rican migration consisted of mostly skilled workers who settled in Chelsea, the Navy Yard in Brooklyn, East Harlem and the Lower East Side (Duany, 2009, February 13). The Operation Bootstrap migrations of lower skilled workers averaged 40,000 people per year at its height (Meléndez Vélez, 2005); and, these people moved into the South Bronx and the Williamsburg and Sunset Park sections of Brooklyn (Duany, 2009, February 13). These neighborhoods came to be known as “barrios,” meaning “neighborhoods” in Spanish. The Spanish and Puerto Rican businesses in these communities expanded to meet the increased demand for goods and services familiar to the new arrivals.

Some of the new migrant workers were not well received in NYC. The rejection came at factories where they sought employment; in the neighborhoods where they moved; and, even in the New York periodicals. Those who had trouble finding employment and housing also had difficulty assimilating into life in NYC (Thomas, 2010). They sought assistance within the welfare system and from other social service agencies. These agencies had difficulties handling the numbers of people who spoke a different language; had a different culture; had limited education; and, were unaccustomed to the climate and living in apartment buildings in
overcrowded cities (Meléndez Vélez, 2005). These issues became known as “the Puerto Rican problem.”

During the mid-1940s, the New York Times published articles further denouncing “the Puerto Rican problem,” describing the migrants as very ill and poor, and quickly placing themselves on the welfare rolls (Meléndez Vélez, 2005). This negative reaction spurred the Puerto Rican government to open additional migration offices in NYC and Puerto Rico to further assist the migrants to plan their move and transition more smoothly to life in the US. In 1950 the Puerto Rican government also commissioned the sociology department of Columbia University to conduct a study of the new migrants to identify the sources of the problems and offer solutions (Thomas, 2010). Even though much of the problem was already understood (that is the characteristics of the migrants experiencing difficulties) and NYC welfare agencies had already studied the issues in New York, the Puerto Rican government chose to engage the services of Columbia University to combat the negative propaganda with a world-renowned academic institution (Meléndez Vélez, 2005).

The Columbia study and two others performed around the same time came to the same conclusions. Most of the migrants were lower skilled workers from rural areas of Puerto Rico. Their limited skill set, and English language ability precluded them from better paying jobs, relegating them to unstable lower salaried positions. Their low incomes forced them into crowded housing situations and with limited access to the healthy foods they were accustomed to eating (Ortiz Cuadra, 2006), they became vulnerable to communicable disease (Pérez, 1988). These neighborhoods where they resided then became subject to increased poverty and crime (Meléndez Vélez, 2005). Some of the recommendations from these reports included increased education and vocational training in Puerto Rico to improve the skill set of potential migrants
(Thomas, 2010). The report dispelled the myth of Puerto Ricans coming to NYC to receive welfare benefits and return to Puerto Rico while collecting those benefits. However, further publications based on the study concluded that the people who encountered difficulties in NYC would not be able to assimilate into American society and would remain marginalized in the barrios (Meléndez Vélez, 2005).

**The Diaspora continues.** The Puerto Rican community has moved from a greater concentration in the northeast corridor of the US, and primarily large cities and former manufacturing towns, and into other areas of the US (Rivera-Batiz & Santiago, 1996). Communities are becoming established in more rural areas of the northeast and in Florida. In fact, the Puerto Rican population has developed so rapidly in Florida and, in particular, the central region, that it has been credited with providing enough electoral power to re-elect President Obama in 2012 (Royston Patterson, November 24, 2012). While the Florida Puerto Ricans are doing better financially, the Northeast and NYC Puerto Ricans continue to achieve lower levels of education, and income, and incur higher housing costs (Marzan, 2009).

A report issued by the Center for Puerto Rican Studies at Hunter College (Center for Puerto Rican Studies (Centro), 2012, December), based on the US Census Bureau American Community Survey (ACS) in 2010 and 2011, found that Puerto Ricans had a median household income of $36,558 compared to $50,046 for the rest of the US population. A greater proportion of Puerto Ricans paid more of their income on mortgage costs, 48.5% versus 38% (Centro, December 2012). Poverty rates among Puerto Ricans were higher at 24.2% versus 11.3% for the whole population. This percentage is higher than all other reported subgroups of the population, other Hispanic/Latino, non-Hispanic White, non-Hispanic Black or non-Hispanic Asian (Centro, December 2012). These figures carry over to the NYS comparisons. In addition, compared to
other female-headed households, NYS Puerto Ricans are more likely to be in poverty, 47.8% versus 27.6% (Centro, December 2012). The 2011 ACS examined education and work in the US population and found that 23% of Puerto Rican youth between the ages of 16 and 24 were neither in school nor at work, which is equivalent to the proportion of African-Americans (US Census Bureau, 2011, December).

**Spiritual and religious factors**

*Christianity.* Besides their interest in new lands and natural resources, the Spaniards’ presence in the New World was motivated to bring more souls to the Roman Catholic Church. The conquistadors achieved this by force of the sword, while missionary priests did so by the force of scripture. Missions were established throughout the New World and often connected with the *encomiendas*. Some concepts within Catholicism were not unfamiliar to the Taíno: the belief in an afterlife; and, the belief in the intercession of the holy deceased through prayer.

Many towns were named after saints or religious concepts throughout the New World, for example: San Juan in Puerto Rico, Santa Fe in New Mexico. Even towns not named after a saint have holy patrons, believed to bestow blessings upon the town’s inhabitants. Every year a *festival patronal* is celebrated including religious services and cultural activities, in honor of the town’s saint. Other major holy days in the Catholic calendar continue to be celebrated with the cooperation of the town governments. Good Friday, which commemorates the crucifixion of Jesus Christ, combines church services with a processional march through the city streets, reenacting Christ carrying the cross to his execution. The local governments shut down the streets and provide police escorts to the vehicles and pedestrians participating in the event. These customs are also celebrated in the communities in the US with large Roman Catholic communities.
The majority of Puerto Ricans continue to identify with the Roman Catholic faith; the level of practice beyond participation in the festivals varies. Some Puerto Rican women carry rosary beads and pray the Rosary, a series of prayers to the Virgin Mary, the mother of Jesus Christ, daily. These prayers are also said in novenas, nine days of prayer, for the souls of the recently deceased. The novenas are thought to escort the soul into heaven. Called a Rosario, family members and friends, mostly women, gather in the home of the deceased or nearest relative to pray together and then share a meal.

Most churches in Puerto Rico were centered in the towns or cities. Those who lived in the more rural and mountainous areas of the island, did not have regular contact with the priests for services and major religious ceremonies (García-Preto, 2006). Many of the religious traditions and prayers were shared orally through the generations. Couples, who wished to form a union, often did so consensually (García-Preto, 2006). They may have married in the church or had their union blessed by a priest later or not at all. Baptisms, initiations into the Christian religion, were the way that a child’s birth was registered. Baptisms occurred in groups when the priests traveled to the rural areas, if a family could not bring the child into town. Some families would perform baptisms on their own (bautizo de agua). This practice is permitted in the Roman Catholic Church by a lay person in the case of impending death of a child and is often performed by nurses. However, these families would then want the child baptized again when the priest was available. Requests for second baptisms are denied, and consequently, families would not reveal the bautizo de agua, so that a baptism by the priest with holy water could occur (I. Navarro, personal communication, May 5, 2012).

When Puerto Rican communities began to establish themselves in NYC, the Archdiocese of Boston, which oversaw the churches in Puerto Rico, did not send Spanish-speaking or Puerto
Rican priests to minister to the people (Thomas, 2010). The New York Archdiocese did not have priests to fill this need. Thus, Puerto Ricans in some neighborhoods were unable to utilize an important spiritual resource during difficult times after migrating to NYC. In contrast, their Irish and Italian immigrant counterparts did have strong support from their home churches, which helped them assimilate and acculturate through their faith communities (Thomas, 2010).

In the past century, Pentecostalism, a Protestant denomination of Christianity, has become popular in the Puerto Rican community. The tenets of this religion include a strong spirituality in which the Holy Spirit can speak through people during church and other religious services. This religion also contains similarities to the Taino religion in which communication with the *cemís*, spiritual beings, was sought during religious ceremonies. Pentecostalism became popular in the Puerto Rican communities in NYC because these churches reached out to the communities by inviting them to services in Spanish (Thomas, 2010). After a time, these churches sought to establish themselves in Puerto Rico as well.

**Santería.** Another popular religion within the Caribbean Latino community, including Puerto Rico is *Santería*. It is a “religious system that honors the ancestors and recognizes a direct contact between man and the forces of nature which are manifestations of God, himself” (González-Wippler, 1984, p. 11). The religion is a syncretization of the Orisha religion of the Yoruba peoples from Western Africa and Roman Catholicism (Fernandez Olmos & Paravisini-Gebert, 2011; González-Wippler, 1984; 1982). When the Yoruba were forced to become Roman Catholics, they wanted to continue their own religious practices, but were severely punished for it. To hide their fidelity to their own religious practices, they identified saints with similar traits to their *orishas*, spirit gods, and combined them. The combinations were not bound by gender, for example, Saint Barbara who is associated with lightning in the Catholic religion is connected
to Changó, the greatest orisha who is male and also associated with lightning. The feast days of the saints celebrated in church also included home based celebrations of the corresponding orishas.

Each member of the religion has a patron orisha, based on personal characteristics that are favored by that orisha. The person is encouraged to wear the favored colors of the orisha, either in their clothing or in beaded necklaces or bracelets (González-Wippler, 1982). This identification with the orisha is believed to have a protective effect. By praying and making offerings of food, drink, flowers or animals to the orishas, people can petition favors in love, luck, and health. While the orishas are considered strong and their intercessions are primarily for the good of the petitioners, the spirits of the deceased who are not at peace can be bribed with sacrifices to exert influence on others (González-Wippler, 1984). These sacrifices can take place in a cemetery which is thought to strengthen the action, also called a trabajo, literally meaning work. These practices describe a very organized religion because these actions reach into all aspects of life (Newby, Riley & Leal-Almeraz, 2006). The priests of Santería are called santeros, who train for many years with a babalao (high priest) to learn about the orishas, the prayers and the practices, which underpin the religion (Newby, Riley & Leal-Almeraz, 2006). The trainees are designated as the godchildren of the babalao. When a santero completes training, there is an elaborate ceremony and subsequent festivities to celebrate this accomplishment and the favor of the orisha. Santeros are known for wearing all white during any official activities and their training.

Espiritismo. Espiritismo is a philosophical approach to life that became popular during the 18th century. Initially associated with French intellectuals, Puerto Ricans who were educated in France brought the philosophy to Puerto Rico upon their return (Rodriguez Escudero, 1991;
Espiritismo views “the visible world surrounded by an invisible world inhabited by good and evil spirits who influence human behavior” (García-Preto, 2006). Practitioners of Espiritismo would gather in each other’s homes and hold séances to communicate with these spirits. Burning candles, incense, and powders could appease the spirits. Espiritismo has become a syncretized religion, merging with Roman Catholicism, Santería, and the herbology of Puerto Rico (Fernandez-Olmos & Paravisini-Gebert, 2011; Romberg, 2003; Singer & García, 1989). Not all espiritistas know the folk healing practices of Puerto Rico, but all will interpret the spirits surrounding the individual. The spirits may be protective and well intentioned, such as a deceased loved one, or may wish harm upon the individual. The espiritista will thank the spirits of good will, remind the deceased who are too close to the living to move on before causing harm, or break the “spell” of ill will (R. Amezquita, personal communication, October 13, 2012). After a ritual spiritual reading and cleansing, the espiritista makes recommendations to continue the work started during the session. These folk practices were forced “underground” for some years during the mid-20th century as politicians in Puerto Rico attempted to modernize the Puerto Rican people (Romberg, 2003).

The ability to communicate with the spirits and orishas can be frightening experiences at a young age and in a variety of ways. It may occur through vivid dreams when sleeping or through trance-like states when awake. During the trance-like states, the person will speak with the spirits in altered voices or with unfamiliar words. Body movements can be uncontrolled, and people can injure themselves (R. Amezquita, personal communication, October 13, 2012). For those unfamiliar with espiritismo, observing an experience like this can be frightening, and they can believe that the person is in the midst of a psychotic episode. In fact, many Puerto Rican
individuals have been diagnosed with psychotic or neurological disorders by health care
providers unfamiliar with the religion (Gherovici, 2010; Younoszai, 1993).

Cultural Values, Beliefs, and Lifeways

The values of the Puerto Rican culture are grounded in the Roman Catholic religion, as
well as the Taíno, Spanish, and African cultures. Some practices were not well received in the
US and have been portrayed negatively (Holliday, 2008; Newby, Riley & Leal-Almeraz, 2006).
Some of the cultural practices in present day Puerto Rico and in the Puerto Rican communities
throughout the US now reflect blending with American values after 120 years of exposure. The
Americanization of Puerto Ricans, and other Latino groups, has been described as detrimental to
their health in some aspects (Borrell & Lancet, 2012).

Marianismo and machismo. Marianismo and machismo are two concepts in Latino
cultures that together define the relations between men and women, and parents and children.
These concepts have modified over the years and the following discussion describes more
traditional modes of thought, and some corresponding actions. Marianismo describes female
roles that women and girls should assume. From the name of the Virgin Mary, a woman should
remain a virgin until marriage and should be subservient to her husband (Stevens, 1984). She
should be responsive to his personal needs and those of her family to the point of putting her own
needs last (D’Alonzo, 2012). A daughter should emulate her mother and she begins her training
by helping her mother to care for the household and her siblings, including older brothers. A
young woman, known to be religious, who goes to church and prays, cares for her family
members and helps her mother at home, is a desirable mate for marriage (Vázquez-Nuttall &
Romero-García, 1989). She will perform her duties as a wife and mother. A young woman who
is strong-willed or exhibits sexual desire is called a puta, the slang term for a promiscuous
woman. She brings shame upon herself and her family because she is not viewed as
marriageable. She may be put out of her home, if her sexual activities become known. One of the contradictions of marianismo is that a wife can be perceived as too pure to engage in sexual activity for more than its procreative possibilities. A man may not wish to ask more of his wife for fear of offending her sensibilities and fulfill his sexual desires elsewhere.

On the other side of Marianismo, is Machismo. As applied to the male counterpart in marriage and family life, he is viewed as a provider for the family. His responsibility is to provide housing, food and clothing for his wife, children and parents, if they are still alive. He is also expected to rule his home, making sure that his wife’s and children’s actions in the community are honorable (Purnell, 2013). He is expected to show respect for his wife as the mother of his children and the example of the Virgin Mary in their home. As stated previously, that respect could create a situation of disrespect if he sought sexual satisfaction with another person. In another example of the contradictions of machismo/marianismo, a child fathered through extramarital relations, could be brought into the home and raised with the children by his wife (Christensen, 1979).

**Familismo.** The cultural concept that governs the interactions within families is *familismo*, in which parents are given respect in all ways. This includes obedience as a child, and even into adulthood, caring for their needs in their old age (Davis, 1996). Parents are also expected to be caring and loving to their children as infants and toddlers and prepare them for their future roles from an early age. If a child misbehaves, a parent is expected to physically discipline the child (García-Preto, 2006). This can include a spanking on the buttocks (Purnell, 2013) or making a child kneel on uncooked rice in a corner. Severe beatings are not the norm, but any physical punishment can be classified as abuse; and, parents not socialized in other forms of discipline, can experience difficulties during child rearing (García-Preto, 2006). As described
earlier, *marianismo* and *machismo* concepts also come into play in the dynamics of *familismo*, when socializing children into their future roles (Vázquez-Nuttall & Romero-García, 1989).

An example of the connection between children and their parents/grandparents is *la bendición*. Every day before a child leaves home or the home of a grandparent, the child is expected to ask for a blessing, *la bendición*. The mother, grandmother, or aunt then declares “*Que Dios te bendiga,*” “May God bless you.” This petition may also happen at the end of any interaction, phone call, or written communication (C. Predraza-Silva, personal communication, August 18, 2011). In more elaborate blessings, the parent may make the sign of the cross on the child and the child will then kiss the parent’s hand. The blessing is believed to protect children outside of the watchful eyes of the parents. It also reflects the belief that the parent has the power to invoke God’s special protections over their beloved children.

*Compadrazgo* is the extension of family connections beyond the immediate nuclear family. When a child is baptized into the Roman Catholic Church, godparents are selected to support the parents in raising the child in the Catholic faith. There is also an expectation that they would assume responsibility for the child if the parents could no longer care for the child due to illness or death (Gill-Hopple & Brage-Hudson, 2012). The child would then be called a *hijo de crianza* or foster child (García-Preto, 2006). Being chosen as godparents is an honor bestowed upon those individuals and welcomes them into the family. The godparents can be relied upon for any type of assistance in raising the child. The godmother is called *madrina* (godmother) by the child and referred to as *comadre* (co-mother) by the parents. The godfather is called *padrino* (godfather) by the child and referred to as *compadre* (co-father) by the parents. Usually a godparent is a sibling, cousin or a best friend of the parents. In some situations, a personal contact with economic means, such as an employer, may be chosen as a godparent.
A godparent can also receive the benefits of children, such as a caretaker in their old age, through compadrazgo.

**Personalismo/respeto.** Personalismo and respeto are the cultural concepts governing interactions with others outside of the family unit. Personalismo describes the preference that a warm interpersonal relationship be established for interactions that may be sensitive in nature. This level of relationship may develop over time in business relations but will need to develop more quickly in intimate settings, such as health care. Personalismo is often cited as a factor in healthcare provider patient relations (Campesino & Schwartz, 2006; Davis, 1996). Respeto defines the boundaries in all relationships, recognizing the authority of others through education, economics, family relationships and age. If a person has a title of respect, it should be used every time that person is addressed. Therefore, a person with a doctoral degree is always called doctor or doctora. Respeto explains the practice of Latino patients calling their nurse practitioners, “doctor/doctora,” in recognition of the advanced education of their healthcare providers. Children are taught to treat all elders, even those not related to them by blood or compadrazgo, with respect. This respect is demonstrated by adding the salutation don or doña to the first name of the person. In contrast to other customs, which require the use of the elder’s last name, the use of the first name reflects personalismo for Latinos.

**Curanderos/espiritistas.** In Puerto Rico, there is an extensive healing tradition that is used to treat physical, psychological and spiritual ailments. This tradition started with the Taíno people and was augmented by the African traditions. Like all healing and herb lore, it has been passed on through an oral tradition and apprenticeships that favored women (Benedetti, 2000; 1999). These midwives and healers were respected in their towns and their assistance was sought by all. Healers and espiritistas were maligned during the mid-20th century when the
Puerto Rican business elite wanted to build the medical establishment transported from the US (Holliday, 2008; Romberg, 2003).

In the 1970s, there was a public resurgence in the herbalist/curandero/espiritista traditions as part of the overall revival in the Puerto Rican heritage (Romberg, 2003). Books were published which provided ethnographic interviews of curanderas and listings of the herbs they use and what ailments they can treat. This renaissance of the curanderas and espiritistas is visible by the presence of botánicas in Puerto Rican neighborhoods on the island and on the mainland. The botánica can be found in the local business listings as a religious article store, but it offers much more. The proprietor is also a practitioner and will provide the individual with a spiritual reading (assessment) and diagnosis. The curandera/espiritista will begin the healing process with a spiritual cleansing and then recommend herbs to make teas, or baths and rituals to complete the healing process.

Physical, psychological, and spiritual health are all interconnected in this belief system and the work of the curandera/espiritista addresses the problem from this holistic perspective. Because of this emphasis there are many who prefer this approach and will seek the counsel of the curandera/espiritista before consulting a medical professional (Holliday, 2008; Swanson, 2012). Some of the remedies include the use of elements that cause severe reactions and illness in elevated doses (Newby, Riley & Leal-Almeraz, 2006) and local municipalities have determined that some products and practices are illegal (Holliday, 2008). Some Puerto Ricans and other Latinos have been instructed by medical and legal personnel that their cultural practices should be abandoned (Holliday, 2008). Thus, Latinos may keep their cultural health practices from their healthcare providers; or, opt to forgo the care of the espiritista; or, the healthcare provider.
Kinship and Social Factors, Influenced by the Post-Colonial Experience

**Puerto Rican identity and citizenship.** Puerto Rican identity is a composite of three cultures that came together through the Spanish colonization of the Americas. The cultural concepts, religious, linguistic, and musical traditions have blended as have the physical features of the Taíno, European (Spanish) and African peoples to become the Puerto Rican people (Jiménez Román, 2001). The results of the blending of physical features are found in the range of phenotypical expressions within families. It is not uncommon for a family unit to have a spectrum of physical features. There is no concept of racial differentiation among the Puerto Rican people, because Puerto Rican is considered a “race” of its own (Rivera-Batiz, & Santiago, 1996). There are preferences for fair-skinned people, but this does not manifest as racial hatred and discrimination as in the US. In the past 40 years, there has been a rebirth in the interest in the Taíno and African lines of heritage. As part of a nationalist pride movement, the “rediscovery” of these roots is an effort to maintain the distinct Puerto Rican identity (Haslip-Viera, 2001). Figure 4 (Appendix F) provides a visual depiction of the concept of “Three Races: One Culture” campaign. As discussed previously this movement has included a renewed interest in the healing and spiritual practices of Puerto Rico.

There are variations of sentiment regarding the “American” identity that developed since the occupation of Puerto Rico by American forces nearly 120 years ago. There are those who have welcomed the association with the US and desire that Puerto Ricans take the next step to statehood that started with the Jones Act in 1917 (Cabán, 1993). There are also those who wish to further distance themselves from the US and US citizenship and the American culture (Cabán, 1993). In 1900, Puerto Rican citizenship ceased to exist when the residents of Puerto Rico became US nationals. Juan Mari Bras, an attorney and nationalist, renounced his US citizenship
in 1994 and it was not until 1997 that the Puerto Rican Supreme Court granted him Puerto Rican citizenship, allowing him to vote in elections in Puerto Rico (Thomas, 2010).

**Puerto Rican identity on the mainland.** The perceptions of identity that new Puerto Rican migrants experienced upon arriving in the US have varied through the years. The Puerto Ricans who arrived before the Spanish American war were Spanish nationals and renounced their Spanish citizenship, if they became US citizens. From 1900-1917, as US nationals, it was unclear how citizenship change would occur when a Puerto Rican came to the US mainland (Thomas, 2010). As US citizens after 1917 with the Jones Act, they expected to be treated accordingly when they came to the US mainland. Instead, they experienced discrimination on many levels, including educational, economic, and racial.

The racial discrimination was a new experience for Puerto Ricans, because in Puerto Rico, one’s social station, education and economic standing were recognized, and everyone was respected per the cultural concepts of *personalismo* and *respeto*. When identification papers with pictures were issued in Puerto Rico, the height, weight, hair, eye and skin color were described, but this was not an identification of their race (Fox, 1996). When the Puerto Ricans came to the US, they were asked to identify themselves as either “white” or “black.” The identification cards of Puerto Ricans, issued in Puerto Rico, were altered if the word “white” was used to describe them, even if they were fair-skinned (Thomas, 2010). The word “white” would be crossed out and the word “dark” was typed onto the document. To reduce the self-doubt and build a sense of pride, some Puerto Ricans did choose a race and became acculturated accordingly (Roberts, 2001). The Puerto Ricans in NYC became known as “Nuyoricans” to Puerto Ricans on the island. This was not a term of endearment but an insult calling attention to the marginalized Puerto Ricans who were unable to realize the dream of America: better jobs,
better pay, better education and social mobility (Jiménez Román, 2001). In recent decades, there has been a movement to reclaim the title, “Nuyorican,” and instill it with a sense of pride for the youth (Santiago, 1995).

A unique development for the Puerto Rican community, due to the easy travel between the US and Puerto Rico, is the strong maintenance of familial and social ties with communities of origin. Reciprocal waves of migration for economic purposes (García Coll & Mattei, 1989; Rivera-Batiz & Santiago, 1996) both to and from Puerto Rico and the US have developed with families spending a few years at a time in each location. Some children have been raised in both the US and Puerto Rico, living during the school year in the US with their parents and then spending their summers and long holiday breaks with their grandparents in Puerto Rico. It has been said that there is an air bridge, or aeroguagua, meaning air bus, between the US, and especially, NYC, and Puerto Rico (Duany, 2002). In fact, as early as the 1950s, relocating to the US from Puerto Rico was referred to as brincando el charco or jumping the pond (Jiménez Román, 2001). Individuals have been called “bicultural” because they maintained such strong identification with both the US and Puerto Rican cultures and can easily switch between the two.

**Roles, responsibilities and reproductive health choices.** For many women, finding work outside of the home saved their families. Their spouses may have been unemployed or only had seasonal work, resulting in no steady income. If a woman had skills such as cooking, crocheting, knitting, or sewing, she could supplement her spouse’s income and remain in the home by selling home-cooked dishes or hand-made clothing or other items. If she was not skilled as a cook or seamstress, she would need to find a paying job outside of the home (Whalen, 1998) to assure that her children were fed and clothed. The chance of another pregnancy would make the women less employable. A mother might be concerned about
feeding and caring for the children she already had (López, 2008). Per marianismo, a woman was not able to refuse her husband’s sexual advances, nor could she require the use of condoms, if she knew what they were, to prevent a pregnancy. For these women tubal ligations, also known as sterilization, was a way to control their lives by reducing the number of children they had to care for, thus simplifying their existence and providing them with the opportunity to work in the growing industries in Puerto Rico during the mid-20th century.

Although never an official policy, while sterilization was illegal in the US, it was encouraged in Puerto Rico. The family planning movement in the US found “fertile” ground in Puerto Rico for testing their ideas and methods. Gynecologists could train in sterilization procedures in Puerto Rico and the birth control pill was infamously tested on Puerto Rican women, on the island in the late 1950s (López, 2008; Miranda King, 1979). The risks of these procedures and medications were not fully explained to the women, as occurred in the United States Public Health Syphilis Research Program at Tuskegee University. Early testing doses for the birth control pill, estrogen only, used higher than required doses, resulting in the deaths of women due to emboli (López, 2008; Miranda King, 1979). Women had believed there were different surgical procedures for sterilization, some of which could be reversed, if so desired, by tying versus cutting and cauterizing the fallopian tubes. While early procedures did result in failures (i.e., pregnancies), recent advances have reduced this result. Yet, some Puerto Rican women do not know which procedure was performed on them and believe it is still reversible (López, 2008).

During the mid-20th century, sterilization campaigns frequently occurred in Puerto Rico in conjunction with electoral campaigns as political candidates offered free procedures to women in exchange for their votes. Even though there were incidents of sterilization abuse, and the use
of deception on women in poverty with low literacy, or developmental challenges, the procedure became so common and recommended that it came to be part of the vernacular as *la operación* (the operation) (López, 2008). Puerto Rican women both on the island and the US mainland have the highest numbers of sterilization rates worldwide (López, 2008). In a multigenerational ethnographic study conducted over 20 years, Puerto Rican women interviewed cited achievement of their desired family size; concerns for raising children in dangerous neighborhoods; desire to control conception when their partners do not wish to use condoms; and, difficulties or lack of knowledge of other methods of contraception as reasons for requesting tubal ligations (López, 2008).

**Female-headed households.** Puerto Rican families are more likely to be headed by a female, like African-American families (Torruellas, 1995, June 26). A larger proportion of female-headed households is viewed as a by-product and a cause of inner-city poverty. For the most part, the women, who head these households, have achieved a lower level of education and consequently are unable to attain steady employment that can adequately support a family (Acosta-Belén & Sjöstrom, 1979; Ramos, 2012). These women may find themselves unable or unwilling to rely on the income of a male partner either due to divorce, separation or death, and these men are unable or unwilling to contribute to the financial care of their children (García-Preto, 2006). These women must rely upon government benefits to support their children. They live in poorer neighborhoods, are exposed to higher levels of stress, a less nutrient-dense diet, and have more difficulty accessing high quality services, such as, health care, education for themselves and their children. Their children are more likely to not complete their education and continue the cycle of poverty (Olds, et al, 2010).
In Puerto Rico and Puerto Rican communities, there are several cultural and ethnohistorical factors, which may contribute to the higher number of female-headed households. As discussed previously, consensual relationships were common in Puerto Rico due to the limited rural access to priests to marry couples. Consensual relationships are easier to dissolve, as there are no religious and legal ties between the partners. With the economic development on the island and the migration to the US, women increasingly became the breadwinners in the household (Guilamo-Ramos, 2000; Rios, 1995; Rivera Quintero, 1979). With women’s increasing workload outside of the home, increased tensions occurred in the home if the male partner, either equally or less employed, was not willing to assist with childcare or housework, which was a departure from the traditional gender roles of the time (Muñoz Vázquez, 1979; Pico de Hernández, 1979; Ramos, 2012). These gender role change stressors resulted in marriage/relationship dissolution (Landale & Ojena, 1995; Muñoz Vázquez, 1979; Ramos, 2012). Other stressors were the contraceptive choices women made without the consent of their male partners (López, 2008) that could also lead to separation.

Women with sufficient education and training and steady job prospects can, depending upon the size of their family, support themselves and their children. For others, their job prospects and family care options are not enough to provide them with the comfort level to work outside of the home. These women will choose to rely on government benefits for the permissible timeframe to stay at home with their children, even if it may offend their pride (Torruellas, 1995, June 26). This self-sacrificing behavior can even extend to avoiding new relationships until the children are adults. Another commonly known issue for the number of female-headed households is the penalty that families in poverty suffer if there is a male financial presence in the household. For these families, a conscious choice is made to not report
the presence of the male household member to receive the maximum financial benefit (E. Cabassa, personal communication, May 21, 2012).

**Substance use.** Illegal drug use has been cited as a problem in the Puerto Rican community on both the island and mainland. The colonial relationship between Puerto Rico and the US is a factor in this problem. There has been a prolonged exposure to the American culture, which has a relatively more permissible view of drug use (Córtes, et al., 2003), in comparison to the Puerto Rican culture; the economic issues in both Puerto Rico and the urban centers where Puerto Ricans migrated have resulted in increased unemployment rates; Puerto Ricans have endured discrimination and disparities in education and employment; acculturative stress is another factor which has been implicated in illicit drug use (Córtes, et al., 2003; Deren, et al., 2011; Pérez Torruella, 2011; Zerden, 2009). In a study examining the profile of Latinas, mostly Puerto Rican, in residential treatment for substance abuse in Massachusetts, Amaro and associates (1999) found that many of the women had limited educational achievement; were the heads of their households and unemployed; had mental health diagnoses and medical diagnoses; and had suffered emotional, physical and/or sexual abuse.

Other studies have indicated that complicated acculturation and assimilation resulting in either “biculturalty” or marginalization caused increased psychological distress. Initiations into substance use became a way to fit into social groups or self-treat the psychological distress (Andía, 2000; Guilamo-Ramos, 2000). For many Puerto Ricans smoking marijuana and injecting heroin are the drugs of choice. Substance use, itself, is an added source of stigma, further marginalizing them from the mainstream community, and strengthening their association with their substance using peers (Pérez Torruella, 2011). Substance using networks developed in
NYC and in Puerto Rico and users would travel the air bridge, between their island and mainland networks (Oliver-Velez, et al, 2002).

Cultural norms in Puerto Rico include the sharing of food and resources within one’s network. The positive benefits of this have been seen in the concept of *hijos de crianza* and welcoming of relatives and friends into one’s home, which helped new migrants, establish themselves in their new communities. This idea was continued into the injecting drug using community through the sharing of drugs and drug paraphernalia as a bonding experience (Andía, 2000). This sharing would occur within the US and the Puerto Rican substance using networks (Zerden, 2009). Some other cultural norms that flowed into the drug using culture are *marianismo* and *machismo*. Women would follow their male partners into drug use and in the sharing networks would put the male first where he would inject/use first followed by her, putting herself at greater risk for acquiring infections (González-Guarda, et al, 2008; Rivera-Oquendo, 2007). For these groups the risks of HIV infection are magnified by the multiple ties (sexual and drug using) leading to multiple exposures (adams, Moody & Morris, 2013). The US Mainland Puerto Rican injecting drug using communities have incorporated safer injecting practices into their substance use behaviors since the advent of HIV, yet the communities in Puerto Rico have been slow to adapt these lifesaving practices (Oliver-Velez, et al, 2002; Rivera-Oquendo, 2007; Zerden, 2009) and they continue to be at high risk for HIV infection (Deren, et al, 2011; Deren, et al, 2014; Leff, et al, 2017; Rivera-Oquendo, 2007).

Language

Spanish is the primary language of the Puerto Rican people and is a remnant of the colonial relationship with Spain. It remains the official language of Puerto Rico and is often spoken in the homes of Puerto Ricans who have relocated to the US mainland. When the US assumed control of Puerto Rico, English became a prominent language on the island (Benson,
As part of the Jones Act, English was declared the official language of Puerto Rico and all educational, business and governmental activities were conducted in English. Teachers were required to teach in English without knowing English themselves (Fox, 1996). During this time the rejection of the imposition of the English language counteracted the efforts to improve the education system in Puerto Rico. When Puerto Rico became a commonwealth of the US, Spanish was reinstated as the official language (Benson, 2003).

English remains an important language in Puerto Rico and is a required second language throughout elementary and secondary school. However, many Puerto Ricans have not achieved fluency in English (Rivera-Batiz & Santiago, 1996). The Puerto Ricans who work in tourist industries or reside in the major cities are fluent in English and Spanish, but the rural population is mostly fluent in Spanish.

The Puerto Ricans who have migrated to the US have varying levels of fluency in both English and Spanish. The quality of primary school education has determined the fluency of the following generations of Puerto Ricans. The level of Spanish fluency is determined by exclusive use of Spanish in the home, which is known to wane in subsequent generations (Zentella & Otheguy, 2009, February); and access to Spanish language education, either as a second language or through bilingual education, in the school system. Many youth of Puerto Rican descent speak a combination of Spanish and English, which is called code-switching in the linguistics and anthropology literature; and, Spanglish, colloquially. The Spanglish speaker or code-switcher moves easily and at any point in a sentence between Spanish and English (Duany, 2009, February 13; Kharkhurrin & Wei, 2015; Martinez, 2014; Zentella & Otheguy, 2009, February). This linguistic ability rooted in bilingualism is most common in first and second generations (Otheguy & Zentella, 2012). Puerto Ricans are not the only Latinos to code-switch.
Spanish fluency is maintained throughout the Puerto Rican and Latino communities with the ready accessibility of Spanish language periodicals, reporting both local and country-of-origin news. Another major source of exposure to Spanish is television and the internet. Spanish language networks are available through free television programming as well as cable network programming for a monthly fee. Spanish language websites exist and the America Online (aol) website has a Spanish language site.

**Biological Factors**

Puerto Ricans are not known to have specific biologic or genetic conditions as a group. The mixed heritage of Puerto Ricans (Taíno, European and African) creates a unique presentation of health conditions. Individuals with African or Mediterranean heritage have an increased risk and incidence of sickle-cell anemia, and yet an individual’s appearance may not lead a health care provider to consider this factor, an important consideration during differential diagnosis. Much of the health disparities, commonly seen in the Puerto Rican community, demonstrated by increased incidence and prevalence of health conditions, are influenced by the lived experience of acculturation, environmental factors, behaviors and the experience of discrimination (Gallo, et al, 2014; Molina & Simon, 2014; Verrissimo, Grello, Amaro & Gee, 2014). Examples of these conditions are Type 2 Diabetes Mellitus and heart disease; mental illness and substance use.

The extensive acculturation of Puerto Ricans both on the island and the mainland mutes the effect of the Hispanic Paradox (Borrell & Lancet, 2013), often seen in other Latino communities. In a recent CDC report, Lucas, Freeman and Adams (2016, June) compared health conditions among Latinos in the US from the National Health Interview Survey, 2010-2014. Their findings indicated that Puerto Rican adults have reported being in fair or poor health more
than among all Latinos (19.2% vs. 16.8%). Puerto Ricans were also more likely to suffer from multiple chronic conditions as compared to all Latinos (27.3% vs. 20.8%); suffer from psychological distress in the past 30 days (6.2% vs. 4.1%); and, were unable to work due to these and other health conditions (11.4% vs. 5.2%) (Lucas, et al, 2016, June). These findings were similar to previous reports on health of Latinos.

**Educational Factors**

When the US colonized Puerto Rico, there were efforts to develop an educational system which focused on English, as noted above. The frustrating learning environment led many youths to end their education early and try to find work. Even when Spanish was reinstated as the language for education, the poverty of the people still led them to leave school early to work (Benson, 2003; Rivera-Batiz & Santiago, 1996). The private education system (primary, secondary and higher education), consisting of mostly Roman Catholic schools, achieved academic results and became notable institutions of learning worldwide, while the public-school system’s results are less laudable. The public university system in Puerto Rico is also well-recognized. The teachers in the public-school system, though well-educated in the university system, are very poorly paid (R. Silva-Llinás, personal communication, July 11, 2012). The low wages of the teachers reflect the lack of investment in the education system in Puerto Rico (García Blanco & Colón Morera, 1993; Rivera-Batiz & Santiago, 1996).

In the US, most Puerto Rican families reside in lower income neighborhoods in large cities. In these neighborhood public schools, there is also little investment by the school system in the success of their students (Meléndez, Plaza & Segura, 2012, December). Part of the problem is the lower expectations that the teachers hold for their students in these neighborhoods. Anecdotal evidence discovered by this researcher reveals that in the 1950s and
60s Puerto Rican students were placed in special education classes or held back a year based on their surnames or when speaking English with an accent (I. Navarro, personal communication, July 6, 2012). There were no English as a Second Language (ESL) classes at that time and children were expected to learn English by sitting in the classroom using American teaching strategies that were different from those in Puerto Rico (López, 2007). Parents, who spoke only Spanish or whose English language skills were not strong, were unable to help their children with homework or even advocate for their children with school administrators (I. Navarro, personal communication, July 6, 2012). Some children were tracked into vocational classes (López, 2007) if they remained in the school system. Even with ESL classes and bilingual education, a result of the advocacy efforts of the Puerto Rican community and concerned educators (López, 2007) in the 1960s and 1970s, recent efforts to dismantle these programs run the risk of once again creating disadvantages for Puerto Ricans as they enter the workforce (De Jesus & Pérez, 2009). Puerto Rican children are still at risk of economic underachievement due to being undereducated as is demonstrated by the high drop-out rates, low employment levels and continued reliance on government benefits (Reyes, 2012).

One great lament of various Puerto Ricans in the US was the lack of information on Puerto Rican history and culture during their educations, both public and private. These children, as adults, reported being told by their teachers that Puerto Rico had no history or that there was nothing to learn about Puerto Rico (López, 2007). Some of these individuals were surprised and delighted to learn of the many poets, artists and historians who write regularly about the Puerto Rican experience on both the island and the mainland (Santiago, 1995). Educators rallied against their institutions to establish centers and programs of study for the Puerto Rican community (Jiménez, 2009). In New York City, after protests against the City
University of New York (CUNY) led by faculty of Puerto Rican descent, a community college, Eugenio Maria de Hostos Community College, was established in 1968 in the South Bronx. In addition, the Center for Puerto Rican Studies, also known as Centro de Estudios Puertorriqueños or Centro, was founded in 1973 (Whalen, 2009) and is housed at CUNY Hunter College. Both these institutions are working to educate the Puerto Rican and the greater New York communities about Puerto Rican history, culture and the experiences of the diasporic Puerto Rican peoples.

**Technological Factors**

Technological factors have been closely tied to the educational and economic factors affecting the Puerto Rican community on both the island and the mainland. It was the use of technology that displaced many farmers from their own farms or the larger coffee, sugar and tobacco plantations, at the start of the 20th century. The new machines for harvesting and processing the crops reduced the number of workers required to do the job and made it essential that the workers who were retained could operate and troubleshoot the equipment. Many Puerto Ricans had a severely limited education due to the need to work the farms (Mintz, 1974). Children would harvest along with their family members as soon as they could reach the crop and follow directions. Any education happened during the off-season for that crop.

With the expansion of economic opportunities that Operation Bootstrap provided at new factories for garment and lace making or other products, an education and ability to work with the new technologies were required to maintain employment (Bonilla, 1993). For those displaced again, the lower skilled laborers were encouraged to move to the US mainland to find jobs that they could perform (Sánchez Korrol, 1983). However, in NYC and other industrial areas, there was competition with other low skilled workers, African-Americans from the south
The Puerto Ricans of today on both the island and mainland have access to the technology that most Americans do. The ability to afford the devices is the only inhibition as most products come with instruction manuals in multiple languages. Families have radios, television sets with access to cable networks and home-based and hand-held computers with wireless internet access. Even for those individuals at the lower end of the socioeconomic scale, there are subsidized programs that offer low cost cell phones with limited minutes for those who qualify for government programs (E. Cabassa, personal communication, May 21, 2012). This allows them to have telephone access when away from home.

**Environmental Context**

**Health care in Puerto Rico and New York.** Private insurance as well as Medicare and Medicaid programs finance health care in Puerto Rico. Since Puerto Rico is not a state, the government receives a block grant to cover the health care of all indigent individuals on the island. Qualifying for Medicaid, called Mi Salud, allows an individual to receive healthcare at the designated public health facility networks (Pan-American Health Organization (PAHO), 2013, April). It does not function as insurance, that is, being able to receive care from a provider or facility that accepts Medicaid for payment, as it does on the mainland. This difference severely restricts access to healthcare leading to de-facto rationing of care to all Puerto Ricans on the island. In addition, there is no Supplemental Security Income (SSI) for Puerto Rico residents. There are also more stringent caps on TANF funding in Puerto Rico. Puerto Rico and other US territories are afterthoughts in the planning for federal policies and programs, both in the allocation of resources and in the gathering of data. For example, Washington, DC, which has representation in Congress, is considered equally with the 50 US States in the allocation of
funds and resources during the budget planning process. In 2012, the representative for Puerto Rico introduced a bill requesting that Puerto Rico and the remaining US territories be given equal consideration during the budgeting process, especially for any health and social service programs (gov.track.us, n.d.). In 2005, PAHO, part of the World Health Organization, issued a report, which described the healthcare system in Puerto Rico as “not effective, not efficient and not equitable” (2007, September).

In contrast, New York State has one of the most generous Medicaid programs in the US. The program functions as an insurance program, permitting the individual to present the card for covered healthcare services at facilities and providers that accept Medicaid. Medicaid is often the primary payer for nursing home services. Medicaid recipients can also receive extended home care services based on the medical diagnosis. In recent years, to control costs, NYS has required Medicaid recipients to enroll in a managed care program, administered by private companies, to offer expanded preventive care services and reduce other costs. This requirement was extended to Medicaid recipients with an HIV diagnosis in 2011 (NYS DOH, 2013, November). To qualify for Medicaid an individual or family must either meet the income requirements and/or be diagnosed with a designated health condition.

The implementation of the Patient Protection and Affordable Care Act of 2010 (ACA) in 2014 greatly changed the health insurance landscape in the US. Health insurers can no longer deny coverage for a pre-existing condition and employers with companies of greater than 50 employees and must provide insurance options for full-time workers. Individuals who do not acquire insurance coverage through their employers, can purchase insurance through the Marketplace (state and federal options are available) which allows individuals to search through various plans and select, register and pay for their plans. Subsidies are available to those with
financial need. In addition, Medicaid eligibility criteria could be broadened to permit an expansion of the population with Medicaid coverage. Many states opted to not expand Medicaid eligibility or create statewide marketplaces requiring individuals to seek coverage through the federal marketplace. New York State is a full participant in the ACA. Recent efforts to dismantle the ACA and change the funding for Medicaid have created great uncertainty among the healthcare insurance market and individuals who receive their healthcare through these programs (Kaplan, 2017, July 18). However, New York has maintained its commitment to the programs developed through ACA.

Puerto Rico, as a commonwealth of the US, and the other US territories were not included in the planning for the ACA. Puerto Rico opted to create its own version of the ACA and adopted some of the rules, such as the pre-existing condition clause and expanding Medicaid (Mi Salud) coverage. However, there is no individual mandate for coverage. There are subsidies to Puerto Rico from the federal government to assist with the expanded Medicaid coverage, but there are restrictions regarding when they can be accessed, and individuals do not have access to the Marketplace. The fiscal crisis in Puerto Rico and the reluctance of the US government to permit options available to states for managing the financial situation places further strain on the opportunities to provide healthcare services to the people (New York Times Editorial Board, 2015, December 26).

**Substance use treatment in Puerto Rico and New York.** Access to successful substance use treatment programs has been a continual problem both on the mainland and in Puerto Rico, as it is globally (des Jarlais, et al, 2013; Jarlais, et al, 2012; Simmons & McMahon, 2012). The main issues are the shame and stigma associated with substance use; limited conceptualization of substance use as a disease; and, limited funding for treatment (des Jarlais, et
al, 2013; Jarlais, et al, 2012; Pérez Torruella, 2011; Zerden, 2009). There is also an abstinence approach to substance use cessation, in the culture, religions, and programs in Puerto Rico (Deren, et al, 2014; Pérez Torruella, 2011; Zerden, 2009). In contrast, in the mainland US there is a broader conceptualization of substance use as more than a behavioral problem with treatment receiving more funding and being more widely available (Deren, et al, 2014; Pérez Torruella, 2011; Zerden, 2009). The concepts of harm reduction and medication treatment for substance use are hard to find in Puerto Rico (Deren, et al, 2014; Rivera-Oquendo, 2007).

The air bridge has been used to send people in need of substance use treatment to the US to access the services that would more appropriately meet their needs, that is needle exchange options and methadone and buprenorphine treatments, because these services are unavailable in Puerto Rico (Pérez Torruella, 2011). Even with the greater availability of medical treatment for drug addiction there are deficits in the treatment of the social issues that accompany substance use. Amaro and colleagues (1999) have recommended drug treatment programs that also provide mental health treatment and assist with educational programs; job training and placement; and, assistance with housing to move people through recovery. Another issue in substance use treatment is the limited number of programs that focus on cultural issues and interpersonal dynamics, for example, underage dependents or a drug using partner, for some. Simmons and McMahon (2012) propose that couples’ treatment, either at the same or different programs, would be an effective modality as the partners can be supportive of each other in their individual recovery processes. Along with a program like this, social supports such as, housing and job training are necessary to support long-term recovery. This level of coordination continues to be a challenge in NYC and is non-existent in Puerto Rico (Deren et al, 2014).
**Pharmaceutical industry in Puerto Rico.** Section 936 of the Internal Revenue Code encouraged the movement of pharmaceutical industries into Puerto Rico (Meléndez, Edwin, 1993). While opening new employment opportunities for Puerto Ricans, as with most industries the products were intended for export out of Puerto Rico. When the HIV epidemic began, these pharmaceutical companies moved to the development and production of the antibiotics and antiviral medications used in the treatment of HIV disease and opportunistic infections. Even though Puerto Ricans were working where these medications were manufactured, many of the people were not able to benefit from these therapies since these novel treatments were only being prescribed by the leading physicians in the field in the US mainland (Reyes, 1997-1998).

The block grants for Medicaid, the main source of health care coverage for people living with AIDS, could not cover the costly fees for HIV-related medications, in addition to providing medical care and medications for the other conditions of the indigent population of Puerto Rico. In the early years of the HIV epidemic, there was no separate funding for medications, like the AIDS Drug Assistance Program (ADAP), which was available on the mainland. Furthermore, while drug trials were expanding in the US and with increasing complaints of lack of access to these same trials by African Americans and Hispanics, these pharmaceutical companies refused to establish clinical trial groups in Puerto Rico (Reyes, 1997-1998). The medical authorities cited the lack of medical care at the Puerto Rican clinics meeting the same criteria as those in the US mainland as the reason for this decision. These actions were protested by community-based organizations, such as the Latino Commission on AIDS, situated in NYC and the National Puerto Rican Coalition (Barron, 1992; National Commission on AIDS, 1992, June).

**Summary of Cultural and Social Structure Dimensions of Puerto Ricans**

The ethnohistory of Puerto Rico is intertwined with experiences of colonialism. The Spanish colonial activities, in which the Taíno and African people were dominated, forced the
melding of culture, religions and social structures of Puerto Rico. With the switch to the American colonial experience, further influences on culture through economic pressures have occurred throughout the 20th century. The colonial association with the US has increased the economic standing of Puerto Rico but has not consistently benefitted the Puerto Ricans on the island or those who were encouraged to migrate to the US. Limited educational and job opportunities and assaults on the identity of Puerto Ricans have resulted in higher levels of poverty and female-headed households and substance use for Puerto Ricans. Substance use is also a problem in Puerto Rico. As a commonwealth of the US, Puerto Rico is not considered the equivalent of a state and is ineligible for equivalent benefits and representation, even though the political activities of the US government greatly determine Puerto Rico’s economy and subsequently every other aspect of the lives of the Puerto Rican people, in particular, health and healthcare.

On September 20, 2017, a category four Hurricane Maria devastated the island of Puerto Rico, destroying the power grid and cellular phone tower networks in Puerto Rico, as well as many homes and communities through the dense tropical hillsides (Ferre-Sadurni, Alvarez & Robles, 2017, September 21). The devastation of the island was poorly communicated due to the loss of electricity, telephone and cellular phone service (Robles, Alvarez & Fandos, 2017, September 25). Individuals in need were unable to access services as downed trees blocked roadways. Transportation to a hospital did not guarantee care as there was no electricity there either. Non-functioning water pumps could not deliver potable water into homes and sewer systems were unable to remove waste water appropriately. The commonwealth status of the island combined with the fiscal crisis has further complicated the delivery of disaster relief
services. Individuals with the means, financial and familial, and desire have migrated to the mainland or have sent their minor children to live with relatives (Alvarez, 2017, November 17).

**HIV Epidemic in the Puerto Rican Community**

When the CDC first reported the incidence of pneumocystis carinii pneumonia and cytomegalovirus in previously healthy gay men in Los Angeles (CDC, 1981, June 5), New York City was also reporting incidences of these same diseases usually seen in immunocompromised individuals, in men who have sex with men (labeled as gay men, at the time) as well as injecting drug users. The HIV epidemic in the US was mostly concentrated in large cities, which became known as epicenters, one of which was and continues to be New York City. Disparities in lower socioeconomic groups and racial and ethnic minorities were seen early. Hispanics who were diagnosed with HIV had very similar risks to other US groups. There were larger numbers of infection in men who have sex with men, and bisexuals; then, injecting drug users; heterosexuals, particularly female partners of bisexual men and injecting drug users (CDC, 1983, January 7); children (CDC, 1982, December 17) and recipients of blood products (CDC, 1982, July 16). However, in the Puerto Rican community there was a difference, most of the cases were at risk through injecting drug use (Deren, et al, 2014; Menéndez, et al, 1994). This in turn increased the risk of the sexual partners of these individuals (Castro de Alvárez, 1990; Menéndez, 1990).

**The air bridge.** The phenomenon explaining the connection between the NYC and the Puerto Rico HIV epidemics; and, the frequent travel of infected persons between both locations is known as the air bridge (Colón, 1992). The familial connections on both the island and the mainland and the poor economic prospects experienced by many Puerto Ricans in both locations and low air-fares facilitated frequent travel back and forth (Guilamo-Ramos, 2000). The communal nature of injecting drug use patterns, particularly in the early years of the AIDS
epidemic, facilitated the movement of the virus within networks on the island and the mainland through drug use and sexual contact (Córtes, et al, 2003; Deren, et al, 2011; Zerden, 2009). The significance of the air bridge inspired a day-long conference for medical providers in NYC and Puerto Rico to discuss the challenges of effectively caring for the population using it (Colón, 1992).

Early in the epidemic, Puerto Ricans had choices regarding where to reside. As US citizens, they were not subject to the State Department ruling in the late 1980s that prohibited the entry of HIV positive persons into the US. This ruling was officially rescinded in 2010 (Preston, 2009, October 30). If they had engaged in high-risk behaviors, injecting drugs or having same sex partners, not condoned by the family, they might continue to live in NYC to avoid the shame from and for their family (Rivero, 1994; Roldán, 1999). If they were receiving treatment and responding well to the therapies, they might also remain in NYC to continue receiving care and benefits available in NYC. Those initially diagnosed in Puerto Rico might travel to NYC to initiate treatment for HIV disease, especially opportunistic infections, that was unavailable in Puerto Rico or, to put some distance between them and their family to spare them the stigma associated with the diagnosis (Brett, et al, 1996; Menéndez, et al, 1994). However, as the disease progressed, and treatments became ineffective, a return to Puerto Rico could indicate a desire for treatment from the hometown curandero or family care. For some, an HIV diagnosis did not change their cyclical migration to and from NYC and Puerto Rico due to their established familial or communal supports (Deren, et al, 2014; Zerden, 2009).

Continuity of care for people living with HIV was difficult to achieve in NYC with many duplicated services by different health care and social service agencies within the same geographic area. The movement of people between NYC and Puerto Rico further complicated
the care of these individuals, as they may have been unable to report medication changes, allergies or the development of new conditions (Centro Journal, 1994; Lima, et al, 2009). For those who used the air bridge frequently, the errors with medications and treatments happened more often. Therapies were unavailable in Puerto Rico due to cost and availability; and, drug treatment options like methadone or needle exchange were even more limited in Puerto Rico (Deren, et al, 2014; Pérez Torruella, 2011; Zerden, 2009).

**Disparities in HIV for Hispanics/Latinos.** While highly active antiretroviral therapy (HAART or ART) has been available since 1996 and efforts have been made to increase funding to cover the costs of these medications in the US mainland and in Puerto Rico, disparities in care remain for all Hispanics/Latinos. Puerto Ricans continue to be one of the largest groups of Latinos affected by HIV disease. With a prevalence case rate of 458.8 per 100,000 people in 2012 (Gray, et al, 2015) this amounts to Latinos accounting for 21% of all people living with HIV, even though they account for only 17% of the US population (Gray, et al, 2015). Teasing out the statistics for Puerto Ricans is a difficult endeavor for the following reasons: reporting requirements and methods vary by state and territory (HIV infection versus AIDS diagnosis); self-reporting of risk and race/ethnicity; classification of Puerto Ricans by place of birth can vary (born in US versus Puerto Rico); designation of Puerto Ricans born in Puerto Rico as “foreign-born” also varies; reporting delays; and, movement of individuals from place of diagnosis. To achieve statistical significance in studies or to minimize the number of categories for reporting purposes, researchers will often consolidate the data on ethnic and racial groups. This practice has implications for all racial and ethnic groups, in that while it statistically will strengthen the results, at the same time it weakens those same findings for the individual groups by creating distance and diluting meaning (Deren, et al, 2014).
Latinos with HIV and their families can experience more reported stigma than other groups related to cultural perceptions of behaviors associated with HIV transmission (CDC, 2018, February 23; Holtz, 2010; Relf, et al, 2005; Roldán, 1999). Culturally women bear more shame due to their caretaking responsibilities for self and others, inherent in familismo, and marianismo (Ortíz, 2000; 2005; Rivero, 1994; Roldán, 1999) which have been described as burdensome by Latinas who do not live with HIV (Maldonado, 2017). Other sources of stigma, which can be experienced by all individuals and communities living with HIV, are interactions with healthcare workers (Davtyan, et al, 2016; Farley, et al, 2014; Gagnon, 2015).

In a study of people living with HIV attending an urban clinic, Relf and colleagues (2005) used a mixed methods study to examine the relationship between stigma, depression and quality of life. While the quantitative measures documented prevalence of stigma and provided descriptive characteristics that demonstrated increased stigma for the Latino population on the HIV-related Stigma Scale (score 103.71, SD of 11.19, p=0.002), the qualitative arm provided little insight on the phenomenon for Latinos (Relf, et al, 2005). The reason for this discrepancy is the availability of the scale in English and Spanish, while all qualitative assessments were conducted in English only. This study represents a missed opportunity to further explicate the quantitative findings with qualitative data. For Levya and associates (2015) who conducted both on-line and face-to-face interviews with newly diagnosed individuals in Spain, they found their participants described their lives as being full of suffering related to stigma, isolation and fear of discrimination.

Another area of disparity in HIV disease that Latinos experience is delayed testing, entry into care, and, treatment; and, earlier death. Chen, Gallant & Page (2012) have noted that the number of deaths among Latinos had been on the rise and they performed a systematic review of
the literature to determine the risk of experiencing these delays in care. After identifying over 1000 manuscripts for review via the PubMed database and reviewing 92 full-text articles, only 25 were included in the final review because they met the criteria focusing on studies of delays in diagnosis and treatment or survival after diagnosis. The authors noted that they specifically excluded an article based on Puerto Rico because of concerns of different factors affecting entry into care, like language and culture and healthcare system differences (Chen, et al, 2012). They did note that most of the studies either failed to stratify Latinos by country of origin, place of birth; English proficiency; gender; or, did so inconsistently. In nearly all eight studies that examined late diagnosis of HIV disease, defined as either concurrent diagnosis with AIDS; or, an AIDS diagnosis within one year of HIV diagnosis, more Latinos than whites or blacks had a late HIV diagnosis. For all seven studies exploring late entry into care, Hispanics and immigrants were consistently more likely to present for care at later stages of HIV disease: defined as a lower CD4 count; AIDS diagnosis; or, opportunistic infections, potentially due to language barriers; lack of familiarity with the US healthcare system; and, fear of deportation. The remainder of the studies explored survival after diagnosis. In these studies, there was some stratification of Latino groups by place of birth; country of origin; risk factor; and, gender. One study noted that being diagnosed with AIDS in NYC resulted in better survival for Latinos as compared to whites. Yet in another study, being foreign born, including Puerto Rico, led to a higher risk of HIV-related death. Reasons for the disparity for Puerto Ricans included increased behavioral risk; exposure to HIV; and, differences in the healthcare system in Puerto Rico (Chen, et al, 2012). The authors stressed the importance of knowing the local Latino communities to assure that specific risks for delays in diagnosis and treatment can be addressed, rather than lost in aggregated data.
Latinos are less likely to participate in HIV-related clinical trials than whites (George, et al, 2014; Giordano, et al, 2010; Gwadz, et al, 2013; Kim, et al, 2006; Lopez-Cordova, et al, 2010; Polanco, et al, 2011; Shedlin, et al, 2011). There are various reasons that explain the disparities in recruitment, screening, and retention of Latinos. Many of these are like those reported for African-Americans, such as, a lack of trust in medical research (Floyd, et al, 2010; Smedley, Stith & Nelson, 2003). However, there are also language issues, which include the lack of Spanish-speaking study staff (Polanco, et al, 2011); and, lack of, delayed, or inadequate translation of instruments into Spanish (al-Amer, et al, 2014; Santos, et al 2015); cultural concerns (Garcia, et al, 2017); and, fear of deportation, for those with issues with their immigration documentation (Shedlin, et al, 2011). The result of this disparity is a paucity of information on the effects of therapies on the Latino and African-American populations, which combined, comprise a larger number of those in need of these medical treatments.

Giordano and associates (2010) have noted that delays in entry to care meaning advanced disease at enrollment; and, adherence issues were problems for Latinos, [unadjusted hazard ratio of 1.57 (1.09, 2.26; p=0.02)], and African-Americans, [unadjusted hazard ratio of 1.57 (1.17, 2.10; p=0.0025)], resulting in reaching clinical end points (progression of disease or time to death) sooner than whites. Recommendations for improving outcomes as these include improving entry to care for Latinos and African-Americans; and, providing supportive care programs to improve adherence to treatments before enrollment and participation in clinical trials. To address these recommendations, Polanco and associates (2011) report on the building of an interdisciplinary research team that includes members who match the race and ethnicity of the community as well as speak their language. Lopez-Cordova and associates (2010) describe the need to consider the social structural concerns, like travel and childcare, for Puerto Rican
women being recruited for research. Gwadz and associates (2014 & 2015) have increased enrollment of African-Americans and Latinos in HIV clinical and biobehavioral trials by designing research recruitment protocols in which eligible individuals receive training in how to recruit other participants.

**Latino Commission on AIDS and other Community Based Organizations.** The Latino Commission on AIDS (LCA) was founded in the early 1990s in recognition of the unique presentation of the HIV epidemic in the Latino community in NYC and more specifically the Puerto Rican community (Reyes, 1997-98). This group has advocated for Spanish language resources and established programs to develop peer educator resources and outreach to houses of worship for HIV prevention efforts.

An important initiative of the LCA has been to collaborate with other community-based organizations to call attention to gaps in policy making and funding. In 1992, in conjunction with National Commission on AIDS, they issued ten recommendations to address the legal, medical, epidemiological, and service gaps affecting the Puerto Rico community, both in the mainland and the island. In 2008 press releases were issued calling the federal government and CDC to task for failing to address the disparities of late diagnosis and death rates for Latinos (LCA, 2008, June 25) and for flip-flopping on the inclusion of Puerto Rican residents in the HIV/AIDS surveillance reports issued that year, respectively (LCA, 2008, August 4). The CDC did return to including the statistics for Puerto Rico and the Virgin Islands in the surveillance reports. The inclusion of Puerto Rico’s statistics demonstrated, then that 20% of the HIV cases are among Latinos; while without them, the statistic was only 17% (CDC, 2012, October 12). The importance of these more inclusive statistics is the documentation of the continuation of the
disparity of HIV disease in the Latino community, which now makes up 17% of the US population (Gray, et al, 2015).

The LCA is now a provider of services to the at-risk community. Services include HIV antibody testing and social services on site and referrals to off-site programs. Fundraisers and galas are held to increase awareness in the community and to generate revenue to support the programs. It has also become a resource for social science researchers interested in studying the impact of HIV on the Latino community (A. Juarez, personal communication, August 28, 2012) and an information conduit bringing the latest conference information to the local service providers.

HIV Treatment Cascade and the Continuum of Care

Through the data gathered by the Medical Monitoring Project (MMP), the numbers of people living with HIV and receiving HIV care has become better understood (MMWR, 2011, December 2), as well as their behavioral and clinical characteristics (Blair, et al, 2014, June 20). With these data, specialists in HIV care have identified gaps towards achieving medication adherence (Gardner, et al, 2011; Robbins, Spector, Mellins & Remien, 2014) in the care continuum. Mathematical models have projected evidence of the possibility of an “AIDS-free” generation (Nachega, et al, 2014) with ARV use preventing new infections. A two-part public health plan can realize this goal. One arm of the plan is called Treatment as Prevention (TasP), which relies on reductions in viral load significantly reducing transmissions in serodiscordant couples. The other component of the plan is known as Pre-Exposure Prophylaxis (PrEP), which consists of daily ARVs for HIV-negative persons at high risk for HIV infection (CDC, 2017, September). The only currently approved ARV for PrEP is tenofovir (CDC, 2014). Both
treatment plans require awareness of one’s HIV infection status and risk to achieve effectiveness (Ostmann & Saenz, 2013).

Another advance in the care of HIV, based on the data from the MMP, is the treatment cascade which emphasizes that there are many people in the US (approximately 70%) who do not know their HIV infection status; are not taking ARVs; and, are not virally suppressed (Giordano, 2015). With this knowledge, mathematical models have made projections regarding the effects of a lack of viral suppression on transmission rates and estimate that 95% of new infections are transmitted by those who are not virally suppressed (Skarbinski, et al, 2015).

Research is now focusing on closing the gaps in the treatment cascade: engaging, and retaining people living with HIV in care, so that they can be prescribed ARVs and become virally suppressed, now known as the HIV continuum of care (CDC, 2017, July). Thompson and associates (2012) compiled a listing of recommendations for improving entry and retention into care based on the evidence available at the time. The guidelines, thirty-seven in all, address entry and retention into care and monitoring ARV adherence for the public and special populations. While the recommendations do address language and mental health needs, they are singularly focused on the medical provider-patient relationship and medication adherence and not on the cultural needs regarding stigma (Gherovici, 2003; Rojas-Vilches, et al, 2011; Webel, et al, 2016). There is acknowledgement of the lack of efficacy of previously recommended strategies, such as pill counts and electronic drug monitoring. As well, there are recommendations of simplified regimens of once daily and fixed dosing of medications. The use of nursing and community support in HIV care is recommended only in resource poor settings. Unfortunately, the guidelines and the recommendations for further research (Thompson, et al, 2012) do not include

Barroso, Le Blanc and Flores (2017) reviewed the qualitative literature on HIV adherence, in contrast to Thompson and associates (2012) emphasis on the quantitative evidence and organized their findings to support a model of HIV medication adherence that corresponds to Maslow’s Hierarchy of Needs. By doing so, they have provided a framework for identifying differing strategies for corresponding use with individuals, dependent upon their changing needs while living with HIV and corresponding appropriateness for helping them with their adherence to medication regimens. These are nursing strategies and Mignano (2016) issued a call to action for nurses to be full actors in the efforts to retain patients into HIV care and achieve the viral suppression targets of the HIV care continuum.

Nursing research focused on engagement and retention in care and adherence to medication regimens have explored topics that have demonstrated the value of nurses in retention (Bradley-Springer, 2014). This includes the patient provider relationship (Brion, 2014) emphasizing the way the provider engages the patient through communication (Storey, et al, 2014), touch, education and presence to engender trust; and the importance of trust in HIV health literacy (Dawson-Rose, et al, 2016); the patients’ experience of what it means to be engaged in care (Christopoulos, et al, 2013; Cook, et al, 2015; Gill & Krentz, 2015); and, the factors involved in that self-care decision. Understanding the impact of HIV on an individual’s life (Buscher, et al, 2015) is a starting point for understanding how a provider can be a source of support (Gelaude, et al, 2017) for that individual. Supportive others have also been found to be essential to helping someone to engage in HIV care (Kelly, et al, 2014). Social determinants of health impact people’s ability to become engaged in and retained in care, as explored by Dennis
and associates (2015) after release from incarceration and DeVoe and associates (2016) in primary care. Coordinated action by the staff in the care settings are necessary to facilitate patient retention. Findings such as these can be used to develop explanatory models for understanding retention in HIV care (Graham, 2015) bridging patient characteristics, patient provider relationships and social determinants of health to holistically expand our understanding of this complex endeavor.

**Current State of the Art in HIV Care in Puerto Rico and the Mainland**

Over more than 30 years, the quality of HIV care has improved as the life cycle of the virus; the functioning of the immune system; and, the impact of HIV on the immune system, have become better understood through basic science. The most recent recommendations for HIV treatment include: (a) screening for drug resistance; tropism assays for receptors; and, risk for hypersensitivity to determine which drugs can be used; and, (b) starting highly active ARVs as soon as possible to prevent progression of disease and to reduce transmission (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2017, October 17). Other recommendations include effective combinations of drugs; frequency of viral load testing and CD4 levels to determine continued efficacies of regimens; regimen management when there is evidence of antiretroviral resurgence; and, recommendations for special populations, such as co-infected individuals, women, and the elderly (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2016, July 14). In addition, the changing attitudes towards the epidemic have improved access to care and the availability of funds to pay for the medication, medical care and social services required to manage the disease. Consequently, the epidemic has transformed from an acute illness with a relatively quick death to a chronic illness requiring a lifetime of
treatment. These changes, along with the high cost of medication, have resulted in an increased need for funding sources for payment.

While the modes of transmission were understood early on and the risks of behaviors versus group identification was communicated, many individuals continued to react as if it were still 1982, with many Latinos reporting being unsure how HIV was spread and who was at risk (Roldán, 1999). Interestingly, people were quick to identify groups at risk and assure themselves of non-inclusion in that group and, therefore, at a lower risk of acquiring infection. The stigma associated with behaviors that expose one to blood and body fluids, such as unprotected sexual intercourse, and substance use, including the sharing of injection equipment, had prevented people from self-identifying their risk appropriately, creating fear of rejection and retribution for those with the virus (Ortíz, 2000; 2005; Rivera-Casiano, 1994; Rivero, 1994; Roldán, 1999). These factors allowed the epidemic to establish a strong foothold in some Latino and African-American communities.

Thirty years into the AIDS epidemic, the experts have come to realize that behavior change is difficult because social determinants of health are exerting an effect on individuals and communities. Now with increasingly effective medication regimens, policy makers believe that they can “bend the curve” (NYSDOH, 2015, March) by reducing new infections by 80% to 750 per year by 2020. In 2015 New York’s governor, Andrew Cuomo, announced a detailed plan “Ending the Epidemic.” This plan proposed to implement services that could address the Treatment Cascade/HIV continuum of care in New York State and increase the number of people living with HIV who are virally suppressed to reduce the risk of transmission to other individuals. The significance of this announcement and program is that it was developed with the input of diverse stakeholders from people living with HIV/AIDS, to researchers, providers of
care, social service providers and prevention programming experts. Their recommendations address the many social determinants of health: (a.) housing; (b.) education; (c.) access to health care and medications; (d.) access to mental health care and substance use treatment; and, (e.) social services, that impact the diverse communities at risk for HIV infection (NYSDOH, 2015, March).

NYC remains the epicenter of research and care of HIV, as it continues to have the most comprehensive coverage for medical and social service care for people living with HIV and their families. The “Ending the Epidemic” plan in NYS is a striking example of this commitment to reducing new infections which includes care for those living with HIV. In contrast, Puerto Rico continues to experience disparities in care and services to the HIV positive community increasingly complicated by the financial debt crisis and the delayed recovery from the aftermath of Hurricane Maria.

**Important concepts regarding health research in Latinos**

**Identity: Hispanic versus Latino.** The term Hispanic is a US social construct, like race; used to describe people residing in the US whose origin is “Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race” (Office of Management and Budget, 1997, October 30). For the purposes of data collection, the US government first defined Hispanic in the mid-1970s and the 1980 US Census first used it, adding an ethnic dimension to the identity question. For every census since, there is dissatisfaction with the ability of the racial/ethnic identity question to capture the Hispanic/Latino community and the question has been repeatedly revised (Cohn, 2012, August 7). Self-identity cannot be accurately expressed as one ethnicity or race (Amaro & Zambrano, 2000; Cresce, et al 2004) as
the US Census attempts to do every ten years (Taylor, López, Martínez & Velasco, 2012, April 4).

The term “Hispanic” makes a specific reference to the Spanish heritage of the people residing in the US (Ennis, et al, 2011; Zambrana, 2011) and can also be used by those individuals from Spain. In contrast, “Latino” has come to represent the indigenous heritage of the people now residing in the US (Zambrana, 2011). To be inclusive, the terms Hispanic and Latino are used interchangeably or combined for the term Hispanic/Latino. It is important to note that many Hispanic/Latinos prefer to identify themselves by their country of origin (Taylor, et al, 2012, April 4) and place of birth figures strongly in demographic data on Hispanic/Latinos (Selik, et al 1989). The confusion inherent in the use of these terms became salient in 2008 when the CDC could not decide on the inclusion of the residents of Puerto Rico in the statistics on HIV disease and AIDS (Tejeda, 2008, August 5). The issue is that Hispanic/Latino refers to people who self-identify as being Hispanic/Latino and reside in the US. While Puerto Ricans are US citizens they do not technically reside in the US when they live in Puerto Rico. It is only when they “cross the border” or “deplane” that they become Hispanic and have full citizenship. When the CDC reports on HIV/AIDS statistics, that aggregates Puerto Rico with other US territories, it obscures the fact that many cases are from Puerto Rico (CDC, 2013, February).

Consolidating data. Most of the research focused on specific Latino groups in the areas of health, socioeconomic, criminal and educational issues, will extrapolate the findings of the individual to all group members and/or all Latinos (Aguirre-Molina, et al, 2003; Zambrana, 2011). One of the best-known examples of this phenomenon is the Lewis (1965) ethnography of an extended Puerto Rican family living in poverty in Puerto Rico, in which the women supported themselves and their families through sex work. His conclusions about poverty as a self-
perpetuating phenomenon were applied to all people in poverty and spurred the “culture of poverty” area of study in Hispanics/Latinos (López, 2007). Aguirre-Molina and associates (2003) and Zambrana (2011) have called attention to the projection of characteristics of a subset of the Latino population to the whole of this diverse group of peoples. There is an assumption that the data gathered regarding one group, for example, Mexican-Americans who have remained on the land their people have inhabited prior to the Mexican-American War, is applicable to other groups, like recent immigrants from South America.

Most researchers who focus their work on Latinos discuss the existing literature and remark on the paucity of data specific to the community of interest (Aguirre-Molina, et al 2003; Deren, et al, 2014). In a review of the literature on health research on Latinas, prepared for an anthology on Latina health in the US, Aguirre-Molina and associates (2003) found that many researchers’ area of focus did not match the leading health issues presenting for Latinas. In addition, the study designs did not consider the effects of acculturation, gender concerns, and differences by country of origin, socioeconomic status and educational level leading to the perpetuation of negative stereotypes and their broad application to all Latinas (Aguirre-Molina, et al, 2003, p.5). Recommendations have included disaggregating the data; focusing on the nuances of acculturation on culture, gender relations and behaviors; and, considering the impact of the experience of oppression in the US on the health Latinas (Amaro & de la Torre, 2002).

**Acculturation.** Acculturation is a concept that has multiple definitions in the health-related literature. Ellison, Jandorf & Duhamel (2011) have stated that there is no broadly accepted definition of acculturation and that scales to measure it often focus on proxy variables, the most common of which is language. This lack of consensus has led to a call for abandoning this concept, yet others continue to argue that since the concept is universal in this global society,
it must continue to be studied (López-Class, González Castro & Ramírez, 2011). In addition, for
the Latino community, there is also the phenomenon of the “acculturation paradox,” decreased
health problems or deaths for Latinos who are less acculturated (Carter-Porkas & Bethune,
2009), which warrants continued study because of the health implications (Perez-Escamilla,
2011). A recent secondary data analysis linking 1997-2004 data from the National Health
Information Survey and the National Death Index (Borrell & Lancet, 2012) demonstrated that the
acculturation paradox is in effect for the following subgroups of women: Mexican and South and
Central Americans aged 25-44 years; Cubans aged 45-64 years; and Puerto Ricans and Mexican
Americans aged 65 years and over. These findings once again highlight the diversity within the
Latino community and the importance of avoiding aggregation of their data.

In a review of acculturation, Hunt and associates (2004) provide the history of the
development of the concept, moving from a continuum from the culture of origin to the
mainstream culture and measured dichotomously to a multidirectional process that still relies on
two differing cultures. Another conceptualization is the possibility of becoming bicultural and
maintaining aspects of both the original and the new culture (Córtes, et al, 2003). Both
conceptualizations accommodate quantitative methods of measurement. López-Class and
associates (2011) conducted a review of the literature examining the need for including the
contextual factors related to acculturation, for example the receiving community, that impact the
experience of Latinos. They noted that this lack of emphasis on context could account for the
difficulties with the conceptual and operational definitions and explain the inconsistent findings
in the acculturation literature. In a systematic review of different quantitative acculturation
measures performed by Thomson and Hoffman-Goetz (2009) that started with 1855 articles
matching the search terms, and resulted in only 134 meeting the inclusion criteria, they found
fault with the assumptions of homogeneity in the different Latino cultures; the (im)migration process for Latino individuals; and even, the acculturation process.

Most acculturation tools have been developed and tested for the Mexican-American population of the western US (Carter-Porkas & Bethune, 2009; López-Class, González Castro & Ramírez, 2011; Thomson & Hoffman-Goetz, 2009; Wallace, et al, 2010). This calls into question the reports of validity and reliability for use with other Latino groups without testing. There was one acculturation tool developed specifically for use in the Puerto Rican community and it has been tested in both island and mainland communities (Córtes, et al, 2003). This tool measured acculturation to both the Puerto Rican and the American cultures using two different scales. The scales were developed following focus group interviews and factor analysis testing resulting in eight questions for each culture, using a four-point rating, on the following themes: language preference and usage; food preference; ethnic pride; interpersonal relationships and child-rearing practices. Coefficient alphas for the American scale ranged from .78 to .83 and for the Puerto Rican scale from .72 to .73 (Córtes, et al, 2003).

Most research that includes acculturation, defines it as a variable to be measured using a survey tool with ranges of answers. Totals of the score would determine the level of acculturation. The scores are then correlated with other scales or statistics on the health issue of interest. After their own review of the acculturation literature and scales, Wallace and associates (2010) recommend the use of a theory driven model to better explicate the construct and evaluate the effects of diverse cultural norms, values and beliefs of the Latino populations. Leininger (2002a; McFarland & Wehbe-Alamah, 2015) in the CCT and the ethnonursing research method (ERM) uses a qualitative approach to achieve that goal. She defines acculturation as the process by which an individual or group from one culture learns how to take on many, but not all, of the
values, behaviors, norms, and lifeways of another culture (Leininger, 2002a, p. 56). Her two-part enabler, guide for data collection, includes a self-assessment for the individual and an assessment by the nurse. There is no score but rather an evaluation of the individual’s acculturation for various aspects of their lives. While these findings will not generate a correlation score or a relative risk value, they do provide a means to value the emic (insider) perspectives of different cultures regarding their health.

**Trust.** Trust has been cited as an issue in the access to healthcare for Latinos and others (Calo, et al, 2014; Earl, et al, 2013; Julliard et al, 2008). The Spanish word for trust is *confianza* and it is an important cultural construct. Purnell (2013) has reported *confianza* to be necessary for open communication with Latinos, including Puerto Ricans. This *confianza* can lead to disclosure of behaviors and practices that may be difficult to discuss, for example sexual practices, substance use, abuse or cultural healing (Donald, et al, 2015). *Confianza* is built over time (Berry-Cabán & Crespo, 2008) by expressing caring to clients; and, approaching interactions with a more personal, rather than strictly professional perspective (Davis, 1996; Swanson, 2012). Using Spanish as much as possible, even if just for greetings, versus relying exclusively or inconsistently on interpretation services was found to be more helpful in building trusting communications with patients (Fernández, et al, 2004; Mayo, et al, 2016; Phillips, et al, 2011; Sanchez, et al, 2014; Squires & Jacob, 2016).

Boyas and Valera (2011) explored determinants of trust in medical personnel. After identifying the Latino, mostly Mexican, participants (98 of 318 total participants) in the 2008 Quality of Life in Arkansas study, the authors constructed a 35-minute questionnaire in English and Spanish. Non-US citizenship status was proposed to be a correlate of distrust and a possible explanation of the difficulties that Latinos experience when accessing the healthcare system.
Surprisingly, it was those Latinos with US citizenship who were more likely to report distrust of their medical providers, OR=3.607, (95% CI 1.346, 9.664, p≤0.01), and personnel OR=4.468, (95% CI 1.520, 13.128, p≤0.01) (Boyas & Valera, 2011). The authors acknowledge that they did not distinguish between the professional providers, for example nurses, and other staff, nor the setting of care, hospital versus clinic. In their conclusions, the authors identified the need for continued study of the predictors of trust in healthcare providers for all populations.

As part of the Commonwealth Fund 2001 Quality of Care study, researchers identified and contacted those respondents who reported having a regular provider (N=394) and analyzed racial/ethnic concordance between clients and providers and staff; and, client perceptions of mistreatment (Blanchard, Nayar & Lurie, 2007). Associations were found between both racial/ethnic concordance of client and provider and perceptions of mistreatment; and, racial/ethnic concordance of client and health care staff, and perceptions of mistreatment. There was no distinction made among health care staff. A surprising finding for Latinos (10.5% of the sample) is that they were more likely to report disrespectful treatment with concordant providers than with discordant providers (OR=2.42, p<.01, 95% CI 1.23, 4.73). These findings remained after controlling for other socio-demographic variables. On the other hand, those Latinos who received care at a facility with some concordant staff were less likely to report being treated with disrespect or unfairly due to language differences (OR=0.26, p<.05, 95% CI 0.09, 0.75). The authors surmise that the unexpected results in the Latino population may be due to the wide range of cultural variances in the Latino population, and/or language differences. However, as is often neglected in the literature, racial and socioeconomic distinctions within the Latino community are not explored. The authors do recommend cultural sensitivity training for all providers and staff to improve patient satisfaction with care.
Schnittker and Liang (2006) examined the potential for racial/ethnic concordance in the physician-patient relationship. Reasons for misunderstandings in the physician-patient relationship are proposed to be differences in presentation and description of symptoms of disease of the patient; and, healthcare culture superseding the culture of origin of the physician. They performed an interview of participants of the Kaiser Family Foundation Survey of Race, Ethnicity, and Medical Care: Public Perceptions and Experiences, which was conducted in 1999. Questions regarding preference for a concordant provider and beliefs about the occurrence of racism in concordant and discordant physician-patient relationship were asked of the interviewees. All groups reported that concordance would reduce racism, but more Blacks and Latinos felt that racism could still occur in concordant relationships. In these instances, the respondents reported that not having health insurance and not being able to pay contributed to receiving unfair treatment. Other characteristics of physicians and their practice were also evaluated for patient preferences. Some of those characteristics, such as gender, listening, and giving full explanations were valued as highly as racial/ethnic concordance. The authors concluded that racial/ethnic concordance is an important factor in physician-patient relationships when the patient values it and therefore may not be the only way to address healthcare disparities.

In addition to transcultural caring theories and frameworks (Douglas & Pacquiao, 2010; Leininger, 2006; McFarland & Wehbe-Alamah, 2015), the literature has identified various factors that can increase the delivery of culturally congruent care and reduce health disparities. Nurses (Sobel & Meltzer Swain, 2016) and nurse practitioners (Castro & Ruiz, 2009; Mattelliano & Street, 2012) were found to be able to expand the delivery of culturally congruent care into various care settings. The availability and use of patient navigators have been suggested as a
method for reducing health disparities because it helps individuals access more of their healthcare options (Natale-Pereira, et al, 2011).

**Summary of Concepts Regarding Health Research in Latinos.**

Health research of Latinos has been complicated by the failure to clearly define concepts and methods of classifying and collecting data. The fluctuating use of the terms, Hispanic and Latino, even though they do have varying definitions confuses researchers and participants alike. In fact, Latinos prefer to define themselves not by race or a group ethnicity but rather by their countries of origin (Taylor, et al, 2012, April 4). The use of a group ethnicity has resulted in the combination of data, which statistically may be beneficial but has diluted findings because of the diversity of the Latino peoples (M. Shedlin, personal communication, February 5, 2012). Latinos have come to the US for different reasons and have had differing acculturation experiences. Acculturation as a concept has been poorly defined (Ellison, et al, 2011) and the multitude of tools attempting its assessment reflects their inability to truly capture its meaning, which is essentially subjective in nature and bound by context, and consequently, its effect on other health concepts. Differences in language, cultural insensitivity, and fear of legal action have contributed to the lack of trust that many Latinos experience during health care encounters. Another problem has been the blanket application of findings from small studies to all Latinos of differing countries of origin, educational and socioeconomic levels (Zambrana, 2011). These issues must be considered seriously when undertaking research on Latino communities.

**Select Studies on HIV focused on Puerto Ricans and Latinas**

**Risk and prevention.** Many studies have examined HIV-related risk factors in Latinos. The most common areas explored are behavioral risks, which provide direct exposure to the virus, such as, type and number of sexual partners (same or opposite sex partner); sexual activities (penetrative sexual acts or use of barriers); and, types of substances used (injecting
drug use). More recently analyses have begun to examine behaviors and factors that place people at risk for engaging in high risk behaviors. Examples include intimate partner violence, and use of substances when engaging in sexual activity, both of which reduce control over the sexual encounter and the ability to engage in safer sex practices (Gonzalez-Guarda, et al, 2013; González-Guarda, et al, 2008; Gonzalez-Guarda, McCabe, et al, 2011; Gonzalez-Guarda, Vasquez, et al, 2011). The HIV disease statistics in the US have clearly demonstrated that while all people are potentially at risk for HIV transmission, certain subgroups of the population have developed a higher risk over time. While identifying risk for certain groups is helpful for prevention planning activities, a problem remains in that many people self-identify by membership, or not, in a group rather than by risk behavior (Herbst, et al, 2007). Researchers have also perpetuated stereotypes of groups of people by attributing the behaviors of some to all (Aguirre-Molina, et al, 2003; Zambrana, 2011), increasing stigma and possibly generating reluctance to evaluate one’s risk for HIV. The potential for being at risk for HIV infection may not be realized by Latinos until enough of their peers are diagnosed with HIV (Cianelli, et al, 2010).

For Latinos, a search of the literature might lead one to believe that Latinas are physically, emotionally and sexually submissive to their partners (Gonzalez-Guarda, et al, 2013; González-Guarda, et al, 2008; Gonzalez-Guarda, McCabe, et al, 2011; Gonzalez-Guarda, Vasquez, et al, 2011; Orengo-Aguayo & Pérez-Jiménez, 2009). In the same light, they are the moral center of the family and as such are targeted for HIV prevention messages. These programs encourage women to become assertive in their intimate relationships, going against cultural norms and potentially putting them at risk for abuse (Ortíz-Torres, Serrano-García & Torres-Burgos, 2000; Jiménez Muñoz, 1992; Orengo-Aguayo & Pérez-Jiménez, 2009). This
contradiction may be a result of efforts to reduce risk to infants during the perinatal period but hearkens back to viewing women as vectors of disease, rather than being at risk themselves.

González-Guarda and associates have explored the syndemic of substance use, violence and AIDS (SAVA), through the DYVA project (*Drogas Y Violencia en las Americas* -- Drugs and Violence in the Americas) in the South Florida Latino community. The exploratory research study used qualitative, Phase I, (Gonzalez-Guarda, McCabe, et al, 2011) and quantitative, Phase II, (Gonzalez-Guarda, et al, 2008) methods to evaluate the phenomenon. In Phase I eight focus groups, led by the same bilingual and bicultural facilitators, were conducted among women who self-identified as Hispanic or Latina; were between the ages of 18 and 60; and were Spanish or English speaking. For Phase II, these same women completed the quantitative questionnaires later. The women were mostly identified through a community-based organization providing social services to the local Hispanic community. Snowball recruitment efforts were used to reach a total of 81 participants, who preferred the sessions be conducted in Spanish. The women were from various Latin American countries with the majority being from South America (Colombia, Venezuela and Ecuador) and more than half were married and/or living with a partner. Although, on average they had achieved more than 12 years of schooling, their incomes were low as more than half reported being unemployed and not having health insurance.

After transcription of the tapes and translation into English, a group of 5 bilingual and bicultural investigators reviewed the transcripts using the conventional qualitative content analysis approach to “describe the experiences of Hispanic women with the SAVA conditions from an “emic” or insider’s perspective” (González-Guarda, McCabe, et al, 2011, p. 48). The themes identified by researchers included: uprooted in another world; breeding ground for abuse; and, breaking the silence. The women discussed intimate partner violence (IPV) in its relation to
substance use and risky behaviors for HIV. They shared that the gender inequalities inherent in the culture, put women at risk when their partners engage in risky behaviors with others and sexually abuse them (González-Guarda, McCabe, et al, 2011). Bringing the participants together provided an opportunity for them to benefit from the support of the others and perhaps build quality relationships which provides social support for women living with HIV (Matchinger, et al, 2015).

For the quantitative arm of the DYVA project, the women returned to complete questionnaires to describe the relationships between substance use, IPV and risk for HIV (González-Guarda, et al. 2008). They completed a demographic questionnaire, and tools were administered assessing acculturation; sexual history; partner history; and, violence. All the women were acculturated to their Hispanic culture. Only a third of the women also identified as acculturated to the dominant American culture. The women reported lower instances of sexually transmitted diseases (STDs) (15%) and substance use associated with sex (26.3%) than for STDs (42.7%) and substance use with sex (27.3%). In addition, they reported having partners who have had sex with sex workers (40%) and injecting drug users (18.8%). More than half of the women reported some form of abuse from their partners.

There were no differences in age, years of education, years living in the US, income and acculturation levels between the women who reported consistent versus inconsistent condom use; or reported IPV or not. However, the women who reported using substances when having sex had attained higher levels of education (p=0.011), had scored higher on the American acculturation scale (p=0.031) and lower on the Hispanic acculturation scale (p=0.004) (Gonzalez-Guarda, et al, 2008, p. 260). Women who used substances when having sex were more likely to have a partner suspected of risky sexual behavior (OR=4.16, 95% CI, 1.29, 13.47,
Women who reported IPV were more likely to have a history of STDs (OR=6.50, 95% CI, 1.73, 24.44, p=0.005) (Gonzalez-Guarda, et al, 2008, p. 260). Women who reported IPV were also more likely to have a partner who used substances with sex (OR=3.67, 95% CI, 1.31, 10.21, p<0.05) (Gonzalez-Guarda, et al, 2008, p. 261). In their discussion of the findings, the researchers conjectured that the women who were more acculturated to the American culture and more liberal in their behaviors may not have the skills necessary to mitigate the risk behavior. Follow-up semi-structured interviews with the women would have further explored this possible explanation to elucidate how acculturation may increase HIV risk for Latinas (González-Guarda, et al, 2008).

A cross-sectional study of perceived susceptibility to HIV amongst Latinas in the South Florida area, was conducted as part of the randomized controlled trial of SEPA II (Salud, Educación, Prevención y Autocuidado – Health, Education, Prevention and Self-care) a group intervention for US Hispanic women to reduce HIV risk (Cianelli, et al, 2010). The women (N=548) who were between the ages of 18 and 50 and self-identified as Latinas and were sexually active in the three months prior to participation, completed a demographic survey and answered questions regarding their belief in susceptibility to acquire HIV; estimated what percentage of women in their neighborhoods had HIV; rated their chances of acquiring HIV from their partners; and, whether they had ever been tested for HIV (yes or no). Women who were more likely to report feeling susceptible to HIV were also more likely to report that they would get HIV due to their partner’s actions (OR=9.75, CI 95% 4.74, 20.06, p<0.05) and were more likely to not have been tested for HIV (OR=2.05, 95% CI 1.02, 4.12, p<0.05) (Cianelli, et al, 2010, p. 212). The researchers discussed that many in the cohort had been previously tested for HIV and the women reported that their negative test results reduced their perceptions of
continued risk for HIV. On the other hand, those women who perceived themselves to be at risk were not being tested. This presents a need for further study and identifies a knowledge gap that can be addressed through prevention programs.

In a study of Dominican and Puerto Rican women living in New York City, and their self-assessment of risk in their sexual partnerships, Moreno and El-Bassel (2007) found differences in risk assessment. The women in this study were participating in the Project Connect study, a randomized trial of an HIV prevention program geared towards African-American and Hispanic women and their main sexual partners, in the Bronx, New York City. The participants (N=1,266) were at least 18 years of age and had a regular male sex partner during the previous 90 days. The women were on average 34 years old and had up to 10 years of education; were mostly unemployed and the majority expected to remain with their partners for at least the next year. The Puerto Rican women (n=1,012) were more likely to have been born in the US (50% vs. 12%, p <0.01) and resided in the US for a longer period (26 years vs. 14 years, p<0.01) (p. 341). The Dominican women (n=254), were more likely to have fewer partners, less likely to have had a STD or HIV (p<0.01) but they were also less likely to perceive themselves to be at risk for HIV due to their own behaviors (3.1% vs. 13.8%, p<0.01) or their partners’ (4.7% vs. 14.5%, p<0.01) (p. 341). Single Puerto Rican women were more likely to use condoms with both their main sex partners and others, but this finding did not achieve significance. Latinas who were single, had less education, were older and lived in the US for a longer period, were at a greater risk for STDs, and also more likely to use condoms more often (Moreno & El-Bassel, 2007). The authors suggested that exposure to HIV/AIDS campaigns with a culturally congruent component might explain the differences in perception of risk in the women participating in the study (Moreno & El-Bassel, 2007).
Following the identification of risk factors, it is then possible to develop and implement HIV risk prevention programs. People may be exposed to HIV through multiple risk behaviors. Individuals may have different sexual personas in different settings, for example a main sexual relationship and infrequent anonymous sex at clubs after substance use. According to Kurth and associates (2011), the various prevention strategies being utilized, worldwide, are only partially effective because each one addresses only one facet of risk. They proposed the use of multiple prevention interventions in carefully designed packages that reflect the risk(s) of the target population. These programs could affect “the transmission cycle” at various points to decrease infectiousness, for example reduced viral loads due to HIV treatment of infected individuals, while simultaneously diminishing the susceptibility of HIV negative individuals (Kurth, et al, 2011, p. 65). The pervasiveness of the HIV epidemic in the Puerto Rican community both on the island and the mainland provides evidence of the synergistic effects of the multiple risk exposures to HIV that exist for the subgroups of the population. A program such as this, that addresses the multiple risk factors of the community versus only one, could be effective in reducing future infections in the communities at risk. For efforts like those proposed by Kurth and associates (2011) to be effective, it is necessary for people to be truthful about their risk behaviors. In trying to be as inclusive as possible, some programs use a one-size fits all approach, as has been noted in some of the programs discussed previously. Many of these programs attest to the limits of their efficacy, but the magnitude is difficult to assess due to the diversity of the programs, intervention methods and target populations.

Herbst and colleagues (2007) undertook an effort to perform a systematic review and meta-analysis of behavioral interventions studies that sought to reduce HIV risk for Hispanics in the US and Puerto Rico. Twenty intervention studies with 6,173 participants were reviewed...
from an initial pool of 27 intervention studies. These reviewed studies, were exclusively of Latinos; had more than two-thirds Latino participants; or, provided stratified data on Latino participants. The findings showed that for sex risk behavior, these interventions achieved 56% increased odds of condom use; 25% reduce odds of multiple sex partners; 31% reduced odds of getting a STD (Herbst, et al, 2007, p. 38). The average follow-up time reported for the studies in the analysis was 7.5 months. The greater effect was seen for interventions that were focused on one gender only versus joint programs; used non-peer educators; had four or more sessions; and, specifically addressed barriers to behavioral change. For injecting drug use behaviors that pose a risk for HIV, interventions were effective in reducing the odds of injecting drugs and sharing of injection paraphernalia but were not as efficacious in reducing sharing of needles (Herbst, et al, 2007). There were very few studies on interventions for injecting drug users, especially needle exchange, examining cultural factors and thereby meeting the criteria of this review to include Hispanics in the study.

**Acculturation as risk and prevention.** Acculturation has also been studied as a factor in HIV-related risk (Dixon, Saul & Peters, 2010; Ortíz-Torres, Serrano-García & Torres-Burgos, 2000; Rojas, et al, 2016; Rosado, 1993; Sánchez, et al, 2010). Rosado (1993) researched levels of acculturation and sex role conception in Puerto Rican women in East Harlem, New York, regarding HIV knowledge and risk avoiding behaviors. Ortíz-Serrano and colleagues (2000) explored the contradictions of cultural concepts of *marianismo, machismo* and *familismo* in HIV risk and prevention activities and the place of acculturation in the evaluation and planning of interventions. In a study of Puerto Rican women living in the Bronx, New York, Dixon, Saul and Peters (2010) found that acculturation and traditional gender roles both had effects on the evaluation of condom use with primary and non-primary sex partners. While Sánchez and
associates (2010) noted that increasing levels of acculturation led to more negative coping behaviors and consequently increased risky behaviors in a group of HIV positive Latinas.

Rosado (1993) theorized that the differences in HIV knowledge, attitudes and behaviors in Puerto Rican women in New York could be explained by their acculturation, sex role conceptions, educational levels and the importance of their religious beliefs (p. 2). She used random selection to recruit 100 single women between the ages of 15 and 44 who were attending a local community clinic. The participants’ mean age was 27.36; 80% preferred English; 82% were Christian and 51% said religion was very important to them; 13% had more than a high school education; 30% were born in Puerto Rico. The women completed an acculturation scale, initially developed for Mexican-Americans and then adapted for use with Puerto Ricans, a sex role inventory, a checklist assessing traditional and liberated roles; and AIDS knowledge and attitudes survey; and a demographic information form. The instruments that were not already available in Spanish were translated using the back-translation method. Rosado (1993) found a positive correlation between increased level of acculturation and AIDS knowledge ($r = .21$, $p < 0.05$); increased masculine traits and good prevention knowledge ($r = .21$, $p < 0.05$); and, increased level of education and AIDS knowledge ($r = .34$, $p < 0.001$). She also noted the possibilities of some limitations in her study, such as translation and literacy issues; the limited representativeness of her cohort; potential for self-reporting, and participant bias; and the recent media attention to AIDS at the time of data collection. Some other confounding factors for her study are that Puerto Ricans in the US can have a higher acculturation and that increased knowledge of AIDS is not the equivalent of behavior change to protect one’s self from HIV infection (Rosado, 1993).
Relationships among acculturation, coping styles, substance use, sexual risk behaviors, and medication adherence issues for Latinas living with HIV in the Los Angeles, CA were examined using structural equation modeling (Sánchez, et al, 2010). Two hundred nineteen women, who self-identified as Latinas and participating in a family-based intervention, completed interviews, including a demographic questionnaire; questions on acculturation, medication adherence, sexual risk behaviors, substance use; and, a tool assessing coping styles. The acculturation questions assessed place of birth, percentage of life lived in the US and choice of language for the baseline assessment during the interview.

The model demonstrated that the more acculturated women used negative coping styles, like passive problem solving, avoidance, or withdrawal, \((r=.26, p≤0.01)\), and negative coping was associated with non-adherence \((r=.26, p≤0.01)\), substance use \((r=.48, p≤0.01)\), and sexual risk behavior \((r=.29, p≤0.01)\) (Sánchez, et al, 2010, p. 406). Being acculturated was associated with being more educated \((r=.24, p≤0.001)\) and being educated was associated with the positive action style of positive coping, like seeking social support, using positive action and hope, \((r=.21, p≤0.001)\) (Sánchez, et al, 2010, p. 406). This study demonstrated the mediating effects of coping styles on risky and protective behaviors regarding HIV (Sánchez, et al, 2010). While this study is limited by its reliance on proxy measures of acculturation, it does provide some evidence of both the protective and risk inducing effects of acculturation through coping styles. Other limitations include the lack of information on cultural gender roles and relationships, which can also have mediating effects on coping through support systems.

Using the Information-Motivation-Behavior Model, Dixon, Saul and Peters (2010) hypothesized that women with more HIV-related knowledge, and higher HIV prevention self-efficacy would use condoms more often with their sexual partners. The one hundred and eighty-
seven Puerto Rican women from the Bronx, between the ages of 18 and 35; in a relationship with
an opposite sex partner for over a year; and, having sexual relations during the past six months,
completed demographic questionnaires and surveys assessing HIV/AIDS knowledge; mastery
over life events; HIV/AIDS prevention self-efficacy; acculturation; hyperfemininity (high
identification with feminine cultural roles); erotophobia (reluctance to discuss sexuality); and,
condom use. The women were mostly Catholic; more than half were living with a husband or a
boyfriend; more than half completed their high school education; and, nearly two-thirds thought
they could be at risk for HIV from their partners. The findings showed that not having children,
not living with their partner, having more education and a job were predictors of more frequent
condom use ($r^2=.26$, $p<0.001$) (p. 285). Another four percent of the variance on condom use was
explained by adding the block of being less hyperfeminine; more acculturated to US culture; and
having less mastery (Dixon, et al, 2010). The contexts of primary and non-primary relationships
further determined the frequent use of condoms during vaginal sex for the women in this study.
Other sexual acts were not explored. Women who ascribed to more traditional gender roles and
were cohabitating used condoms less often. The researchers have considered the importance of
trust in the relationship as a factor in the decisions to use condoms with partners and that this
may be presented as a rationale to encourage condom use (Dixon, Saul & Peters, 2010) and this
was also found in other groups like African-American women (Smith, 2015).

Culture can be used to support HIV prevention efforts. Cultural constructs are full of
meaning and have multi-faceted effects. Most of the discussions of Latino culture regarding
gender roles and relationships and family and respect are presented negatively regarding HIV
disease, in that they are referred to as risk factors and barriers to prevention, for example
marianismo and machismo. Ortíz-Torres and associates in 2000 presented an examination of the
literature and findings from their own work exploring the effects of culture on gender roles, power in relationships and sexuality. They discuss *marianismo*, *machismo* and *familismo* in their cultural scripts, yet also suggest that these scripts can be viewed from another angle to find support for enacting protective behaviors against HIV. They recommend the consideration of differences within ethnic groups based on acculturation and other factors when planning interventions and support programs. Most importantly, they reject the idea that culture is a breeding ground for oppression of Latinas (Ortíz-Torres, et al, 2000).

**Living with HIV and medication adherence.** Living with HIV disease is a theme that had not received as much attention as risk for and prevention of HIV transmission, until recently. Nonetheless, as HIV is a chronic illness, it is an area that deserves greater exploration. Articles can be found on stress and coping (Rivera-Casiano, 1994); symptoms and quality of life (Rivero-Méndez, et al, 2009); changing relationships (Orengo-Aguayo & Pérez-Jiménez, 2009; Pérez-Jiménez & Orengo-Aguayo, 2011); and adherence (Robbins, et al, 2012). These articles focus on the Puerto Rican community, on either the mainland or the island and do not reflect the full array of topics regarding living with HIV disease nor of the Latino cultural groups that could be studied. Chase’s (2011) ethnographic study of seventeen Puerto Rican women living with HIV in northern New Jersey in the late 1990s comes closest to the domain of interest.

**Stress and coping.** Rivera-Casiano (1994) performed a descriptive study using a post-test only, multi-group design-using equivalent and non-equivalent comparison groups to explore stress and coping in Puerto Rican women with HIV infection in the San Juan metropolitan area. The women were patients at the high-risk prenatal clinic and HIV clinic and grouped as follows: pregnant and HIV-infected women (non-random selection, N=29); not pregnant and HIV-infected (random selection, N=30); and, pregnant and not HIV-infected (random selection,
A social-ecological perspective of coping and stress guided the research questions focused on stressors related to pregnancy and HIV status. Stressful incidents included diagnosis with HIV and disclosure of HIV positive test results. The women with HIV were older, had less education and were more likely to have used drugs (40% vs. 3%), and had more sex partners. About two-thirds of the women with HIV were concerned about symptoms and reported feeling depressed, desperate, frightened, frustrated and disappointed in their partners. More than half of the women with HIV reported feelings of anxiety, anger and shame. About one-fifth of the women were concerned that they would not be able to meet their responsibilities of caring for their children. There were not any significant differences among the three groups in perceived stress and the use of coping strategies to manage stress. However, non-pregnant women with HIV were significantly more likely to report greater changes in their lives when first receiving their diagnosis and having higher scores on coping. Certain coping strategies were more likely to be beneficial for reducing perceived stress, like distancing, staying away, \( r = -0.34, p<0.01 \), seeking social support \( r = -0.36, p<0.01 \), and, reappraisal strategies, rethinking their situations \( r = -0.38, p<0.01 \). The number of available persons in the social network (8.33, \( p<0.05 \)) and the level of perceived support from that same network (3.24, \( p<0.05 \)) were found to better explain the differences among the women’s perceptions of stress and coping ability. Rivera-Casiano (1994) noted that the low-income women in her study had increased stress levels, especially those who were pregnant. She also concluded that the number of relationships in the social network and the perceived supports from those in the network were important for helping women to cope with stressful events in their lives.

**Symptoms and quality of life.** As part of the International HIV/AIDS Nursing Research Network, Rivero-Méndez and associates (2009) explored the frequency of symptoms
experienced by a sample of people living with HIV in Puerto Rico and how those symptoms affected their quality of life. A cross-sectional descriptive design was used to collect data using self-reports on the symptoms of a convenience sample of 44 participants (22 male, 21 female, and 1 transgender) using a socio-demographic questionnaire and an HIV-related quality of life tool and a sign and symptom checklist for HIV. This cohort was part of a larger research network, and instruments were translated into Spanish by a panel of experts in HIV care. The participants reported the current use of substances including tobacco (55%), alcohol (32%), marijuana and cocaine (66%), and former heroin use (45%). Twenty-two percent of the participants reported comorbidities, including asthma, anemia and depression. The most common symptoms reported were muscle aches (81.8%), depression (77.2%), weakness (70.5%), fear and worries (70.5%), and difficulty concentrating (65.9%). For those who reported greater symptom frequency, there was a noted effect on quality of life in the following dimensions: overall function (r=-0.58); life satisfaction (r=-0.59); health worries (r=0.32) and worry about HIV medications (r=0.59). There was no effect noted on financial worries, disclosure worries or sexual functioning. The researchers found that those participants who reported taking HIV medications also reported fewer HIV-related symptoms (t=3.061, df=42, p<0.01) (Rivero-Méndez, et al, 2009, p. 57). The researchers concluded that the more frequently reported HIV-related symptoms in this study population were similar to other populations, as was the profile of substance use and risky HIV–related behaviors. They also noted that future research is needed on the relationship between the reported co-morbidities in this sample and HIV-related symptoms and how this may increase the complexity of HIV-care management (Duncan, et al, 2014; Holtzman, et al 2013; Krentz & Gill, 2016).
Adherence. Adherence to HIV medications is complicated and often studied in various populations to develop an understanding of the complex attitudes and behaviors which support this endeavor. In 2012, Robbins and associates reported on the cultural influences on ARV adherence that they found in a cohort of Puerto Ricans attending a NYC HIV clinic. They hypothesized, based on the literature, that being more acculturated to the US and having more bicultural self-efficacy would improve adherence to ARVs. Seventeen English-speaking, self-identified Puerto Rican participants who were prescribed ARVs for at least twelve weeks and were willing to use a special medication bottle and bottle cap for four weeks participated in the study.

The participants had lived in the US for either at least twenty years (n=3) or their whole lives (n=14). All parents were born in Puerto Rico, except one born in the US. The participants completed the Bicultural Scale for Puerto Ricans (Córtes, Rogler & Magaldy, 1994) and a scale assessing bicultural self-efficacy. Demographic data were collected during the interview and viral loads and CD4 counts were obtained through chart review. The participants used the Medication Event Monitoring System (MEMS) to objectively measure the dates and times bottles are opened to self-administer medication. Univariate analyses were used for the demographic data; participants were categorized by adherence (≥ 95% adherence, optimal, vs. ≤ 94% adherence, suboptimal); Chi-square testing was used to evaluate the viral loads and CD4 counts by adherence category; bivariate Mann-Whitney U tests were used to compare the group means on the variables. Less than half of the participants were optimally adherent (n=8) with a total mean adherence of only 70.1% for the whole group. While there was not much of a difference between CD4 counts for both groups there was a significant difference in undetectable viral loads between those with optimal and suboptimal adherence ($\chi^2=7.24, p<0.05$) (Robbins, et
The participants’ scores on the Bicultural Scale for Puerto Ricans indicated that they were highly bicultural and identified highly with both the US and Puerto Rican cultures and this was associated with optimal adherence. Per the researchers, the limitations of the study in the small sample size, low power and homogenous group may have confounded these results (Robbins, et al, 2012). However, this study does emphasize the importance of considering culture in ARV adherence.

**Changing relationships.** Few studies have examined the effect of HIV seropositivity on the serodiscordant couple. Most choose to explore the effect on the individual level. As many HIV-related studies that use a cultural framework have discovered, HIV affects families and relationships. In 2009, Orengo-Aguayo and Pérez-Jiménez, reported on a small exploratory study of the relationship dynamics of five serodiscordant couples in Puerto Rico who had participated in a group-based intervention for promoting safer sex practices among serodiscordant couples. The intervention included four three-hour group sessions in which the first and last were attended by all participants and the middle two sessions were separated by gender (Pérez-Jiménez & Orengo-Aguayo, 2011). The content covered included basic HIV information, condom use and negotiation, mutual masturbation, and experiences with HIV and disclosure issues (Orengo-Aguayo & Pérez-Jiménez, 2009, p. 32). A month later the researchers conducted individual semi-structured interviews to evaluate the intervention, which included process and content, and logistical questions about all the phases of the study.

The participants were heterosexual couples in which one of the partners (male in two couples and female in three couples) contracted HIV, through injecting drug use or heterosexual contact. The audiotaped interviews were transcribed and coded using a double coding technique which lead to the emergence of themes of protection: ways to protect; women and men as
facilitators and barriers to protection; being in a relationship as a facilitator and barrier to protection; and the perceived importance of the roles of women and men in protection (Orengo-Aguayo & Pérez-Jiménez, 2009). The researchers found that the participants engaged in both traditional and non-traditional gender roles, which could be facilitators and barriers to protection. The participants shared that communication, collaboration and support were important to protecting their partners and their gender roles could not be separated from the dynamics of their relationships (Orengo-Aguayo & Pérez-Jiménez, 2009). While the findings of this qualitative study are limited due to the small size of the study, there is potential for transferability to other serodiscordant couples. More importantly, the idea that gender roles are fluid can be useful to the development of programs that support serodiscordant couples.

Chase (2011) performed an ethnography over three years following seventeen Puerto Rican women living with HIV from 1998-2001. A Spanish-speaker, she used participant observation, semi- and unstructured interviews; accompanied the women to their medical and social service appointments to understand their “help-seeking pathways;” in addition to other observations of people living with HIV during the same time. She was able to learn of the day-to-day struggles of these women as they navigated the healthcare and social service system to obtain treatment for HIV disease and the services, housing, transportation, substance use treatment, food, medications, for themselves and their families. Using Bourdieu’s concepts of social capital, cultural capital and habitus, she found that being able to access the habitus of other socioeconomic groups and being comfortable with English, aided the women to receive the care and services they needed. The findings are important for understanding some of stressful coping (DeGrezia & Scrandis, 2015) of Puerto Rican women living with HIV, yet are representative of an emphasis on a patient’s responsibility for activating personal, healthcare and social service
resources, alone (Chase, 2011). Disclosing their HIV status was difficult for these women and only done as necessary to access services, whereas, disclosure was found to be an important step towards developing resilience in living with HIV for a group of men and women of color in a qualitative study in South Florida (DeSantis, et al, 2013).

**Familial care.** A unique area of research in HIV care has been the care that family and loved ones provide to people living with HIV. In addition to concerns about the physical toll of caring for someone with HIV disease and the caregivers own behavioral risk, there are worries about the stigma of this disease, as well as, stigma of identity and stigma of behaviors. Latino and other families living by the cultural norms of *familismo* and *respeto* take on these stigmas of their loved ones, too. Nurses and social workers (Ortíz, 2000; 2005; Rivero, 1994; Roldán, 1999) conducted these qualitative studies exploring familial care and stigma.

Rivero (1994) wanted to “explore and generate an accurate and detailed description of Puerto Rican families’ perceptions of their experiences and processes of functioning when the HIV phenomenon is present in the family unit” (p.4). Using theoretical sampling, she identified six family units with a member attending an ambulatory clinic at a large public teaching hospital in San Juan, Puerto Rico. The semi-structured interviews were conducted with 29 family members in their homes or at the clinic after a period of participant observation. Some of the identified themes were facing the diagnosis; reacting to the diagnosis; revealing the illness; living with concerns; and seeking balance. Participants described HIV as a “culturally marked illness,” (p. 96) and noted that there was “a lack of empathy and compassion” (p. 98) that is seen with other illnesses. One of the major limitations for this study as reported by the researcher was the number of clinic clients who would not provide names of their family member as potential informants because of disclosure and stigma concerns.
Roldán (1999) performed a qualitative naturalistic inquiry guided by grounded theory method to answer the question of “How do Puerto Rican families respond when a family member has AIDS?” This study took the perspective of the person living with AIDS and not the family. Families were a primary source of support, particularly the female family members, out of a sense of obligation. Using purposive sampling and semi-structured interviews, sixteen people living with AIDS and three care partners were interviewed for one to two hours and when necessary second interviews were conducted. The identified themes were: finding out; bochinche (gossip); the battle; in the end; and, secrecy. Finding out was described as an experience of multiple losses in which the family member with AIDS was “a physical, spiritual and social threat to the family” (p.44). The family needed to be protected from bochinche and the accompanying rejection, and shame. This protection becomes extreme (secrecy) when people do not participate in care or HIV clinics are hidden in the community. The battle is defined as accessing care and medication and for women with AIDS to accept care from others. “In the end” was not defined as a true end as the participants felt that the suffering of AIDS would not end with death. In describing the Puerto Rican family as relationship-centered Rivero (1994) concluded that for these families AIDS brought changes to the family dynamic resulting from a loss of connection and intimacy and then a progressive decrease in all contact to reduce that psychic pain.

Ortíz (2000; 2005) studied the disclosing patterns of Latinas with HIV infection in the San Francisco Bay, California area. Nineteen women over the age of 18 participated in semi-structured interviews in this cross-sectional descriptive study whose goal was the exploration of the interactions, consequences and social contexts of Latinas disclosing their seropositive status. The major identified themes were timing of disclosure, needing to disclose, controlling
disclosure, supportive disclosing, and strategies for selective disclosing. Participants had chosen when to disclose to reconcile with family, to prevent others from disclosing and out of obligation to disclose when they were asking for help in self-care. The cultural concept of *familismo* was acknowledged as a compelling factor in disclosing an HIV diagnosis.

**Summary of HIV-related studies on Latinos and Puerto Ricans.**

The selected quantitative and qualitative studies presented reflect the emphasis in the HIV literature on assessing risk for HIV for people at risk for HIV, including intimate partner violence (Gonzalez-Guarda, et al, 2013; Gonzalez-Guarda, et al, 2008; Gonzalez-Guarda, McCabe, et al, 2011; Gonzalez-Guarda, Vasquez, et al, 2011) and acculturation (Sánchez, et al, 2010); and, evaluating prevention programs with an overwhelming focus on knowledge acquisition and some behavioral modification. The literature demonstrated that acculturation could also have a protective effect (Ortíz-Torres, et al, 2000). A smaller number of studies concentrate on living with HIV: stigma (Ortíz, 2000; 2005; Roldán, 1999), coping (Rivera-Casiano, 1994), medication management (Robbins, et al, 2012), symptom management (Rivero-Méndez, et al, 2009), and the effect of HIV on intimate (Orengo-Aguayo & Pérez-Jiménez, 2009) and family relationships (Rivero, 1994). Studies on living with HIV were located and presented with an emphasis either on Puerto Ricans, living in the mainland, mostly NYC, or on the island. As with all studies the limitations of focusing on a subset of a population that is motivated to participate in research must be respected and healthcare providers should be careful when applying this evidence to their own clients.

**Ethnonursing and Ethnography Studies using the CCT with Puerto Rican communities**

Three ethnonursing and ethnography studies on Puerto Rican communities, which used the CCT as a theoretical framework, were found in the literature. All three studies focused on Puerto Rican communities in the northeastern US: upstate New York; Philadelphia,
Pennsylvania; and Western Pennsylvania. Only two of the studies, Fliszar (2004) and Higgins (1995), used the ERM. Martin-Plank’s (2008) study was an ethnography. The domain of inquiry of Fliszar’s study (2004) was culture care meanings, beliefs and expressions of the elderly Puerto Rican community in a mid-sized urban setting in western Pennsylvania. Higgins’s study (1995) explored infant feeding practices of Puerto Rican mothers in upstate New York. The goal of both studies was identifying generic and professional care practices to plan culturally congruent care. Martin-Plank’s study explored the culturally based healing practices of the Puerto Rican community in Philadelphia, PA.

Higgins (1995) spent over a year working with the Puerto Rican community at a neighborhood clinic and community center in Buffalo, New York. She interviewed ten key informants (seven women and three men; five born in PR and five born in the US and between 18 and 60 years of age) and found that feeding practices of infants had changed over time with acculturation both in Puerto Rico and in the US. She also found changes over time in the familial relationships, such as the influence of the grandmother on a new mother and family roles between husbands and wives. Her findings led to the following universal themes: family love and togetherness; religious beliefs in God; superstitious belief in mal de ojo (evil eye); changing lifeways (man-woman relationships); respect-deference; baby is a healthy baby; overfeeding infants; folk practices of using pónche (a drink made with egg yolks and juices, believed to increase weight); being rice people or eating most meals with rice; occasional breastfeeding to none; early introduction to the bottle and late introduction to solid foods; grandmothers and kin teach feeding practices; and, change from coffee for children to other non-nutritive drinks. The diverse themes were as follows: education; health care; virginity; no prejudice; breastfeeding; and adding green vegetables and lower fat intake in the diet (p. 98).
Based on these universal and diverse themes, the following recommendations were made for culture care preservation and/or maintenance: reinforce family caring values of nurturance; respect and understand the use of religious and protective care symbols; touch infants and bless them when offering compliments; treat family with respect (maintaining eye contact and use a professional demeanor); promote continuity of care. For culture care accommodation and/or negotiation: the researcher recommended the following actions: use of the Spanish language to facilitate incorporation of all family members, especially the grandmother, into the care planning; promote *respeto* and *confianza* by accommodating or deferring to family and cultural values; encourage the introduction of cultural foods at the appropriate time for baby; encourage the use of the traditional drink *pónche* with additional health considerations; develop a comprehensive bilingual feeding assessment tool to promote anticipatory guidance. Lastly the researcher discussed the following for culture care repatterning and/or restructuring: include grandmother and kin in a co-participatory approach to infant feeding; emphasize cultural ideology and beliefs regarding larger and healthier babies; anticipatory guidance regarding over feeding and the introduction of solid foods; developing outreach programs including bilingual brochures, interactive cooking classes, and, media campaigns (Higgins, 1995, p. 163).

Fliszar (2004) conducted an ethnonursing study whose domain of inquiry was elderly Puerto Ricans in a mid-sized community in Pennsylvania to discover cultural care meanings, beliefs, expressions and practices of the urban elderly Puerto Ricans. The goal was to identify generic and professional care practices that promote health and wellbeing of elderly Puerto Ricans to plan and implement culturally congruent nursing care for elderly Puerto Ricans living within the community. She identified the following cultural practices of importance to the community: the *bodega* as a social, economic and political center of the community; racial and
socioeconomic identity; the use of curanderos/espiritistas and botánicas for health care services; the importance of family; and the will of God.

After conducting semi-structured interviews with thirty-three key informants and analyzing the transcripts, she identified four universal themes: care as kinship and family cohesiveness (p147); caring nurses as supportive, friendly, compassionate and empathetic (p. 154); non-caring nurse approaches care as just a job (p. 157); and, health as being physically able to do things, feeling satisfied emotionally and spiritually (p. 161). From these universal themes, Fliszar (2004) identified the following areas where nurses could focus culture care preservation and/or maintenance actions: respecting kinship ties during health care encounters; using Spanish when possible to communicate with patients; and, respecting the faith of the patients and the role of religion in their lives. Culture care accommodation and/or negotiation actions of the nurse would include including the family’s presence in the hospital room during illness and involving the family in professional care activities by either explaining procedures or enlisting the assistance of the family. The nurse could also learn key phrases in Spanish to communicate directly with the patient. Culture care repatterning and/or restructuring activities of nurses would be overseeing the modification of the fat, salt and sugar content in the traditional meals served at the community center or hospital and seeking nursing education in culturally competent care practices, such as an understanding of the holistic care practices involving curanderas or espiritistas.

Martin-Plank (2008) performed an ethnographic study of the Puerto Rican community in Philadelphia, Pennsylvania to discover the healthcare beliefs and practices grounded in the Puerto Rican culture. She wanted to explore the effects of acculturation on concepts as expressed by Puerto Rican women. Using semi-structured interviews of thirty-seven women
identified through purposive sampling with snowball recruitment; observation; and, participation, she identified the following themes: being between two worlds and staying connected to one’s roots; gardens as symbols of the motherland and creating the environment; the holistic nature of health; and surviving the system, healthcare perspectives in Puerto Rico and Philadelphia. The respondents had varying levels of acculturation as measured by a quantitative tool. Martin-Plank (2008) demonstrated the interconnectedness of the four themes in her discussion. The women described themselves as being between two worlds: Puerto Rico and Philadelphia, PA, USA. The gardens of their traditional healing herbs allow them to stay rooted in both worlds. Their holistic healing practices of herbs and other cultural practices helped and hindered them in accessing healthcare services in the Philadelphia, PA area. The women encountered healthcare providers who were not open to respecting the healing herbs these women used to care for themselves and their family members. Martin-Plank (2008) made the following recommendations, based on her findings: further translational research on integration of culturally based healing practices into professional nursing care and effects of acculturation on culturally based healing practices; continued incorporation of culturally based content in nursing education using innovative methods; systematic development of culturally competent nursing practice and its implementation in everyday practice; and, addressing gaps in the healthcare system that prevent people from accessing healthcare services in a way that promotes continuity of care.

The ethnostudies using the CCT with Puerto Rican communities presented here were focused on communities in the Northeastern US. The key informants were primarily first and second-generation women. All three studies emphasized the importance of the family, the need for healthcare providers to approach the care encounter with respect and the use of herbal
remedies for nutritive and curing purposes. No studies were located that focused generic or professional care for specific health conditions for Puerto Rican people.

**Ethnonursing and Ethnographic Studies using the CCT with HIV care**

Few ethnonursing and ethnographic studies using the CCT to explore HIV care were found in the literature. Both studies were focused on communities in Africa, which were severely impacted by the HIV epidemic. MacNeil (1994; 1996) explored AIDS caregiving by women in the Baganda culture of Uganda using the ERM. Aga, Kylmä & Nikkonen (2009a & 2009b) used ethnography to study the AIDS caregiving in Addis Ababa, Ethiopia. In MacNeil’s study (1994) some of the caregivers were also had HIV, while in the study by Aga and her associates (2009), the female family caregivers did not have HIV. These studies focused on family caregiving of HIV positive persons in the home setting in African countries. No other ethnonursing studies were located.

MacNeil (1994) had resided and worked for ten years in Uganda when she traveled to the Masaka/Rakai region of Kampala, the capitol of Uganda, for this ethnonursing study. It was the center of the Baganda people and the region with the highest incidence of HIV in Uganda, as well as the center of HIV/AIDS community-based support services. Twelve key informants, Baganda women who were the main caregivers for a relative with AIDS and twenty-five general informants who were involved in family caregiving were interviewed in either English or Luganda. The researcher was not fluent in Luganda but was familiar with many key phrases. The interpreter who assisted with the interviews was a known and trusted member of the home care team working with the caregivers. The researcher performed observation activities by following the home care team on regular visits to the patients’ homes and participation activities when the researcher assisted the nurse transporting supplies. The researcher used only a pen and paper to record her notes during the interviews with the key and general informants.
MacNeil (1994) identified six universal themes about culture care from her findings: responsibility, love, and comfort are derived from their kinship, religious, cultural beliefs and values (p. 77); survival to secure a future for the next generation (p. 95); and, continuing in the face of adversity and despite the burden of caring over time (p. 102). Additional themes are major changes in traditional gender roles and spousal care meanings and expressions of basic life sustenance in the face of AIDS (p. 107); culture care for preservation of life helped to fill the void left by those who had died, enhancing the life of Baganda women caregivers (p. 111). The diversity theme was making the most out of life for Baganda women (MacNeil, 1996).

From these universal themes, MacNeil suggested nursing actions that can enhance culture care of Baganda women caregivers. For culture care perseverance and/or maintenance, nursing decisions and actions would include maintaining kinship ties for caregiving and caring for orphans; enculturating kinship caring patterns to ensure that continuing generations identify with these caring practices; religious practices which are supportive of caregivers and ill should be respected. The giving and receiving of culture care was noted to be beneficial and should be encouraged by home care nurses working with Baganda women. Baganda people use of generic and professional care practices to maintain health and these activities should be encouraged as well. Culture care accommodation and/or negotiation decisions and actions would involve monitoring folk and professional caring practices that may in combination or alone be harmful to people living with AIDS. Planning for support of widowed caregivers after the death of the family of a spouse through inheritance of land can be facilitated by speaking on her behalf to government authorities. Kinship ties can be supported by assisting families to plan for the care of children when their parents die. Culture care repatterning and/or restructuring decisions and actions of the nurse would include supporting Baganda families through changes in family
In their ethnography of AIDS care in Addis Ababa, Ethiopia, Aga and colleagues (2009a) wanted to describe the conceptions of familial care. In the Ethiopian culture, women provide familial care. The researchers selected the northwestern section of Addis Ababa called Gulele because of its high prevalence of HIV disease and availability of HIV/AIDS services. A male nurse fluent in the Amharic language spoken by the community members interviewed six key and twelve general informants, chosen by purposive sampling, for up to one hour. The following themes were identified from the findings (Aga, Kylmä & Nikkonen, 2009b): nourishing people living with AIDS while struggling with poverty (p.43); maintaining cleanliness and hygiene of the person and surroundings (p.44); comforting people living with AIDS (p.45); and, sacrificing self to sustain people living with AIDS (p.45). In this study the researchers found that caring for family members with AIDS was grounded in religious and cultural lifeways of the community. For these women, the loss of income and education they experienced and stigma they encountered while caring for their family members did not supersede the obligation to make the sacrifice nor prevent them from sharing in their loved one’s suffering (Aga, et al, 2009b).

The two studies using the CCT to examine HIV care were both focused on family care of people living with AIDS in the home setting in African countries. Women were caregivers in these cultures and served as key informants for these studies. Both studies emphasized caregiving obligations and sacrifices that these women made to care for their family members, but they also noted the importance of maintaining these familial caring traditions. No studies
were located that examined the generic care of people with HIV/AIDS in other cultures nor professional caring associated with HIV care.

Chapter Summary

This chapter presented findings from the literature on the Puerto Rican experience of the HIV epidemic. The ethnohistory of Puerto Rico and its unique relationship with the US is presented through the lens of Leininger’s Culture Care Theory (1991, 2002a & 2006a; McFarland & Wehbe-Alamah, 2015). The economic, political, social structural, educational and environmental contexts that Puerto Rican people live with are tied to their risk factors for HIV. Kinship, religion and culture also play a role in the experience of HIV disease in the Puerto Rican community. A brief history of the HIV epidemic and the response of the Puerto Rican community is provided. Health research issues for the Latino community from labeling, consolidating data, conceptual issues with acculturation and issues of trust complicate understanding health for each Latino group, including Puerto Ricans. These problems were also found through select studies on HIV in Latinos and Puerto Rican women discussed. Ethnonursing and ethnographic studies using the CCT were also presented which offered a different perspective on Puerto Ricans in the US; and, women living with HIV disease in Africa.
Chapter III
Methodology

Chapter Introduction

This chapter begins by describing the ethnonursing research method developed by Dr. Madeleine Leininger (2002b, 2006b; Wehbe-Alamah & McFarland, 2015b) and identifying its fit for discovering the culture care needs of Puerto Rican women receiving HIV care from nurse practitioners (NPs) and other providers. The special emphasis on the role of the ethnonursing research mentor is explained. In addition, the research site, human subjects and ethical considerations for this study are presented. The recommended and planned methods of entering the research setting; using research enablers; and, collecting data are discussed as are the adjustments to the initial plans for the ethnonursing study were made based on need. Next, the criteria used for the selection of the informants are defined. Lastly, the evaluation criteria for ethnonursing research and its application to this ethnonursing study are described.

Ethnonursing Research Method

The ethnonursing research method (ERM) was developed by Dr. Madeleine Leininger to elicit comprehensive data about culture care from key and general informants to cultivate the knowledge base for the Culture Care Theory (CCT). Grounded in Dr. Leininger’s educational preparation and experiences as a nurse and an anthropologist, the method is an inductive open-ended qualitative inquiry incorporating participant observation, in-depth interviews and on-going analysis (Wehbe-Alamah & McFarland, 2015b). It is person-centered rather than researcher-centered, as this emphasis permits an open examination and discovery of care meanings, perceptions, patterns and experiences of the culture of interest. This methodology analyzes the emic (insider) perspectives of people to identify universal and diverse care needs across cultures.
The CCT maintains that meanings of care, wellbeing, health, and illness are embedded in the worldview, social structures, cultural values, and religion, environmental, biological and language expressions of a culture (Leininger, 2006a & Wehbe-Alamah & McFarland, 2015b). These meanings are best understood using an open inquiry method like the ERM, “a way of discovering, knowing and confirming people’s knowledge about care and ways to keep well” (Leininger, 2006b, p. 53).

The ERM was selected for this study of culture care needs of Puerto Rican women receiving HIV care from NPs and other providers because it is the only methodology specifically developed for the discovery and exploration of culture care practices and needs through sharing emic stories, thereby, building the knowledge base of the CCT, as it was designed to do. Therefore, the researcher determined this fit was required for this domain of inquiry. The complexities of the experiences of the Puerto Rican people, and the Puerto Rican female community, as explored using Leininger’s Sunrise Enabler to Discover Culture Care, and as discussed in Chapter Two, further warranted the use of the ERM. In addition, the complexities, evolution and life-long nature of HIV care required a deeper level of exploration of the phenomena, to develop a meaningful contribution to the literature of HIV care management. The depth and breadth of the CCT and Leininger’s Sunrise Enabler to Discover Culture Care (Wehbe-Alamah & McFarland, 2018) (Figure 1, Appendix C) opened avenues for understanding the lifeways of the Puerto Rican people that could not be discovered using quantitative methods, nor as comprehensively with other qualitative methods. Exploring the socioeconomics, politics, and environment of Puerto Rico and the US mainland; and, the cultural and religious values of the Puerto Rican people allowed the researcher to begin discovery of their caring beliefs, values and practices.
By using the ethnonursing research process to explore the background of culture care needs, this researcher aimed to help nurses, nurse practitioners, and other healthcare providers working with clients to deliver patient-centered care that is culturally congruent using the three culture care decision and action modes: (a.) culture care preservation and/or maintenance; (b.) culture care accommodation and/or negotiation; and, (c.) culture care repatterning and/or restructuring.

**Ethnonursing Research Process**

The ethnonursing research process delineated the phases of this research from identification of the culture, setting, and domain of interest; through design and implementation of the plan; to analysis of data; and, dissemination of research findings. The purpose of this detailed process was to assure the design of a rigorous study and a carefully explored domain of inquiry to reveal care expressions, meanings, patterns and practices from the unique perspectives of informants or co-participants in research, in this case, Puerto Rican women receiving HIV care in New York City. Please refer to Figure 5 (Appendix G) for a detailed outline of the steps of the ERM (Wehbe-Alamah & McFarland, 2015b, p 67-68) as used by this researcher to design and conduct this study. The detailed conceptualization of the research plan is presented in Table 1 (Appendix A). This holistic approach served to cultivate an environment that encouraged active listening, suspension of judgment and an attitude of learning leading to an appreciation of the emic data shared by informants. To further support the openness that was required for qualitative studies and ERM, this researcher used reflective journaling to facilitate bracketing of bias and emotions to enable identification of patterns in the data; and, relied on guidance from an ethnonursing research mentor.
**Ethnonursing research mentor.** It takes time for a researcher to develop the skills and relationships necessary to elicit the depth and breadth of data desired for an ethnonursing study. As a result, a novice researcher benefits from working with an ethnonursing research mentor, someone who has the experience of implementing a study using the ERM. The mentor’s purpose is to provide support and guidance to the novice researcher throughout the entire research process, especially during data analysis. For example, the novice researcher may struggle to find key informants or individuals who have the most experience and knowledge of the domain of inquiry; or, may question the credibility of data provided due to a lack of rapport or established trust between the researcher and informants. The ethnonursing mentor can help guide the novice researcher via reflective journaling or the use of ethnonursing enablers (guides), such as Leininger’s Stranger-to-Trusted-Friend Enabler to evaluate the work and offer suggestions to enhance the process (Leininger, 2006b). For this study, the ethnonursing research mentor served as an on-going resource as the researcher designed the study, collected data and interpreted findings to assure evaluation criteria for the method were met.

For this researcher, it was important to find an ethnonursing research mentor who was an expert in the CCT and the ERM and had experience studying a culture with which there was also self-identification. Researchers who did not self-identify with the culture of interest have conducted most ethnonursing studies. In this ethnonursing study, the researcher is a second-generation Puerto Rican, who was born, raised and currently lives in New York City and had participated in generic (folk) care and provided professional (nursing) care for people living with HIV disease. After discussions with the dissertation chairperson, Dr. Hiba Wehbe-Alamah, PhD, RN, FNP-BC, CTN-A, was identified as an ethnonursing research mentor who: (a.) was a leading authority on the CCT and the ERM; and, (b.) has conducted ethnonursing studies with
cultural groups with whom she had self-identified. Having any previous experience with a
cultural group can create some bias. Furthermore, self-identifying with the cultural group could
expose additional levels of bias due to a lifetime of familiarity with the customs, religion, and
language, as well as, shared experiences. However, it was the guidance of the ethnonursing
research mentor and the use of several ethnonursing research enablers that provided the
researcher with methods and skills to put bias and emotion aside, to focus on the domain of
inquiry and view people and their lifeways in a holistic and new way. In addition, Dr. Wehbe-
Alamah was also an NP specializing in women’s health. Besides having a knowledge base in
women’s health issues, she brought further dimensions of understanding in the client-nurse
relationships that NPs develop; the value of the CCT; and, how together they foster the
collaborative partnerships that result in culturally congruent care.

Research Site, Setting and Access to Informants

The setting for this study was New York City. New York City has the largest cumulative
number of AIDS cases since the CDC first identified the disease in 1982 (CDC, 2013, February).
New York City is also the mainland US city to which the majority of Puerto Ricans have
migrated through the first decade of the 21st century. Ennis and associates (2011) reported that
over 1.1 million Puerto Ricans reside in New York, according to the 2010 US Census. This
figure corresponds to nearly one third of the Puerto Ricans residing on the island of Puerto Rico
and was more than any other state in the US at the time. A Pew Hispanic Center report noted
that Puerto Ricans comprised 33% (the largest share) of the total Latino population in New York
City (Brown & Lopez, 2013, August 29). The ease of air travel to and from Puerto Rico, other
US cities, and world countries has made New York City, a frequent destination and, for some,
the first or only stop in their (im)migration journey. For people living with HIV disease, New
York City is also a location that provides access to new research and quality health care. For those who qualify for Medicaid benefits or meet the criteria for Ryan White Care Act funded programs, NYC provides the widest array of services (medical and nursing care; medications; and, personal and home care services, etc.). There are also special needs plans (SNPs) for people living with HIV and their dependent children that provide coordination of benefits and special support services regarding adherence and risk reduction (NYSDOH, November 2013).

The researcher has been an HIV nurse for over 25 years in New York City and witnessed the transformation of this disease from a death sentence into a manageable chronic illness. She is certified in advanced HIV care and completed a preceptorship training in 2014 in recent HIV care advances. Although the researcher is a clinical nurse specialist in HIV care and not a nurse practitioner, she has worked closely with NPs over the years in collaborative relationships to provide nursing care to people living with HIV disease. She is familiar with and has counseled people of various cultural backgrounds in the behavioral changes that support wellness while living with HIV disease.

The focus of this ethnonursing study was the culture care needs of Puerto Rican women receiving HIV care from NPs and other providers in NYC. The researcher was interested in Puerto Rican women’s perceptions of that care. The preferred mode to identify potential key informants was through centers of primary care that utilize NPs. Gatekeepers are those who can facilitate access to research participants, such as clinic administrators, official and informal community leaders, as well as, potential informants. The initial plan for this study was to engage gatekeepers and potential informants at a network of community-based clinics that utilized NPs to provide HIV care and served this population of Puerto Rican women in various locations throughout NYC. After a few months of attempts to negotiate a research gathering partnership,
it was decided that the mutual needs of the interested parties could not be satisfied. Afterwards this researcher began conversations with colleagues at New York University Rory Meyers College of Nursing’s Center for Drug Use and HIV Research (CDUHR) and discovered that they were engaging in research aimed at increasing the participation of racial and ethnic minorities in HIV clinical trials and biobehavioral research. After approval by the ethnonursing research mentor and dissertation chair, a research gathering relationship was established.

Potential key and general informants for this study were encountered using a registry of HIV+ persons in New York City who had been screened for potential participation in HIV-related clinical and biobehavioral trials. The AIDS Clinical Trials (ACT) Project is a series of interventional studies, which have worked to reduce the barriers to clinical screening observed in the African-American and Latino communities in the US. ACT1 addressed the individual, social network, health care provider and clinical trial setting barriers. The findings from ACT1 led to the development of a peer driven intervention that was being tested in a randomized control trial in the ACT2 Project (Gwadz, et al, 2013). The principal investigators of the ACT Projects were affiliated with New York University Rory Meyers College of Nursing.

With an N=540, the registry participants at that time were 44.26% female, and 26.48% Latino (n=57) (M. Gwadz, personal communication, October 15, 2013). Of this group, 27 specifically self-identified their Latino subgroup as Puerto Rican. Through the principal investigators of the ACT2 Project study, further details regarding the ethnicity of the participants were obtained and outreach to potential informants was made by their research team members by phone per their IRB approved protocol. At that time, further determination of the receipt of primary and specialty HIV care from NPs was made to identify potential key versus general informants. Those registry participants, who consented to be interviewed by this researcher,
were asked to become potential referrers for other potential key and general informants, who also met the inclusion criteria, via the snowball method and given the researcher’s business card which included all contact information, i.e. cellular phone number and email address. Specifically, one ACT2 participant served as a referrer for all the informants obtained via the snowball method.

**Human Subjects and Ethical Considerations**

The appropriate institutional review boards (The City University of New York [CUNY] College of Staten Island and New York University) were solicited for clearance of this ethnonursing study (CUNY, 2012; NYU, 2013). IRB approved written explanations of the study and consent forms that were provided in English and Spanish to all potential informants participating in the study (Appendix K and Appendix L). For those participants, unable to read English or Spanish, an IRB approved short form (Appendix M and Appendix N) and statement about the research study were available for use but did not need to be implemented in this study. Study screening and consent was performed per IRB protocol. Explanations included details about the study’s purpose and data collection methods (audiotaped interviews and researcher observations); possible risks and benefits of participation; the right to withdraw; and, actions to provide privacy and maintain confidentiality, i.e., use of codes for participants on forms, transcripts and reports; separate and locked storage of consent forms and interview data; storage of tapes and transcriptions of interviews in a locked box located in the researcher’s home accessible only by the researcher; and, destruction of all transcripts and recordings upon participant request or as prescribed by IRB protocol, i.e., three years after completion of the study. All participants were asked to describe the study and their participation in their own words as an indicator of their understanding. Participants signed the consent form indicating their willingness to participate. Preparations were made for the use of a bilingual
transcriptionist, i.e. a confidentiality agreement, however, the researcher performed all transcriptions verbatim from the audiotapes and all translations of the interviews conducted exclusively in Spanish and any Spanish terms used in the predominantly English interviews. The researcher became fluent in Spanish through formal education over a seven-year period spanning late grade school, high school and undergraduate school. Due to limited immersive exposure to Puerto Rican Spanish, the researcher used dictionaries, both online and text, to check any words that were not clear on the audiotape or identified through context or clarifying terms during the interviews. The researcher reviewed all transcriptions and translations during the process and after completion and compared the content to her notes to assist in the veracity of the data (Hendrickson, Harrison, Lopez, Zegarra-Coronado & Ricks, 2014) and identified details of the transcription and translation procedures to maintain transparency of the process (al-Amer, Ramjan, Glew, Darwish & Salamonson, 2014).

**Enablers**

To assist the ethnonursing researcher, Leininger developed enablers, or guides, to facilitate the collection of data, and to evaluate the quality and credibility of the data obtained. The use of the word enabler reflects a concerted effort to avoid terms like tool and survey, which, according to Leininger (2006b), serve to objectify key and general informants on the domain of inquiry and impede the emergence of holistic data. While the word “enable” has become subject to negative connotations, its meaning of facilitation (Leininger, 2006b) is intended to be conveyed here.

**Leininger’s Stranger-to-Trusted-Friend Enabler.** The first enabler is Leininger’s Stranger-to-Trusted-Friend Enabler (Figure 6, Appendix H) (Leininger, 1991, 2002b, 2006b; Wehbe-Alamah & McFarland, 2015a). The purpose of this enabler is to help the researcher evaluate interactions with informants to determine the quality of the data being shared.
by them. When the researcher is essentially a “stranger” to informants, they may guard information that they had been willing to share. Trust has not been developed yet and people may question the genuineness with which the researcher is interacting with them. They may fear what will be done with the data gathered. As informants come to trust the intentions of the researcher, they may become more willing to reveal the meanings of care as they have experienced them in their culture and the healthcare system from nurses and other healthcare providers. When the researcher has become “a trusted friend,” informants take a more active role in the research process to make sure that their truths have been accurately described, interpreted and understood.

The researcher used this enabler, initially, as the gatekeepers of the community of Puerto Rican women receiving HIV care from NPs were being identified; as potential informants were encountered; and, as she described the study to them. The researcher clearly defined her role as a researcher to the informants during all research-related encounters to facilitate this process. The enabler continued to be used until trust was developed with the informants. By being aware of the level of trust, these individuals and groups may feel towards her, the researcher evaluated the credibility of the data they provided and identified what needed further clarification in the follow-up interviews.

The researcher found that she moved from “stranger to trusted friend” for each of the individual informants from the screening through the interview process, because each informant was willing to share intimate details about their lives. All informants were actively solicited by either the ACT2 research assistant or the informant referrer. The informants were approached because they met some of the inclusion criteria. For both the ACT2 and snowball informants, the stranger phase was most active during the screening process. A salient example of the stranger
phase was the informants purposefully screened the researcher to determine her intentions with this research, as she screened them for participation in the study. Examples of the trusted friend phase were apparent when the informants shared pictures of their loved ones and/or offered to be available for future research conducted by this researcher.

**Leininger’s Observation-Participation-Reflection Enabler.** Leininger’s Observation-Participation-Reflection Enabler (Figure 7, Appendix I) (Leininger, 1991, 2002b, 2006b, Wehbe-Alamah & McFarland, 2015a) guides the researcher when becoming engaged with the community of informants. There is special emphasis on observing the community and culture in the beginning of the research process to become aware of the context of the community’s culture. This is very important for nurses and other providers, who are more accustomed to action early in their interactions with clients. Once the context is understood, then the researcher can move to becoming more of a participant in the interactions. Throughout the process, the researcher engages in reflection which is integral to all research activities. Reflection is not a solitary process, as all notations must be confirmed with informants to determine if they present an accurate description of the meanings, values, beliefs and lifeways of their people and culture. Therefore, this enabler facilitates the ethnonursing research process by serving as a reminder that there is a “process” to move through when gaining the trust of gatekeepers and informants; and, ensuring trustworthy findings. Staying with the process also permits the researcher to more closely observe movement from a “stranger to trusted friend.”

The documentation of field notes is an important way to keep track of the simultaneous processes as they occur.

This enabler was utilized throughout the research process; and, was helpful when the researcher began to seek potential sources of participants: clinics, nurse practitioners in HIV
care, and HIV social service agencies providing services to Latinas with HIV. Using this enabler, the researcher observed and reflected on a reason for gatekeepers of a network of clinics to be hesitant to engage in meaningful discussions about this study and the method as noted previously.

They did not return my calls or emails requesting a meeting to discuss my proposal or tell me how to prepare it according to their needs for review. How can they understand what I want to do? I’ll insist on a meeting going forward. (Author, Reflection from journal, September 27, 2013).

Since these gatekeepers did not wish to engage in further discussions about this study, the researcher consulted with trusted colleagues in HIV care in the NYC area. These consultations resulted in two actions taken by the researcher to facilitate the implementation of this study. One colleague suggested exploring another method of gaining access to potential informants, through a research registry, as discussed above. Another colleague of the researcher suggested participating in the preceptorship discussed previously to observe, participate and reflect on current HIV care at two clinics. These two activities allowed the researcher to observe practice in clinic settings and engage and interview informants in another setting, through the research registry and an affiliated community-based organization. With this arrangement, the researcher’s observations, participations and reflections of the interviews became focused on direct experiences with the informants. While this process departed from usual procedure of the ERM, it allowed this researcher to create a space between herself and the care providers of the informants. One informant repeatedly expressed concern about who would know what she was saying, even though confidentiality was explained during the consent process and throughout her participation, the researcher found it necessary to inform her explicitly that none of her providers would know she took part in this study. Upon continued reflection on the process and this informant’s concerns, this researcher believed separating observation and participation settings
generated a deeper level of sharing by the informants which may not have occurred if she was perceived to be “a part of” the clinic or care setting.

**Leininger’s Semi-Structured Inquiry Guide Enabler to Assess Culture Care and Health.** For this ethnonursing research study with Puerto Rican women receiving HIV care, the researcher used Leininger’s Semi-Structured Inquiry Guide Enabler to Assess Culture Care and Health (Wehbe-Alamah, 2018) to create the semi-structured inquiry guide (Appendix O) that was guided by holding knowledge derived from the thorough review of literature performed and input from the ethnonursing research mentor. The adapted semi-structured inquiry guide enabler also included questions that assessed perceived acculturation of the informants and addressed standards of HIV care, sexual health, medication usage and risk behavior change. It was translated into Spanish by the researcher before initial IRB application (Santos, et al, 2015) (Appendix P). Basic demographic questions were asked first, and then, topics were explored as guided by the informants’ responses to as closely reflect a conversation as possible, to increase comfort with the interview process. While using the semi-structured inquiry guide during the interviews, the researcher chose to let the informants guide the sequence of questions. Some informants moved straight into information on their HIV status and to maintain the fluidity of the conversation, the researcher followed their lead yet made sure that all topic areas were covered during the interview.

**The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler.** The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler was developed to ease the coding of large amounts of cultural data during the ethnonursing research analysis process (Wehbe-Alamah & McFarland, 2015a). This enabler was used during the coding process after the transcription, and when indicated, translation of interviews. Most of the coding labels came
from the words of the informants or terms from the holding knowledge of the Puerto Rican culture or HIV care. Once coding was completed the researcher identified the corresponding code from The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler to facilitate analysis of the findings in the CCT. The list of codes used by the researcher is listed in Table 2 (see Appendix B).

**Selection of Key and General Informants**

For this ethnonursing research study, the researcher worked with gatekeepers, the research assistants for the ACT 2 study, to aide in the identification of potential informants. A total of 21 women were identified as potential informants and participated in the screening activities. Criteria for selection of key informants were as follows:

a. At least 18 years of age,

b. Self-identified as Puerto Rican (of Puerto Rican origin or background and as being a member of the Puerto Rican culture),

c. Self-identified and born as female,

d. Residing in New York City,

e. Currently receiving HIV care in New York City from Nurse Practitioners,

f. Their primary language is English or Spanish, and,

g. Willing to participate in the study.

General informants were individuals who met all the inclusion criteria as noted above, except they were not currently receiving HIV care from an NP, although they did receive some care from NPs. Their source of HIV infection, except for perinatal transmission; staging of HIV disease; or, ARV status were not exclusion criteria. Any potential informants with untreated mental illness were excluded from participation in the study. No exclusions occurred for this
reason. Two women did not meet the inclusion criteria (one did not identify as Puerto Rican and another was not seeing an NP for any care) as noted above and another woman met the inclusion criteria and agreed to be interviewed but never showed for the appointment time and was unreachable afterwards. Six key informants and 12 general informants were interviewed for a 1 to 2 ratio, qualifying this study as a mini-ethnonursing study. A mini-ethnonursing study can have between 6 and 8 key informants and 12 and 16 general informants, whereas a maxi-ethnonursing study would have 12 to 15 key informants and 24 to 30 general informants (Wehbe-Alamah & McFarland, 2015b). The researcher achieved saturation with the amount of data collected for a thorough analysis of the domain of inquiry in this vulnerable population.

Most screening calls lasted between 10 and 20 minutes during which time the researcher explained the study and reviewed the inclusion criteria with the potential informant. After ascertaining that inclusion criteria were met and which category of participation the informant met (key versus general) a verbal invitation to participate in the study was made. Upon acceptance of the invitation, a mutual agreeable time was agreed upon for the interview and the location of the building and meeting rooms were shared. It was anticipated that interview sessions which were audiotaped with key informants would last between 60 and 90 minutes and with general informants would last between 45 and 60 minutes. Most initial interviews of key informants lasted from 90 to 120 minutes and interviews with general informants lasted between 60 and 90 minutes. These longer interviews included time spent establishing rapport during the taped portion of the interviews, as informants shared their stories in minute detail, at times, with the researcher. In these cases, the focus of the data analysis centered on the content specific to the research questions. Second interviews, lasting up to one hour, were conducted in the same
location to confirm findings with the six key informants and three purposively selected general informants who demonstrated enhanced knowledge of the domain of inquiry.

**Data Collection Plan**

Data was collected using field notes of observations, journaling, and audiotaping of interviews; photographs and/or videotaping were not used to document objects pertaining to the domain of inquiry. Measures were taken to preserve the privacy of participants, including coding of all data and notations referring directly to informants. The consent forms were stored separately from any data in a safe deposit box in a bank, accessible only to the researcher. All taped interviews and notations made during interviews were stored in a locked fire safe box maintained in the researcher’s home and to which no-one else had access and all electronic data was saved on an encrypted flash drive.

As described earlier, a semi-structured inquiry guide was used for data collection. All interviews were conducted in the preferred language of the informants, English or Spanish and code-switching was used fluidly by the informants and researcher. All interviews occurred in one of three designated meeting rooms to which the researcher had access through her affiliation with the ACT2 study. The rooms are in a building that was once a television recording studio and is now the location of a large community-based AIDS services organization (ASO). The building is in the midtown area of Manhattan in New York City and is a few blocks from a major transportation and shopping hub in the city. A few major construction projects were taking place on the same block as the building limiting walking along some of the sidewalks and there was construction scaffolding outside the building, camouflaging the entrance, as explained to each informant when scheduling appointments. Administrative, fundraising and service offices are located on the two floors occupied by this ASO. The floor where all interviews were conducted was on a floor where people met with their caseworkers.
The room where the interviews were conducted was available every week day during business hours. The interviews were conducted at a mutually agreeable time and often were scheduled on dates to coincide with other meetings, such as groups at the organization. To establish a comfortable environment, the researcher arrived early, usually 30 minutes, to the interview space and arranged the chairs and table in the room to include a cushioned chair for sitting and another chair for coats and bags. On the table, the researcher set bottles of water, snacks, including individually wrapped cookies, pastries and chips, and tissues. All paperwork was maintained in a closed folder and the audio recorder was set-up on the table between the researcher and the informants. The room’s door had a small square-shaped windowed section. The room was arranged so the researcher faced the window and the informant’s back was to the window. In addition, the table was long enough that the informant could sit at the end and not be visible through the window in the door. Being a former television studio, the rooms were sound-proofed to reduce noise from other areas when the door was closed.

The researcher met each informant in the reception area on the floor of the interview room and escorted her to the space allowing her to use the restroom when necessary. During these walks, there was casual conversation to continue the development of rapport. The researcher also escorted the informants to the hall and directed them out of the building. The interview room was closed, and the researcher carried any sensitive material with her always in a closed bag. Most of the informants were quite familiar with the building and were members of the organization and therefore had identification cards which they could easily swipe to gain access to the building. The researcher quickly became known to the security staff at the location through affiliation with the ACT 2 research study.
The researcher had the contact information for a mental health care provider at a different community-based organization that provided services to the Latino community for referral to support resources should any portion of the interview have caused psychological distress. The researcher discovered that each informant had their own mental health resources and did not require the contact information. Any time, in which a topic became difficult for an informant, the researcher paused the interview to allow the informant to compose herself and as needed the researcher provided other comfort measures, such as offering tissues and water.

While the initial explanations of the study occurred during the screening call, each interview began anew with an explanation of the study to determine continued consent to participate in this research study as required by the IRB protocol. All documents used directly with the informants, consent forms, and enablers, were translated into Spanish by the researcher. The researcher conducted all the interviews in the preferred language and performed all transcriptions and translations to assist with data analysis. While this did prolong the initial analysis process, the researcher developed an in-depth understanding of the data shared by the informants and this assisted with the subsequent phases of the data analysis. The ethnonursing research mentor reviewed the transcription of the first interview and provided guidance for conducting subsequent interviews. The researcher confirmed and validated transcribed data with the informants.

The researcher documented impressions and ideas regularly in her field notes. She used the field notes to record and reflect upon all the events during the research process, beginning with the start of her exploration of the domain of inquiry and developing the research questions. This field journal recorded her thoughts on facilitators and obstacles to the research process and impressions of the informants during the screening, initial interview, second interviews and
check-ins post transcription. These field notes were an essential technique for bracketing that helped the researcher to establish and maintain an objective distance. Many of the informants made the researcher think of family, friends and herself. The intensity of the interviews was at times overwhelming. The field notes put these feelings into perspective to allow the researcher to remain separate from the informants. At the same time, the field notes contained specific information about their unique qualities to quickly differentiate among them. The researcher then reviewed entries when analyzing the data and writing about the findings. With the extensive efforts spent on the field notes, the researcher found that as she carefully analyzed the content of the interviews, she quickly identified important patterns and themes, for later confirmation by the key informants.

**Leininger’s Phases of Ethnonursing Data Analysis Enabler for Qualitative Data**

Leininger (2006b; Wehbe-Alamah & McFarland, 2015a) delineated four phases for the analysis of data (see Figure 8, Appendix J) during which data is gathered, documented, and subsequently analyzed and synthesized. Throughout the entire process, the researcher consulted with the ethnonursing research mentor, the dissertation chairperson, and the informants. At the same time, the researcher often reflected on the data, for content and depth, and the data collection process, for authenticity. Computer programs were utilized to assist in this process. After consultation with the ethnonursing research mentor, it was determined that the NVIVO 10 program from QSR (Qualitative Solutions and Research) which is used for organizing and assisting with analysis of qualitative data was a good fit for this ethnonursing study.

During the first phase of ethnonursing data analysis, the researcher collected raw data, as described above, transcribed it and then imported it into NVIVO 10. All transcripts in English were reviewed by the ethnonursing research mentor and dissertation chairperson. The second phase involved the coding of data by identifying any descriptors, indicators and categories along
emic and etic lines to organize the data and facilitate analysis, for which the ethnonursing mentor shared best practices for performing. The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler was then used to determine which categories of data were identified during analysis. Any categories that the researcher identified, specific to this domain of inquiry, were also categorized using the same enabler. The listing of these categories was discussed with the ethnonursing research mentor and dissertation chairperson. During the third phase the researcher began to recognize recurrent patterns of both similar and different meanings, expressions, and interpretations of data. Saturation of data was determined during this phase, when similar information was shared by the informants and then, no new interviews were sought. The fourth phase began with a face-to-face day long brainstorming session between the researcher and the ethnonursing research mentor, focused on synthesizing patterns and major research findings into major themes. Afterwards all notes were compiled into structured outlines by the researcher and reviewed by the ethnonursing research mentor and dissertation chairperson for further refinement and alignment with the CCT. In addition, concepts recognized in the patterns that had been explored by other researchers were identified for further discussion and the development of recommendations for future ethnonursing and HIV care studies.

**Evaluation Criteria for Ethnonursing Research Findings**

Leininger (2006b; Wehbe-Alamah and McFarland, 2015b) established criteria for evaluating that the standards of qualitative studies and the ERM have been met. Credibility is the truthfulness of the data as offered by participants and key informants (Wehbe-Alamah & McFarland, 2015b). As noted above by using Leininger’s Stranger-to-Trusted-Friend Enabler, the researcher evaluated the truthfulness of the data being provided. Confirmability is the verifiability of the data collected during the research process. This can be achieved through
confirmation of findings from the interview and the researcher’s observations with informants, during the second interviews (Wehbe-Alamah, 2005). In this study, the researcher compared data from the transcripts and field notes and during the second interviews asked specific questions to confirm the observations and overall findings. The informants took the opportunity to add more information to clarify meaning. One topic that was revisited during second interviews to clarify and confirm the researcher’s understanding was factors leading to decisions to leave a provider’s care. The researcher wanted to be clear on the impetus and execution of these decisions because of its importance in maintaining clinical outcomes in HIV care.

Meaning-in-context refers to findings that are understood through the living and environment setting (context). Actions and events as explained by informants are substantiated by observations of the environment (Schumacher, 2007). For this ethnonursing study, meaning-in-context was assessed through follow-up questions to clarify any statements made, seeking examples for future reference during transcription and analysis. For example, when the informants discussed religious practices, they often showed the researcher the rosaries they used to pray or other religious items (religious beads, crosses) that they carried with them every day. In addition, the researcher’s observations of their clothing, and other items of importance on their persons served to clarify their personal experiences (cell-phone use) as shared during the interviews.

Recurrent patterning is the documentation of repeating patterns, and themes demonstrating uniformity in lifeways and behavior (Leininger, 2006b; Wehbe-Alamah & McFarland, 2015b). During the analysis of the data, the researcher identified recurrent patterns in the cultural beliefs, and practices of the informants, surrounding food, for example, as well as their experiences with HIV disease, particularly, their responses of denial and anger when
receiving the diagnosis. Saturation is the presence of redundancy in the data collected from different informants. Through the continued analysis of the data, the researcher recognized that no new information was emerging from the patterns. Lastly, transferability is ability of the findings to have similar meanings to other cultures, situations or contexts (Leininger, 2006b). The researcher identified similar cultural beliefs and practices in ethnonursing research studies with Puerto Rican communities, such as the use of herbal remedies and concepts like familismo and personalismo (Higgins, 1995 & Martin-Plank, 2008); and fears of dying of HIV and not being able to care for family (MacNeil, 1994, 1996). As a result, these findings can be added to the growing knowledge of care/caring constructs of the CCT (McFarland & Wehbe-Alamah, 2015).

**Chapter Summary**

This chapter described the ethnonursing research methodology used for this ethnonursing study on culture care needs of Puerto Rican women receiving HIV care from NPs and other providers in NYC. The planned and actual methods utilized were presented and the developments requiring adaptations to the plan were presented. The role of the ethnonursing research mentor as a vital resource to the novice researcher for reducing bias and improving the quality of this research was explained. The setting of this ethnonursing research study, New York City, was presented in its relation to the cultural community of interest, Puerto Rican women living with HIV disease. The human subjects and ethical considerations for this study were discussed, specifically addressing issues of privacy and language. The plans for accessing the community through established contacts were introduced. The ethnonursing research enablers selected for use were outlined and their relevance to this study was presented. The participant inclusion and exclusion criteria were explained. Data collection, storage and analysis
plans were described. Lastly, the criteria for evaluating the quality of this ethnonursing qualitative research study were delineated.
Chapter IV

Results and Presentation of Findings

Chapter Introduction

This chapter presents the results and findings of this ethnonursing research study as discovered by the researcher. The findings emerged during data collection and analysis performed by the researcher. Sources of data included interviews of key and general informants and researcher observations of the behaviors, verbal and nonverbal cues of the informants in the environmental context of the interview process. The demographic information of the informants is provided. The findings elicited, utilizing a semi-structured inquiry guide are organized for discussion using the categories outlined by Leininger’s Sunrise Enabler to Discover Culture Care developed by Dr. Madeleine Leininger (Wehbe-Alamah & McFarland, 2018). In addition to the cultural and social dimensions depicted in the enabler, categories of culture care needs, specific to generic and professional HIV care are also presented. Lastly the emerging patterns and themes as revealed through the data analysis to the researcher are introduced.

Study Organization

To fulfill the purpose of this ethnonursing study to discover, describe and interpret the culture care values, beliefs, expressions, practices and needs of Puerto Rican women receiving HIV care from nurse practitioners (NPs) and other providers in the clinic setting, the researcher determined that face-to-face informant interviews would best procure the emic perspective of the women. The researcher intended to interpret the emerging culture care needs to guide the culture care decision and action modes that nurses, and providers of HIV care could use to preserve and/or maintain, accommodate and/or negotiate, and repattern and/or restructure culture care beliefs, practices, patterns, and experiences of Puerto Rican women living with HIV in New
York City (NYC). Since the researcher shared the same cultural background as the informants and could communicate in Spanish and freely code-switch, a level of understanding emerged which opened new areas of discovery, yet also created potential for bias. To address those concerns and bracket that bias, the researcher used field notes throughout the research process as described in Chapter Three.

**Study Participants/Informants**

To maintain the privacy of the informants, findings were de-identified and presented in aggregate. When necessary to further explain the findings, quotations were shared with coding notations assigned during the transcription process. Six key informants were identified for interview and an additional twelve general informants were interviewed over a five-month period from March 2014 through July 2014. Follow-up interviews with the six key informants and three general informants were conducted during the months of August 2014 through December 2014. Additional contact with the informants who were interviewed twice occurred from July through September 2015 to further clarify findings as needed. The three general informants brought back for a second interview were selected based on their enhanced knowledge of the domain of inquiry as discovered during the initial interviews. Tables 4.1 and 4.2 present selected demographic information of key and general informants. Table 4.3 presents specific information regarding the interview language and HIV status and HIV care of all informants.
Table 4.1

Select Demographic Characteristics of Key Informants

<table>
<thead>
<tr>
<th>Informant</th>
<th>Age</th>
<th>Place of Birth</th>
<th>Years in US/PR</th>
<th>Number of Children</th>
<th>Marital Status</th>
<th>Completed Educational Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>K1</td>
<td>46</td>
<td>NYC</td>
<td>46/0</td>
<td>6</td>
<td>Partnered</td>
<td>7th grade</td>
</tr>
<tr>
<td>K2</td>
<td>52</td>
<td>NYC</td>
<td>52/0</td>
<td>2</td>
<td>Married</td>
<td>General Education Diploma</td>
</tr>
<tr>
<td>K3</td>
<td>64</td>
<td>PR</td>
<td>30/34</td>
<td>none</td>
<td>Single</td>
<td>High School</td>
</tr>
<tr>
<td>K4</td>
<td>44</td>
<td>NYC</td>
<td>44/0</td>
<td>3</td>
<td>Divorced</td>
<td>High School</td>
</tr>
<tr>
<td>K5</td>
<td>45 (38)*</td>
<td>NYC</td>
<td>35/10 (28/10)*</td>
<td>2</td>
<td>Married</td>
<td>General Education Diploma</td>
</tr>
<tr>
<td>K6</td>
<td>56</td>
<td>PR</td>
<td>17/39</td>
<td>4</td>
<td>widowed</td>
<td>4th grade</td>
</tr>
</tbody>
</table>

*Informant reported the age, in parentheses, which conflicted with reported personal milestones (age of marriage, birth of oldest child and age of oldest child at time of interview)
Table 4.2
Select Demographic Characteristics of General Informants

<table>
<thead>
<tr>
<th>Informant</th>
<th>Age</th>
<th>Place of Birth</th>
<th>Years in US/PR</th>
<th>Number of Children</th>
<th>Marital Status</th>
<th>Completed Educational Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1</td>
<td>50</td>
<td>NYC</td>
<td>50/0</td>
<td>1 child</td>
<td>divorced</td>
<td>college credits</td>
</tr>
<tr>
<td>G2</td>
<td>63</td>
<td>PR</td>
<td>14/49</td>
<td>4 children</td>
<td>single</td>
<td>11th grade</td>
</tr>
<tr>
<td>G3</td>
<td>60</td>
<td>NYC</td>
<td>60/0</td>
<td>2 children</td>
<td>single</td>
<td>Bachelor of Arts</td>
</tr>
<tr>
<td>G4</td>
<td>53</td>
<td>PR</td>
<td>49/4</td>
<td>4 children</td>
<td>widowed</td>
<td>college credit</td>
</tr>
<tr>
<td>G5</td>
<td>61</td>
<td>PR</td>
<td>8 (most recent)**</td>
<td>2 children</td>
<td>single</td>
<td>Associates in Science</td>
</tr>
<tr>
<td>G6</td>
<td>66</td>
<td>PR</td>
<td>13/53</td>
<td>3 children</td>
<td>divorced</td>
<td>9th grade</td>
</tr>
<tr>
<td>G7</td>
<td>60</td>
<td>PR</td>
<td>15+/40+</td>
<td>4 children</td>
<td>widowed</td>
<td>college-based training programs</td>
</tr>
<tr>
<td>G8</td>
<td>62</td>
<td>PR</td>
<td>37/25</td>
<td>3 children</td>
<td>widowed</td>
<td>8th grade</td>
</tr>
<tr>
<td>G9</td>
<td>67</td>
<td>PR</td>
<td>30/37</td>
<td>3 children</td>
<td>widowed</td>
<td>4th grade</td>
</tr>
<tr>
<td>G10</td>
<td>51</td>
<td>NYC</td>
<td>51/0</td>
<td>1 children</td>
<td>partnered</td>
<td>General Equivalency Diploma</td>
</tr>
<tr>
<td>G11</td>
<td>59</td>
<td>NYC</td>
<td>59/0</td>
<td>1 children</td>
<td>single</td>
<td>college credit</td>
</tr>
<tr>
<td>G12</td>
<td>53</td>
<td>NYC</td>
<td>53/0</td>
<td>2 children</td>
<td>divorced</td>
<td>General Equivalency Diploma</td>
</tr>
</tbody>
</table>

**Informant reported multiple extended periods of living in the US and Puerto Rico and did not provide a defined timeline when prompted
Table 4.3

Select Study and HIV Care Indicators for all Informants

<table>
<thead>
<tr>
<th>Informant</th>
<th>Language of Interview</th>
<th>Recruitment Source</th>
<th>Years since HIV diagnosis</th>
<th>Years in HIV Care</th>
<th>Viral Suppression Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>K1</td>
<td>English</td>
<td>ACT-2</td>
<td>14</td>
<td>5</td>
<td>Undetectable</td>
</tr>
<tr>
<td>K2</td>
<td>English</td>
<td>ACT-2</td>
<td>23</td>
<td>23</td>
<td>Undetectable</td>
</tr>
<tr>
<td>K3</td>
<td>Spanish</td>
<td>Snowball</td>
<td>26</td>
<td>25</td>
<td>Undetectable</td>
</tr>
<tr>
<td>K4</td>
<td>English</td>
<td>Snowball</td>
<td>15</td>
<td>15</td>
<td>Detectable</td>
</tr>
<tr>
<td>K5</td>
<td>English</td>
<td>ACT-2</td>
<td>15</td>
<td>15</td>
<td>Undetectable</td>
</tr>
<tr>
<td>K6</td>
<td>Spanish</td>
<td>Snowball</td>
<td>23</td>
<td>23</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G1</td>
<td>English</td>
<td>ACT-2</td>
<td>22</td>
<td>22</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G2</td>
<td>Spanish</td>
<td>ACT-2</td>
<td>18</td>
<td>18</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G3</td>
<td>English</td>
<td>ACT-2</td>
<td>24</td>
<td>10</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G4</td>
<td>English</td>
<td>ACT-2</td>
<td>10</td>
<td>10</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G5</td>
<td>English</td>
<td>Snowball</td>
<td>18</td>
<td>10</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G6</td>
<td>Spanish</td>
<td>Snowball</td>
<td>19</td>
<td>19</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G7</td>
<td>Spanish</td>
<td>Snowball</td>
<td>15</td>
<td>15</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G8</td>
<td>Spanish</td>
<td>Snowball</td>
<td>25</td>
<td>25</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G9</td>
<td>Spanish</td>
<td>Snowball</td>
<td>22</td>
<td>22</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G10</td>
<td>English</td>
<td>Snowball</td>
<td>28</td>
<td>***</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G11</td>
<td>English</td>
<td>ACT-2</td>
<td>22</td>
<td>22</td>
<td>Undetectable</td>
</tr>
<tr>
<td>G12</td>
<td>English</td>
<td>ACT-2</td>
<td>25</td>
<td>25</td>
<td>Undetectable</td>
</tr>
</tbody>
</table>

***Informant was in and out of care and could not state specifically how long she was most recently in care at the time of the interview.
The women ranged in age from 44 to 67 years at the time of the interviews. The average age was 56 years. It must be noted that one informant provided conflicting information regarding her age and her estimated age is included in the range noted above, though both ages are reported in Table 4.1. The informants were racially diverse in appearance, but this demographic data was not specifically collected, and only two informants (one key and one general) spoke about it during the interviews. All but one of the women had children; ten had grandchildren; and two had great grandchildren. Five of the informants reported being single (i.e. never legally married, although they had partnered); two informants were married and two were partnered at the time of the interview with one recently engaged to be married; four informants self-identified as divorced; and, five informants self-identified as widows, as their husbands or life-partners had died, and they were not in a new relationship at the time of the interview. For the widowed informants, three of the spouses had AIDS, but only two died of its complications. In addition, three women lost their partners to AIDS.

Four of the informants who were born in NYC had lived their whole lives there; two informants lived for a time in Florida and three lived in both Puerto Rico and New York during their youth. They reported that their parents migrated to the US (NYC) to earn more money to support the family; to start a job promised to them; to get married; to manage their behaviors (sexual) in a new setting. For the nine women who were born in Puerto Rico, their reasons for coming to NYC included to be near family (3); to access better health care (5); and to be in a more socially acceptable environment (1). These women migrated to the US between the ages of 13 and 30 years and had lived in the US from 8 to 49 years. The informants lived in lower-income neighborhoods in New York City, either in public housing or in subsidized rental units.
They also received some form of government benefits, based on either their age; diagnosis with AIDS; and/or disability status.

All but two of the women were raised in the Roman Catholic faith; three became Protestants as adults and another seven combine Roman Catholic practices with Protestantism (1), Espiritismo (4), or Santería (2). The informants who incorporated Espiritismo or Santería with their Roman Catholicism were raised combining these religious and spiritual practices. Two women were raised as and remained Jehovah’s Witnesses, although their attendance at services was not consistent. Thirteen of the women were not working and instead received disability payments while five of them did report a regular full or part time job. At least two of those women reported working “off the books,” that is for cash and without reporting the income to the government. Only one informant never worked outside of the home and three women were involved in drug trafficking and each was jailed for a time due to that activity.

The informants had, on average, known about their HIV status for an average of 20 years (range 10-28 years). The risk factors for these women were sex with an infected partner (12); sex with an infected partner and injecting drug use (5); and injecting drug use alone (1). Thirteen of the women had been in HIV care since their diagnosis with HIV infection, including all living in Puerto Rico at the time of diagnosis. Three of the informants reported being in and out of HIV care over the years due to substance use issues and one started care one year after diagnosis and another ten years after diagnosis. Six of the women reported seeing an NP for all their HIV care at the time of the interviews. An additional four women had received HIV care from an NP in the past and six women reported seeing an NP in the same practice when their MD was unavailable for a visit. Two of the women had received care from an NP for gynecological services only.
All the informants had been prescribed antiretroviral medications (ARVs) and their reported regimens, except one, were within the acceptable guidelines as per the US Department of Health and Human Services (2014) in effect at the time. Most of the informants (16) reported their most recent CD4 count: greater than 500 for thirteen of the informants; between 200 and 500 for one of the women; and, less than 200 for two of the women. The two other informants could not recall their most recent CD4 count. All informants reported an undetectable viral load except for one, due to inconsistent adherence. Eleven of the women reported an AIDS diagnosis which occurred an average of 7.9 years (range 1-21 years) after receiving a positive HIV antibody test. Eight of the women became pregnant after they were diagnosed with HIV. One of became pregnant, a second time. All but two of the women received ARVs, to prevent mother-to-child transmission per the approved protocol at the time. All the children, nine in total, were born free of the virus.

**General comparison of key and general informants.** The key and general informants were more similar than anticipated during the conceptualization of this study. While the key informants were younger with a mean age of 51 versus 60 and a mode of 49 versus 61.5 years, there were numerous similarities. The informants in both categories knew of their HIV infection for many years (19.6 years for the key informants versus 20.65 for the general informants) and had been in treatment for a mean of 18 years for both groups. All informants reported being adherent to the guidelines for frequency of visits with their providers and all reported the importance of establishing and maintaining a strong working relationship with their providers. Very few of the informants described receiving care from one provider or practice exclusively, whether NP or MD. All but two of the informants received HIV care from an NP at some point. The key informants received exclusive HIV care from NPs from less than a year to
up to more than 20 years. All the informants reported satisfaction with the care they received from nurses and NPs. The informants receiving care from MDs during the study, also reported satisfaction with their care. None of the informants were dissatisfied with their current care provider or were considering changing providers. Consequently, there was little differentiation in the information shared by the informants between professional HIV care received from NPs or MDs.

**Presentation of Categories**

The description of the preparation of the transcripts for data analysis using ethnonursing research study methods was presented in Chapter 3. The identified categories described were organized following the order used in Leininger’s Sunrise Enabler to Discover Culture Care starting with the worldview of Puerto Ricans and the environmental contexts in Puerto Rico and NYC including language and ethnohistory as discussed by the informants. Specific to living with HIV, categories emerged regarding generic caring and non-caring experiences with HIV; professional caring and non-caring experiences with HIV; folk and emic expectations of care; professional expectations of care; care diversities in the Puerto Rican and US health care systems; and barriers to HIV care. During the interviews, the informants often described care exclusively through the lens of HIV. In these instances, the researcher made specific efforts to direct the informants to describe care during their youth and before they knew of their HIV status, which they did when redirected. Coding was used to separate between HIV specific care and other care. Many of the findings overlapped multiple patterns and themes and it was impossible to isolate them. In many ways, this reflected the interconnectedness of all facets of their lives which the presentation of the findings echoed.
Presentation of Findings

**Worldview.** The worldview of Puerto Ricans was presented as an evolving phenomenon in Chapter Two. The informants expressed a worldview that reflected the acculturation of Taíno traditions with Spanish, African and American culture. The Taíno culture’s matrilineal strength enforced the masculine emphasis of the Spanish society. The African influence expanded the spiritual and herbalist practices at the core of family activities, America’s imposition of colonial status on Puerto Rico introduced expanding economic roles for women outside of the home, while shrinking them for men and creating migration patterns and subsequent family patterns that the informants reported. Each of the informants expressed a sense of pride in the unique cultural, historical and economical forces that created the Puerto Rican people. This pride in identity was evident no matter how they identified, that is being more Puerto Rican or American. One informant stated that she was “más Boricua que el coqui” (K3). In this phrase, this informant invoked both the traditional Taíno name of the Puerto Rican people and the indigenous tree frog which is believed to be unable to survive outside of Puerto Rico. Another informant also spoke with great pride of being a Puerto Rican woman, explaining “We carry ourselves well, with confidence, you know” (K1).

All informants discussed the strength of the maternal influences, positive and/or negative, in their lives, which was most often expressed through the maternal caregiving role. The informants spoke of the ways that their mothers cared for them by feeding them or by moderating their behavior. Even when disagreeing with their mothers, a connection remained between them. Once they became mothers they influenced their own children. This caregiving role in their children’s and grandchildren’s lives was a powerful motivator for these women, “family is very sacred,” as reported by K2 and four other key and all general informants.
The strength of the family was another important aspect of the worldview of Puerto Ricans as shared by these informants. Each of them discussed the importance of their families and the ways that they stayed connected: family reunions over the holidays or during the summer months; regular phone calls and travelling to visit family regularly or on special occasions when finances permitted. Living with family was another demonstration of family interconnectedness. Three of the general informants lived with their adult children and their families.

My children live with me too. My daughter just recently came back home…We have enough space. As Latinos, we make space, if one of us has to stand up in the closet (G12).

Many of the informants expressed pride in the way their families were supportive of each other during difficult times and disappointment. When there was a serious breakdown in relationships the informants were greatly distressed.

That’s one thing about my family, it’s fxxxxd up but if I’m in trouble, they all come no matter how mad we are at each other. That’s what I think all Puerto Rican families are like (G10).

Spirituality was another component of the worldview of the informants. Even though the informants shared various expressions of faith, with a strong foundation in Christianity each informant spoke of the power of their faith and prayer in their lives before and after their diagnoses with HIV. The informants reported giving thanks to God each morning for another day of life. Even the one informant who distanced herself from organized religion, discussed her daily prayers of thanks.

I had had enough that year and I started to move away little by little to the point that I don’t even know where the door to church is. But I spent a lot time involved with all that… I believe in God…I don’t think that I need to be there (G9).

The last element of the worldview, expressed by these informants was the influence of their HIV status. The presence of HIV infection permeated every aspect of their lives and
resulted in a shift in their worldview. For some of the informants, two key and seven general, HIV was an immediate wake-up call to focus their lives on healthy behaviors and relationships. “I’m not dying, this thing is not taking me out. I have HIV, but HIV doesn’t have me, and I am not leaving my son” (G11). For the other informants (four key and five general), having HIV infection was initially another complication in their difficult lives they could not handle, and they tried to put it aside.

When I first found out I was in denial for a long time after that. So, for the first three years I didn’t bother going to the doctors or nothing (K1).

Before transforming into a focal point in their recovery, as described by a key informant, “I had decided that I wanted to be well” (K6), HIV shadowed every aspect of their lives, work opportunities, family interactions, residential choices, romantic relationships and the way they cared for themselves and others.

**Environmental context**

**New York City.** New York City is traditionally known as the epicenter of many phenomena. For the Puerto Rican community, it was the first stop in their (im)migration story as with many other groups seeking a better life than that offered by their country of origin. The informants or their families had migrated to the US within the past 60 years, making them either first generation (two key and seven general informants), or second generation (four key and five general informants). Two thirds of the informants, four key and eight general, maintained family and/or economic ties to Puerto Rico, making them users of the air bridge, with some doing so more frequently. Some informants’ families relocated to other parts of the US (two key and three general) or returned to Puerto Rico (two key and seven general informants), mirroring migration patterns of Puerto Ricans.
As one of the epicenters of the HIV epidemic NYC established itself at the forefront of HIV care and research; and, treatment funding. In response many individuals relocated there to avail themselves of those benefits. Four of the informants, (one key and three general), turned down offers to move to Puerto Rico to be closer to family because of the medical care they were receiving in NYC.

They’re always like ‘Come over here’ But I don’t like Puerto Rico too much to live. I like to visit. And I love them they’re great but it’s not the same living in New York. It’s not the same. They don’t give you what they give you here. (G1)

All four of the informants, one key and three general, who lived in Puerto Rico at the time of their diagnosis, relocated to NYC from Puerto Rico at the request of their families so they could receive better HIV care.

When I came to the US, it was because my son sent me. Because when I was there I was lost in Puerto Rico and he told me, ‘Mami, I want you to get yourself together’ and here they give me so much assistance and thanks to God, now I am no longer using drugs. I was in a rehabilitation program. (K6)

**Neighborhoods and housing.** The informants lived in NYC at the time of the study and received their HIV care there as well, as per the inclusion criteria. One key and three general informants continued to reside in the same neighborhoods, where they were raised. In their youth, these neighborhoods were predominantly Puerto Rican and had lower-income residents. These neighborhoods were also more likely to have public housing complexes, known as NYC Housing Authority (NYCHA) buildings. Most NYC neighborhoods became gentrified as higher income residents took up residence. Two key and four general informants shared that they liked the new diversity in their neighborhoods yet feared violence as these new residents were not careful with their personal belongings and there was still poverty in some pockets of these communities. “It’s like a danger zone to other people…People are gonna get mugged or people are gonna get murdered for their stuff” (K2). Other informants (four key and five
general) lived in neighborhoods where gentrification had yet to reach and they reported fearing for their own safety and would keep to themselves or walk quickly from their homes to public transportation.

I don’t like the neighborhood. It was… lonely. It was a place that was very dangerous. You didn’t see people. And so, from there I wanted to move (G2).

Two key and all general informants related their own sense of personal safety because they were well known in their communities and respected by their neighbors. However, they also shared that a sense of personal surveillance was a survival skill that developed long ago and which they used every day.

Everybody knows us for a long time, so nobody bothers us. Everybody knows my kids and they know me for a long time. It’s a little rough, in certain areas. But like I said I pass through there and they don’t bother us. I could come in any time of the night and they watch over me (G4).

One key informant reported feeling unsafe in her own building and apartment due to personal conflicts with a neighbor.

I asked for a transfer and it’s taking too long, they told me because I want to move to W. I’m accepted over there but it’s taking kind of long and the situation with her ‘cause she even threatened me, throwing her little words in the air. Telling my husband, she can’t stand me and that she wished she could kill me (K5).

Three key and five general informants lived in subsidized housing units, private rental units for which a portion of the rent is paid by the city for low income families and disabled individuals, scattered throughout the city. Some of these units were in high-rise luxury buildings, in accordance with agreements with the municipal government in exchange for tax incentives. These informants reported enjoying the benefits of a doorman to screen visitors, “I tell the doormen, when they (family) show up, tell them I’m not here,” (G5), or to check-in on them when they do not see them for a few days.
Ethnohistory.

Air bridge. As noted previously, quite a few of the informants maintained close ties with family members in Puerto Rico and elsewhere in the US. Some of the informants were sent to or remained in Puerto Rico as children while their parents worked in NYC.

Well I was born in Puerto Rico and my mother and my father came here to get life, they left me there with my grandfather and my aunt, you know, and I stayed there. My grandfather didn’t want me to come back with my father and mother and we stayed there (G2).

Some reported frequent trips between NYC and Puerto Rico to visit with grandparents and other relatives. “I’m going for Christmas…I go every year…I stay a month and I visit everyone” (G8).

Even with no travel restrictions between Puerto Rico and the US, as American citizens, the cost of travel for large families was prohibitive. Many of the informants spoke of saving their money for trips to Puerto Rico “I go every year, …but we don’t know how the pocket’s going to be… I told my husband, if you can’t go, ‘I’m sorry’ …He’s alright with it” (K2); or, how they missed their family because they could not afford to travel to visit the other.

They come when they can because of work. Every two years. Yet when they don’t have money, or if we get together or better to say that we don’t get together because of the money, because the tickets are so expensive and because it’s so expensive, then everything else is, too. That when someone says they are going to buy something, it is because they have the money and you have to have the money, and so it is (K6).

Often a visit to Puerto Rico or NYC occurred due to a death in the family and the need to attend the funeral services. A key informant was returning to Puerto Rico at the time of the interview as she did every year since coming to NYC. While her mother was alive she spent up to three months each year with her but now that she was deceased, this informant would go for the anniversary to visit her grave: “For the last 3 years after I lost my mother, I go only to do the Rosary in April. I go in April because she died in April” (K3). She would pray the Rosary with her relatives for the repose of her mother’s soul.
One key and one general informant who were born in NYC relocated to Puerto Rico during their youth and returned as adults, one before and the other after her HIV diagnosis. Two other general informants were born in Puerto Rico but lived for a time in NYC and Puerto Rico during their youth. For these informants, there were serious disruptions in their education, and a sense of not quite fitting in with their peers while growing up. One informant still reported not being where she most wanted to be, Puerto Rico. “I stayed in Puerto Rico for 20 years I had a beautiful life” (G5).

Some informants’ adult children relocated to other areas of the US mainland for work and education and then, established roots in these new communities. Some of these locations were already long associated with Puerto Rican communities, while others reflected the emerging population trends of Puerto Ricans relocating from NYC or directly from Puerto Rico to central Florida, the southeast and the southwest US. Those informants who could afford to travel, visited with their children or their children visited them, “I go every year. In August. They already know, don’t book nothing” (G4); unless there was a dislike of NYC, “Mom if you move to Florida we could see each other more. But while you’re living in New York, I’m not coming” (G2).

The effects of this distance were discussed by all informants. For some it was a painful separation, “Here I am alone, but when they say they are coming I am happy, very happy, and very content because they are here” (K6). Yet for others it created a healthy environment, in which they could live according to their needs.

When I came to New York, it was to look for a better life and mostly because I am homosexual, too. In those years, you know, you could imagine the environment at the time, because I was stigmatized but mostly because I was homosexual. I wanted to become independent (K3).
Some of the informants accepted the distance between them and family in pursuit of employment. “They were grown and made their own lives…and my sister told me ‘Come to New York’ and I came here, and I got started at a job here” (G2). While others desired greater distance between them and their family members, when the relationship was strained (G5, G10). Each informant adjusted accordingly, voicing acceptance of their situations and noting that there were more pros than cons in the choices they made in their places of residence.

**Language.** All but one of the informants could speak in English to communicate their needs and each of the informants spoke Spanish as well, since they were raised doing so. The levels of fluency in Spanish and in English varied for each informant depending upon what the primary language was; where they were raised; their educational level; and, where they were educated. The key informant who could not speak English shared that she attended multiple English classes but that she was still unable to learn English. Another key informant described her English skill by saying, “Me defiendo (I defend myself)” (K3). As described previously code-switching was used in all interviews, as is common with bilingual Latinos in the US. This happened more often during the predominantly English interviews (four key and seven general informants).

As noted previously the informants chose which language they wished for the interview and one of the general informants (G2) opted to switch from English to Spanish about one third of the way into the interview. Another informant stated that she was fluent in English but that she wanted to do the interview in Spanish, “when I have no other option, well, I speak English,” (G9). Even though each informant selected one language for the interview, the other language, eventually, found its way into the dialogue. This occurred for various reasons: an informant demonstrating that her pronunciation was as “bad” as her children told her (G7); the word of
choice for an HIV-related term was only known in English by the informant; the word of choice for a cultural, religious or food-related term would lose its meaning in English. There were instances throughout the interviews when a desired word in the language of the interview was not readily available to the informant or the researcher, but this did not impede understanding or interrupt the interview.

**Biological factors.** The informants had other health conditions besides HIV disease. While these conditions were also present in their families and not uncommon in the Puerto Rican community, like Type 2 Diabetes Mellitus (T2DM), hypertension, and heart disease; these conditions were comorbid with HIV disease. Three of the key informants and nine of the general informants were managing metabolic conditions: T2DM or hypercholesterolemia. The management of these conditions was carefully included in the self-care activities of those informants. However, for one key informant, the management of her diabetes took precedence over HIV because she nearly died from it.

Because before December forget it when I became diabetic my focus and my fear went on the diabetes. I got scared. I focused more on my diabetes I was making sure I took my sugar level. I was making sure I was taking the pills. I was taking insulin 45 units twice a day with the insulin two years ago. Today I’m down to 20 units once a day. I worked hard for the last two years, so my focus was on the diabetes… My thing was just to go to the doctor and monitor my sugar. I put all the focus on the diabetes that I wasn’t even thinking about the virus. It was like the virus didn’t take me nowhere. I wasn’t going to let the diabetes (K4).

**Technological factors.** All informants used technology in their everyday lives. Most communications between the informants and researcher occurred exclusively by cell phone. Two informants (one key and one general and both born in Puerto Rico) shared only their landline information and preferred communicating with the researcher using that number, but they did have and used cellphones. Most of the informants used smartphones for phone calls, to access the internet, play video games and take and store photographs. The informants showed
the researcher these photographs of their children and grandchildren; documenting an evening out or memorializing an important milestone.

The informants discussed the use of technology during visits to their health care providers. They reported the benefits of the technology to improve access to their latest test results and the enhanced communications among providers when consulting with specialists. In addition, the informants did report that from time to time, their providers spent more time looking at the computer screen than making eye contact with them during visits. “When he be looking at that computer all the time he don’t look at your face. He knows that that’s a no-no” (G4). She would reorient him to her presence by saying, “I’m here to see you” (G4). A general informant related her concern about the confidentiality of the electronic medical records and questioned who could access her personal information. While key informant reported a fear of retaliation by someone at the hospital accessing her medical information and using it in an inappropriate manner

There’s a lot of people that work there I thought you know probably they would take somebody’s password and look into my records or something (K2).

A difficulty with the electronic medical record was discussed by one general informant regarding an incident in which false medical information was not corrected, resulting in her being treated as if she were non-adherent to a medication regimen.

**Religious, spiritual and philosophical factors.** While all informants spoke of a spiritual practice, a smaller group discussed specific religious practices. The informants who identified as Roman Catholic reported regular or at least frequent attendance at weekly mass; keeping statues of saints in their homes; saying ritual prayers such as the Rosary; and attending retreats lead by religious leaders. Two of five informants (three key and two general) who identified as Protestant reported a more fluid identification with a specific denomination and
would refer to themselves as “born-again,” but did not name a specific church that they attended. They discussed attending prayer and Bible-study groups at their churches and other locations as well. If an informant did not feel well enough to attend mass or a service, they reported being able to watch one on local cable network channels.

Each of the informants invoked the names of God and other saints in casual conversation as is customary in the Latino tradition, in either English or Spanish. “Ay, Dios mío” (Oh my God); “Gracias a Dios” (Thanks be to God); “Ave María” (Hail Mary or Oh Mary) were peppered throughout the interviews. Terms of endearment referring to Jesus Christ: “Niño Jesús” (baby Jesus); God: “Papa Dios” (Daddy God); and more formal references: “Señor” (Lord) were used as is customary as well. Some of the informants (one key and six general) described a renewal of their religious practices by either returning to regular church attendance as in their youth or discovering a new expression of faith. This renewal was connected to their recovery from substance use and/or a major illness. One informant shared her efforts to learn to pray the Rosary, “The pastor of my church has told me that I need to learn the Rosary. I never learned it. I have given myself this goal and I will learn it” (G6). On the other hand, a few of the informants also discussed mixing tenets of various faiths, as one informant described,

I believe in a higher power. I’m Catholic but I respect other places. I cover up in the mosque, I take off my collares (necklaces) in church in Puerto Rico. I feel that God comes in many forms I believe that everybody worships God. The Hindu with the elefante (elephant). The santeros with the collares (G3).

Quite a few of the Roman Catholic informants revealed that they incorporated Espiritismo and Santería, described in Chapter Two, into their faith practices. Some reported practices included communication with spirits, including saints and the dead, and extensive rituals meant to seek the favor and intercession of those spirits for assistance in day to day matters. A general informant revealed being able to communicate with spirits herself and stated
they often warned her of troublesome situations which she was then able to avoid. ‘But thank God, I am spiritual, I see things… I listen when my things talk to me’ (G5). Informants shared that they kept statues of these saints in their homes, leaving flowers, lit candles, food and drink for them in offering. One informant described the altars she maintained to invoke the protection of the saints, “I had everything from Eleggua (St. Anthony), and I had Santa Barbara bendita (blessed), and I had Ecche Oggun (St. Peter)” (K6). Three of the informants (one key and two general) reported spending large amounts of money on these activities; becoming dissatisfied with these expenses; and, no longer actively participating in Santería or Espiritismo.

I am a santera. I had a Cuban godfather. I had my godfather from Santería who was Cuban… I said, ‘I’m going to retire.’ And the money you spend on this. If it’s not $200, then it’s $300, it’s $1,000 and to become a santo it’s $30,000 and where am I going to get that. I preferred to leave. (K6)

All the informants provided details about their spiritual and prayer practices used for caring and healing for themselves and others. They believed in the power of prayer in their everyday lives. Each of the informants reported a prayer practice that began with thanking “God” each morning for another day of life.

I always get up every morning and before I open my eyes and get off that floor I say, ‘Thank you God for giving me another day to live’ (G5).

Sometimes it was a simple prayer uttered before getting out of bed and other times it was a more involved ritual including herbal baths, and prayers said during daily bathing. Prayers continued throughout the day as needed: before leaving their homes, for protection outside of their safe environments; and, general prayers of thanks throughout their day. Prayers were most consistently used when an informant was not feeling well or waiting on test results. There were also prayers of thanksgiving at the end of the day. Expressions of gratitude were grounded in their belief that their faith was an important part of their survival as shared by a general informant, “I don’t think that left to my own devices I would have been here” (G12). The
language used in prayers (Spanish versus English) provided an added sense of protection, as the
more serious discussions of protective prayers occurred in Spanish.

All the informants reported some exposure to a *curandero, espiritista* or a *santero*, as
described in Chapter Two, at some point in their lives for the purposes of managing a health or
spiritually related personal situation. One key informant, who reported being born-again,
provided a detailed report of an incident when a gynecological problem was diagnosed and
treated by a *santera*, she had encountered at a party. The problem was attributed to a spell cast
by her first husband who was jealous of her new relationship at that time.

So, I did what she told me and the next day I was like ‘oh my God’ I was amazed. I went
to the doctor and they was like whatever it was it cleared out. You don’t got no
inflammatory, no none of that (K1).

Even though, she stated she did not believe it, she followed the instructions given to her and her
pain resolved.

**Kinship and social factors.** Each informant spoke very strongly about the role
of families in their lives. Whether they were sharing a story from their youth that was a happy
memory or recounting an example of dysfunction, each informant made it very clear that their
interactions with family were formative in their youth and a current source of strength. When
informants were discussing difficult times from long ago or recently, the researcher could sense
the pain and sadness or the joy these events brought them. One informant proudly spoke of how
her family could be fighting among themselves, but when one of them needed help, the others
would be there in support.

My family we’re very united, and we don’t need to talk every day, but um we talk like
every other week… For me, family is very important. Because you can have friends, but
family is always going to be there no matter what. Even though growing up my brother
and my sisters, we fight and bicker, but like after we grew up, like after 18, 20, now we
got closer and now more closer (K2).
When the informants learned of their HIV status or were ready to engage in self-care, each one shared the motivation their families gave them to survive.

*Parents.* More than half of the informants (five key and six general) were raised by both parents. The rest of the informants were raised by their mothers. For these informants, their fathers were never a reliable physical presence in their lives or they abandoned their families. Some fathers were serial monogamists or had multiple relationships with other women during the marriage with their mothers. Whatever the marital relationship, the informants were strongly influenced by it; how it ended; how the parental relationships were managed, and any subsequent marital relationships. One key informant, K5, described her parents as a strong unit who were focused on their children’s wellbeing.

So, by me seeing how *mami* and *papi* was with people of any culture that’s the way I want to be. They was my role models to the fullest… So, I’m proud of my dad, I really am and I’m proud of my mother because I understand why they were so strict with me because they wanted their little girl to do right.

Together, her parents made all the decisions in the home and, even though, only one would speak to the children, it was very clear to this informant that the message came from both.

The single mothers who raised the informants (one key and eight general) worked outside of the home to provide for their children, while an aunt or grandmother lived with them to assist with the care of the children and the home. These mothers remained important forces in the lives of their daughters as they became adults. They often provided care within the Puerto Rican female cultural norms. One of those norms is to be supportive of the child’s needs. This was demonstrated when mothers of informants assisted with child care, for example, by caring for or raising children in the informant’s absence during work hours, incarceration or rehabilitation.

They were ready to discharge him from the hospital, but I was there, and they were getting ready to take him and I lost it there in the hospital. Something I wanted but because of the substance abuse disease I couldn’t have him. I wanted to take him home.
But my mother said ‘mi’ja (term of endearment) I don’t think I did a bad job with you, let me take him home. (G3)

One informant shared that when her husband died, her mother offered to have her, and her four children move in with her.

She wanted me to move in with her when my husband died, and I said ‘Nooow’ That’s a big no-no. She said, ‘Leave all of this, come, come live with me and the kids.’ Uh-uh (G4).

Another informant, who identified as lesbian, reported that her mother encouraged her to leave Puerto Rico and move to NYC, so that she could live in an environment more accepting of her sexuality. According to the informant, her mother never spoke of her daughter’s sexuality, but she knew what she needed, “It’s like with my mother… My way of being” (K3).

While most informants were ready to verbalize their appreciation of their mothers’ actions on their behalf, they did not hesitate to discuss their flaws. These instances usually involved a conflict. Two key informants shared that their mothers ignored their needs in their childhood by not teaching about menstruation. Speaking with her father one informant said, “Why isn’t Mami telling me these things? Doesn’t Mami get this?” (K1). Another informant reported that her mother discouraged her from pursuing a college education by referring to college-educated women as putas (sluts), but she decided to go to school anyway, and in the end her mother was proud of her accomplishment.

I was going to this community and go to an ivy league school, so I had to get her to sign the papers by her and she gave me a hard time. But when I graduated she was so proud she had her chest all open. And I was like wow, that lady put me through hell (G3).

One mother continued to be unsupportive of an informant by shaming her desire to maintain her wellness and remain in recovery by staying away from an abusive sibling (G5). Even though these informants reported tension in their current relationships with their mothers, they still maintained contact.
Mothers served as important first teachers of caring for others and for self. This teaching came either through positive or negative examples, playing pivotal roles in the lives of the women. When the example was positive for two key and ten general informants, these women maintained stable lives and relationships with others and raised their children to independently and successfully care for themselves. On the other hand, two key and one general informant who reported strained relationships with their mothers during their youth, discussed issues with raising their own children. They reported that these children were now struggling to establish themselves independently and provide stable home environments for their own children. These situations were sources of great stress for these informants and while they wanted to be supportive of their children, they recognized the need to distance themselves to maintain their own wellness. “I tried calling her several times, but after the 3rd time I told my husband, ‘I’m not going to keep on stressing over it because I’m the one that hurts’” (K1).

Fathers were also influential in the development of the informants. This was most evident when fathers were very involved in care, as discussed by three key and one general informant. Three of these fathers demonstrated caring behaviors towards their daughters more prominently than the mothers, “My father was my father, he was the man of my life and I miss him” (K2). These fathers filled the void that some informants experienced from their mothers during childhood as discussed in the previous section. “My dad taught me about menstrual. Which my mom should’ve done that” (K1). These men continued to act as protectors of their daughters either by asking a family member to “protect” them in their absence (G5) or by being willing to physically defend the honor of the daughter.

My father went ballistic. So, they call security and everybody and I explain to him and my father wanted to look for my ex-husband and I was like ‘Daddy just be here for me. Forget about him just be here for your daughter’ and my father broke down (K1).
These fathers also supported the informants in their wellness behaviors. One father sent his daughter information on herbal teas to help boost her immune system and checked in with her frequently to make sure that she was drinking them and was taking care of herself.

He’s always like ‘You took your medicine today. You know, ‘Are you still drinking my teas?’ Because he makes these teas for me. I’m like ‘Daddy, Yes, I’m still making the teas.’ Just to make him happy, you know (K1).

One informant, whose father was an important support for her, lamented that since his death, those family members who used to ask about her wellness, no longer do. “Since my father died nobody calls and the only way that I see people is at parties, you know” (G5). She expressed anger that her needs were no longer of concern to them, because her father could no longer advocate for her. Even without their fathers, three key and three general informants reported having relationships with their fathers’ relatives. Aunts, uncles, cousins and grandparents were remembered at family events during their youth and half siblings were welcomed into the family and included in family reunions

Parents shared religious and cultural practices with their children. Most of the informants (five key and eight general) practiced their religion as they were raised, and others moved away from the religion of their youth and sought other faith practices. All informants also spoke of the cultural traditions from their youth that they shared while raising their own children. Parents’ caring, and non-caring actions exerted an influence on their daughters’ relationships with them and other relatives, including step-parents, aunts, uncles and grandparents, and eventually their relationships with intimate partners and their own children.

**Siblings.** Many of the informants had siblings. For nearly half of the informants their family was mostly nuclear in which their parents had only one marriage and all the children were raised together. Other informants knew that their fathers had other children who were
raised separately, and they established contact and developed relationships with them in adulthood.

And my father went out and had other kids. He had a family and there’s like 6 of them. It’s about 10 because one of them I don’t know. I try to keep in contact with them because I’m the oldest (G3).

One informant’s parents were married and then partnered with other individuals and all the children were raised in an extended family network, “My brothers from my dad’s side they used to come… every other weekend” (K1). This informant reported that her siblings came into and out of their household throughout their lives, but they were all well-loved.

The two informants discussed above became a focal point in the relationships among the siblings. They accepted this responsibility and were often the ones to check-in with their siblings and organize get-togethers. Another informant reported having a strong relationship with all her sisters except for one with many personal issues. The sisters remained in frequent contact with each other.

Some informants had adversarial relationships with their siblings beyond the sibling rivalry of childhood. In these households, the children were compared to each other and parents took sides and played favorites as shared by the informants, “Because they spoiled me that all my brothers and sisters were jealous that they would give me anything” (K5). The tension continued into adulthood and these siblings did not serve as support systems for the informants. “Why do you do this to me? I’m your baby sister” (K5). In some informant’s families, siblings also engaged in high risk behaviors, such as injecting drug use, and/or unprotected sexual intercourse that resulted in HIV infection. Five informants had lost siblings to drug use (K1) and/or HIV disease (K1, G5, G10, G11). One informant was the only surviving child after her three siblings died from HIV disease.
No, they all died. Two brothers and my sister died. My two brothers died in the late 80s when HIV was first discovered, they didn’t know what they had but then they were diagnosed, and my sister also had HIV, she died about 8 years ago (G11).

Some of the informants’ siblings were important sources of help and support for them. One informant spoke of her younger sister’s efforts to help raise both her and her brother’s children when they needed help (G3). Two key and five general informants discussed the support they received from siblings to stay well, by assisting in their recovery and checking in with their wellness. One of these informants reported that her sister was sometimes too eager to ask her about “her numbers” (CD4 counts and viral loads), as an indicator of her wellness “I say ‘listen, you’re gonna talk about medicine, we’re not talking.’ But I keep her updated because when we talk she starts asking for my number” (K2). For this informant, it became important for her to set a limit on these questions because she felt that these phone calls should be about more than a report of her numbers.

Spouses/partners. The informants described their past and current romantic relationships. Four key and seven general informants had at least one legal marriage, officiated in a church or municipal government office. In other relationships, informants referred to the men they had romantic relationships with, either as partners or as husbands. They were more likely to use, the word husband, if the relationship lasted a long time or they had children, together. One key informant was lesbian, but she did not share much information about her relationships, either before or after her diagnosis.

The informants’ romantic relationships at times ended amicably or tumultuously. Four key and five general informants related that they were betrayed by the men that they loved. As per their reports these men had multiple other partners of whom they were not aware until after the split-up or death of the partner.
Like I went through so much with this man 17, 18 years. A baby he brought into the marriage, the disease, you know the virus, like the drug addiction, he taught me how to use drugs. He had women in my house that I thought was family and they were his lovers. I went through so much with this man (K1).

Other partners hid their HIV status from injecting drug use from two of the informants.

I found out he was sick, and I said, ‘Oh my God, why didn’t you tell me? And he said, ‘Fxxk them, let them all die.’’ He was on a mission, so I said, ‘Oh really, okay.’… And I went, and I got tested and when they told me I was positive, oh my God, my whole world died, I said ‘No’ I turned cold, my heart, you know (G11).

Another informant’s husband injected drugs with his brothers and transmitted the virus to her (G4). While these women expressed anger, hurt and shame at the betrayals, they were further angered at the fact that these behaviors of their partners exposed them to HIV, leading to their seroconversion. Each of these women reported being monogamous with their husbands/partners and therefore did not use safer sex practices, such as condoms. They felt that the choice of protecting themselves had been taken away by the lack of truthfulness of their partners.

Three informants (one key and two general) reported that their partners were the gateway for them into a drug lifestyle by first using and then selling drugs. All three of these women served jail time for drug trafficking. Another key informant who injected drugs while living in Puerto Rico started using with her husband when their children were grown.

I started when I was older. I started at 38 years and I had already had my children…And I had gotten involved with heroin because I liked the high from injecting and when I was having problems with it, I started snorting it and, in the end, as we say, ‘I broke through.’… My husband was into it too and we did it together (K6).

All the informants went on to have other relationships, while knowing of their HIV status. All reported a desire to regularly use safer sex practices, such as condoms, and dental dams; and adhere to their medication regimens to reduce their viral loads and risk of viral transmission. A few of the informants (two key and five general) reported ending relationships
specifically because a partner did not want to use condoms or was engaging in other risky behaviors that would jeopardize their wellbeing. One informant explained the situation stating:

I’ve been clean 27 years and even some of the people I associate with because some of them relapse and it sounds cold, but I can’t entertain and help you and then I get sucked into the same thing. Some people, I have to walk away from (G3).

One of the key informants was considering ending her marriage because her husband’s extramarital activities were causing her distress and accompanying physical ailments.

I’m not the type of woman that I don’t care how a husband or man is I would not give him that confidence of that look. I respect myself and I don’t like things done to me that way that they did. That’s not good for my health (K5).

She was afraid that she would be unable to remain adherent to her medications and become ill. She did have difficulty recalling her medications and recent CD4 counts during the interview.

After a few failed relationships, some of the informants decided to forgo any future intimate partnerships, whether sexual or for companionship. They opted “to do me,” to quote a general informant. “I don’t want to be (in a relationship). I don’t need it. I’m doing me by myself,” (G4). “To do me,” described the decision to make themselves, their families and their continued health the focus of their energies versus romantic relationships. The one key informant who did not share much information about her romantic relationships, instead did provide details about all the things she did to care for herself.

There were also some informants (two key and two general) who found “love” since becoming HIV positive. These relationships came when these informants were not looking for partners. In each of these instances, the informants were reluctant to become involved with someone because they were nervous about disclosing their status or being distracted from caring for themselves; and, scared about being hurt again.

To be in a relationship with someone takes time. You have to accept the person, you have to have confidence and all that before you go to bed. I can’t go to bed with
someone that I don’t know, and I have to know him well, and I have to tell this person, ‘Look, I have this and if you want to continue with me, good or if not, then we’ll leave it here.’ One doesn’t know how someone is going to react and how that person is going to guard one’s secret. You also need to think about that (G7).

Each of these women spoke in amazement at how these men loved and cared for them: worrying about their illness; cooking and cleaning the home for them when they were ill, and just sharing in their joys and hardships in raising and caring for their children and families; becoming partners in the life journey. One key informant reported how her grandchildren have affixed “Grandpa” to the first name of her fiancé and how they would ask for him when they would call. She described that letting this man into her life was difficult because she could not understand why he wanted to be with her with all her past issues.

I’m like amazed, because I don’t believe that a person could be so kind. Because I went through so much in past relationships and sometimes I feel like, like it’s not. It’s too good to be true. So, I like to look for reasons to fight. You know and he’s like ‘Don’t you know I’m in love with you? I’m not going nowhere.’ And I just sit back and look at him like ‘I can’t believe like you really do love me, don’t you?’ and he’s like ‘Yeah with all your craziness’ … It’s hard for me to accept because sometimes I get scared. I’m positive, he’s not and he’s always at my beck and call (K1).

Another key informant also recalled how she found love, revealing that she felt that the troubled relationships of her past led her to a good one. She shared that she thought that her deceased father, whom she loved dearly, brought “this good man to me,” (K2) because there were so many similarities between them.

Children. All the informants but one had children and nearly two-thirds had grandchildren and two had great grandchildren. The informants were quite willing to discuss their children and shared both the hardships they had experienced as well as the pride of their children. Two key and two general informants readily revealed that some of the problems their children experienced were a result of the choices that they, the informants, made while raising them, resulting in separation during the children’s formative years. They wanted to help them
and did provide support, such as a place to live, but they all found it necessary to set limits for the benefit of the now adult child. They expressed concern over how these children would turn out but felt the situation required them to show tough love to prepare them for life on their own. They were aware of their mortality due to their HIV status and acknowledged the fact that the day might not come for them to resolve their problems. They decided to “care for them from a distance,” (K1) until the children could manage on their own, only lamenting being unable to be more supportive of their grandchildren. For the three general informants, whose children had stable lives, they did not have a problem with their children continuing to live with them at home and in some instances preferred it. These adult children were often the only ones the informants would turn to in times of need.

Children and even grandchildren had the unique role of protecting informants and helping them to achieve wellness. One general informant described how her four-year-old granddaughter helps her stay healthy, “She hears my alarm and she’ll come and go in my drawer, ‘Your medicine, Grandma,’” (G4). Another general informant revealed that her adult son makes suggestions about healthy foods to eat and exercises to try, and even chided her for resuming smoking. For another general informant, her child was the only person who knew of her diagnosis. This adult child became a confidant regarding this part of her life.

Some of the informants viewed their protective role as parents quite seriously. For these informants, even their adult children required protection. This included protecting them from knowing about the HIV diagnosis. One general informant with a mentally challenged child could not reveal her diagnosis to him, though her adult daughters who resided with her were aware. Two general informants from Puerto Rico purposely chose to not reveal their diagnoses
to their children still living in Puerto Rico, at the time of the interview, and had no intention of revealing the diagnosis and no plans of how to do so when their illness progressed.

I don’t know why. I say that if I tell my children or the first ones would be my children, because I know that if another person came to know before them, it would make my children angry, because they go first. Then I’ve always said not only because of the HIV, if it were cancer, I would have kept it a secret, too, because my children are the light of my eyes (G6).

Some of the informants experienced a significant separation from their children when they were young. For some of these women this separation was due to incarceration, related to drug trafficking, (one key and one general) and/or drug rehabilitation in a residential facility (one general). One key and eight general informants experienced short term separations from their children due to hospitalizations to treat the opportunistic infections that occurred with their HIV disease. One key informant experienced repeated separations from her young children due to her health issues. Other informants (one key and four general) became separated from their adult children and grandchildren when they relocated here to NYC to have a new life or to receive treatment for their HIV disease. Some informants reported being fearful of anticipated separations from their children due to illness and eventually death. These separations weighed heavily on the informants.

Two of the informants (one key and one general) revealed the loss of a child in young adulthood. Both these women continued to be profoundly affected by the loss and showed the researcher their tattoos memorializing their children. They marked their bodies to honor the presence and importance of these young men in their lives.

**Cultural values, beliefs and lifeways.** Kinship norms and roles are informed by the values, beliefs and lifeways of a culture. These cultural norms were defined in Chapter Two. The informants discussed these norms as expressed in traditional Puerto Rican lifeways and as
acculturated with American lifeways. The interweaving of these values and beliefs into
everyday life resulted in some informants not specifically using the terms presented below.
Instead their stories and day-to-day actions as recounted to the researcher, described them.

**Familismo.** *Familismo* explained the value placed on family by the informants. Even
when the informants reported stress and separation in their families, they all described the
importance of these relationships to them.

My family used to make me all happy, but now because of all the drama… So, my pride
and joy are my son, my daughter and my grandkids, because they brought me back to life
(G5).

The researcher was privileged to be shown pictures of the children and grandchildren, and
parents of four key informants and be told the stories behind each photograph. As discussed
before, some of the informants had tattoos on their bodies to honor the family members who held
great value to them, like a spouse or a child. Informants cried when discussing the losses, they
experienced in their families and this researcher shared in their sorrow. It was clear that being
part of a family was vital to the informants’ identities and, as some verbalized as well, vital to the
Puerto Rican culture. Even through marital separations, family ties remained strong. One key
informant shared that when she needed help she could rely on her son’s ex-wife.

My ex-daughter-in-law, I’ll call her, and she will stay with my father. If I have an
emergency, well she will help me too. She lives (nearby) and I can call her, and she will
help me out right away (K6).

Another informant maintained close ties with the children of an ex-partner whom she helped
raise. She revealed that they called her Mom, “Her kids call me grandma, she calls me ma in
front of her mother” (K1), even though the relationship with their father ended badly and she was
away from them for a long time.
Family remained connected through gatherings and helping each other in times of need. One general informant lamented when she was unable to attend a family gathering due to lack of transportation and then specifically strategized how she would get herself to the next event on her own and not rely on someone else. Many of the informants discussed how family stood by them when they were in need. Informants reported that family members helped them when they first came to NYC. Examples of the ways that family members helped informants were discussed in previous sections on Kinship.

Another way that families were supportive of each other is through the cultural concept of *hijos de crianza*, which most closely translates into foster children in English. Nearly all the informants reported being taken in by an aunt, uncle or grandparent at some point in their lives. The reasons in childhood were migration of the parents; mental illness of the parent; or, death of the parent. Informants asked someone else to raise their children temporarily as they were entering rehabilitation or incarceration. One informant described how she came to be raised by her maternal uncle and his wife,

> My father was killed before I was born. My mother was pregnant with me when they killed my father and the man who raised me was really my uncle. On the day, my mother gave birth to me I was taken by him to be reared. She was not well mentally. (G8)

Some *hijos de crianza* are the children of a spouse’s other relationships. One informant recalled how her mother and father tried to remove his children from an abusive situation but were unsuccessful.

When families experienced short- or long-term problems that created the need for respite or led to permanent isolation from each other, the informants reported distress over the situation and expressed a wish that these events had not happened. Even when these separations were for
the best for all involved, the informants were not happy that it had to be; they wished for
harmony in their family lives and satisfied themselves by focusing on the good times of the past.

**Personalismo.** *Personalismo,* acts of kindness, was both discussed and demonstrated
during the interviews. Discussions of personalismo centered on the informants’ relationships
with neighbors and friends, as well as their interactions with their health care providers. In
addition, this researcher observed demonstrations of *personalismo* during all interactions with
the informants, starting with the telephone screenings and throughout the interviews. For
example, one of the informants (G7) gave the researcher traditional candies from her recent trip
to Puerto Rico at the end of the interview.

*Personalismo* was demonstrated by the informants by sharing food, time and stories. All
the informants discussed instances when they demonstrated *personalismo* towards others, and
when they benefitted from it themselves. They shared food with neighbors who either liked
Puerto Rican food and the informant’s cooking or had no one to cook for them.

Many of the informants used *personalismo* in a unique way by sharing their stories of
becoming HIV positive and how they became survivors with people they met. Most informants
(five key and six general) were trained as peer counselors and developed a skill set leading to
employment for some and participation in research, the ACT2 Project and others like it.
Informants purposefully reported to this researcher that participating in this study was a way for
them to help other Puerto Rican and Latina women living with and at risk for HIV: “…help you
help us. That’s why I kind of joined the ACT2 Project...You know because I want to help people
who are HIV positive” (G1). By sharing personal stories and being honest, the informants felt
that they were fully engaged with their providers by creating a level of respect for their work on
their behalf. “I always say that ‘to lie to my doctor is like lying to myself’” (G2). Receiving a
phone call from a provider was an important indicator of caring that developed through personalismo as expressed by informants.

You know, and I was taken for a mammogram and they seen something, and she called right away. And I’m like ‘Wow…’ She’s really interested in my well-being and I love that about her. I can talk to her about anything, anything. Not just HIV. And that’s a good thing (K1).

The informants were aware of the time and expertise that their providers gave them and respected it by keeping their appointments. The examples of personalismo on the part of their providers were the respect shown for their time, opinions and life circumstances.

Machismo, marianismo and intimate partner violence. The cultural concepts of marianismo and machismo, described in Chapter Two, figured prominently in the lives of the informants. In their childhoods, their family lives often reflected the accepted norms of these concepts with a mother staying at home to raise the children and cook and clean for the family and the father being the breadwinner and having the freedom to come and go as he pleased. The roles that the informants were expected to assume in their families included being caretakers of their parents, partners and children and even their siblings.

Many of the informants incorporated the “caring for other family members first” aspect of marianismo into their perceptions of wellness and seeking assistance. When asked who, they turned to in times of need, many of the informants had trouble with this question. All the informants spoke of not relying on anyone and taking care of things themselves. When asked, who helps them when they are ill, they reported that they do everything they can to not get sick. “Me, I try not to get sick,” (G3); “Well, when I am sick, I take care of myself,” (G8); “Well when I get sick, I try, try, try, try, try to not get sick,” (K3). One informant stated that she avoids getting sick because there is no one to help her. “Because in my house, if I get sick, then I have to take care of myself… Because I have no one that I can call on.” (G6). A key informant
reported that she often felt bad when her husband cleaned the house and cooked for her when she wasn’t feeling well because she was not supposed to let him do those things for her.

It depends on what it is which I hate it, but he does. I’m supposed to do my things. I’m supposed to be able to do my things. Like the laundry or sweep and cook, stuff like that. When I’m sick, I can’t do that. So, he cooks, he does the laundry and I feels so bad and I get up and I can’t be out of bed sometimes…. But I was raised that we gotta be strong and we’re the ones that’s supposed to be. We don’t got time to be sick” (K2).

Her concern stemmed more from her own cultural perceptions than from concerns of infection control.

At the same time, some of the informants (two key and seven general) fought to break with some of these roles by teaching their male children to be caretakers, too.

Yeah, when I’m sick he takes care of me. He goes to the hospital; he don’t miss a day. He argues for me. He advocates for me, that’s what he does (G10).

These sons were often the only people that these women would turn to in times of need, especially when these sons were their only children or relatives. It is important to note that the informants were willing to accept their children’s help as part of the family connection (familismo) but would only reach out for help from these children as a last resort when they could not manage the situation on their own.

While intimate partner violence (IPV) was not an expected cultural norm for the informants, some responses to it were. One informant was expected to accept her husband’s physical and emotional abuse to not leave her children without their father.

And you know in countries like Puerto Rico, they say that if your husband hits you, you’re not supposed to leave him, even if he hits your kids, you can’t divorce him. The only thing you can do is pray to God. In my case, it’s not like that anymore. But I took it all. I dealt with my husband for 15 years (G8).

The expectation that IPV would be accepted as part of a woman’s wifely duties stems from marianismo. The use of physical violence to exert masculine control is the spirit of machismo.

The acceptance of physical punishment by a child for bad behavior would fall within familismo.
Five key and seven general informants experienced IPV by observing it during their childhoods between their parents. In addition, some were the direct recipients of IPV from their partners. Other forms of IPV, included physical, verbal, emotional, sexual, and financial abuse, and these occurred with romantic partners and other family members. Some of these incidents have been described previously. Abuse became a common thread throughout all these informants’ lives.

If experienced during childhood, IPV caused financial and emotional strains during the informants’ formative years. One general informant reported that her mother spent time in a mental health care facility due to the IPV she suffered at the hands of her father.

But when he got here, he started drinking, playing dominoes, seeing other women and he would beat her so badly that she wounded up… in the mental ward for 6 months because he hit her with a bat and an iron and pulled out a whole handful of hair. They told me I was terrified of her because she looked like a monster (G11).

One key informant was herself abused by a partner who constrained her to a room and forced her to engage in sexual activities with others. Her recovery from this abuse was a long journey for her that carried over into distrust of others, and heightened reactions to conflicts, which she described as post-traumatic stress disorder.

Because I have PTSD and I was raped and abused by my second husband. There are certain smells that really get to me… And my stress level has been down a little…but he was fxxxing up my mind, excuse the language, because I was in half of this room and I was locked up and I had to pee and sxxt and eat there for days and my second husband/boyfriend, whatever you want to call it, I had to do whoever he brought (K2).

One general informant revealed a lifetime of abuse, starting with the physical abuse by the aunt and uncle who raised her:

Because I had no adolescence, I had no childhood, none of that. They treated me bad, they hit me, you know. My stepmother hit me a lot and I had to do all the chores and if I didn’t do the chores, then I was hit hard, I was abused. That child didn’t want to tell anyone, and then my uncle tried to rape me. Yeah, that was the worst (G8)
to the emotionally and physically abusive first husband who took her salary to go out drinking
with his friends and have sexual relations with other men:

My husband was shameless. He did to me what daddy did to mommy. He hit me, he hid
his history from me, he would come home drunk, he hit me, he hit my kids (G8).

After leaving that marriage coming to NYC, she married again, and this second husband also
cheated on her but with women and died of AIDS, “He was a womanizer. What kinds of
husbands did I get!” (G8). Two other general informants discussed emotional abuse from family
members, siblings and cousins, who wanted money from them:

It’s like that when my brother comes to talk to me, he wants something I know he wants
something. Like before when he was shooting up drugs and I was working in the school,
he knew when I get paid and then he would wait for me in front of the building and I look
out the window and they’re arguing over who’s going to ask me for the $10 para curarse
(cure himself). You know, I always knew it, you know but I always saved a little money
for I didn’t want them to get killed in the street for a single trampa (scam), selling
dummies, you know and stuff like that (G10).

Three key and eight general informants who were infected with HIV through sexual
activity, identified a partner who emotionally abused them, as discussed previously. One key
and one general informant became ill first and their partners attempted to blame them for the
infection, when the men had the documented risk factors. Three key and one general informant
reported that their partners or ex-partners, informed them of the need to be tested for HIV in
cruel ways, such as leaving a cryptic note and then disappearing; making the women manage
their HIV status without support or recourse. “The little note said that he was HIV and I better
go check myself and my son. I haven’t heard for 23 years since” (K2). This key informant who
learned of the need to be tested had just given birth to their child and had refused HIV testing
during the pregnancy because she did not think there was a risk. Her child tested negative, while
she was positive.
Food. All the informants discussed the importance of food in their culture. They described favorite dishes, such as *pernil* (roasted pork shoulder), *arroz con gandules* (rice with pigeon peas), and *asopao* (soupy rice). Fried foods such as chicken and pork chops, *pastelillos* (pastry filled with meat, cheese, seafood or fruit paste), *baclaitos* (cod fish fritters), *alcapurrias* (pork, and olive filled plantain patties), *morcilla* (blood sausage) and *surillitos* (cornmeal and cheese sticks) figured prominently in the diets of these informants during their childhoods. The informants all reported cutting back on these foods to reduce the amount of fried and fatty or carbohydrate rich foods in their diets, but they would eat them as special treats especially when served as part of a family celebration. The informants who grew up in Puerto Rico all spoke of the use of fresh foods from the gardens or farms near their homes. Even the informants raised in New York spoke of using a freshly slaughtered chicken in the preparation of chicken soup for a sick individual.

Rice, beans, chicken and plantains were staples in the childhood diets of the informants. Many of the informants also discussed the incorporation of other dietary practices through acculturation. Informants discussed American versions of seafood dishes and the reduction or elimination of pork from their diets. Two informants (one key and one general) who reported dietary changes related to pork, shared that they had been in a relationship with an African American or Muslim man who did not eat it.

I was involved with these Muslims who told me a lot about pork so since I was 16, I haven’t eaten pork and maybe 10 years ago I stopped eating beef. If I didn’t have to take medication I would be a vegetarian, but I have to eat protein (G1).

They became accustomed to this dietary change and reported they felt better digestively, as a result.
Food also figured prominently in other culture lifeways of the informants. This included caring for family in familismo and demonstrating personalismo and hospitality. The informants reported using food to demonstrate caring for others and recognizing relationships. Certain traditional dishes were prepared for celebrations, such as pasteles for the Christmas holidays, “All the Christmas food, that in Puerto Rico is rice and pigeon peas, roast pig, blood sausage, pasteles; they have them all year round. But I never get tired of that food” (K3); and to care for a sick individual, such as chicken soup made with a freshly slaughtered chicken.

Chicken soup, donde vivero (from the butcher) … I know I’ve got an aunt, she made me some chicken soup when I was taking the broth when I was really sick. And she knows I hate chicken de vivero (from the butcher). And I was taking and taking then when I got better, she said, ‘You’re good and fat, good thanks to all that chicken soup.’ I said ‘Yeah, thank you.’ And she says, ‘No that was chicken de vivero’ (from the butcher) and I said ‘What?’ Every day she went to the vivero (butcher) every day she got a chicken and made me some chicken soup. Every day (G4).

Knowing the importance of food and unable to make, transport and store traditional treats at the interview location, the researcher provided store-bought snacks and water at each interview. The snacks were readily accepted by the informants and they sometimes asked to take extra for the trip home or for a grandchild, which was readily offered.

Celebrations. All informants spoke of the importance of family celebrations for sharing good times, food, music and customs. Each informant recounted the holidays that were celebrated, including religious and national holidays and birthdays. Each of the celebrations included traditional, Puerto Rican food and when the families relocated to NYC, foods from American and other cultures. The venues of the celebrations were usually in people’s homes, but also included parks, and beaches during the summer season.

Religious holidays accompanied by a celebration, in addition to attendance at church services, included Noche Buena (Christmas Eve) and el día de los Tres Reyes (the Three Kings
or Feast of the Epiphany). The national holidays discussed included New Year’s Eve, the 4th of July, Thanksgiving and Mothers’ Day. Birthdays were often included in the listing of holiday celebrations. Each of these celebrations included the gathering of family and friends and the preparation of specific foods for the event. For example, traditional foods for the Christmas season included: *pernil, arroz con gandules, pasteles, morcilla*, roast ham, potato salad and *coquito*: a coconut, milk and egg drink, prepared with and without rum. The informants reported having eaten these dishes as part of their Christmas celebrations and looking forward to eating them each year. Thanksgiving, an American holiday, was celebrated with the traditional foods, like roast turkey, stuffing and mashed potatoes and then traditional Puerto Rican dishes were added to the menu. Any celebration occurring in an outdoor setting, such as a birthday party, 4th of July celebration or a reunion would include barbecued foods.

*Music and dancing.* Included in the discussion of celebrations were music and dancing. The informants discussed traditional Puerto Rican music and the dancing styles that would accompany them, such as salsa. One musical tradition that the informants raised in Puerto Rico highlighted, is *La Parranda*. Like Christmas caroling, during the Christmas season, from *Noche Buena*, December 24th, until *el día de los Tres Reyes*, January 6th, people go from door-to-door singing traditional Puerto Rican Christmas songs; while a few members of the group played a guitar or *cuatro*, a *güiro, maracas*, (traditional musical instruments) and castanets. Once the singers arrived at a home and began to sing, they were invited into the home for traditional Christmas food and drink and then the group including the most recent hosts left to the next home. *Parrandas* were known for lasting well into the next morning. One informant reported the disappearance of this tradition due to safety concerns.

The Day of the Kings and when they come… The *parranda* in Puerto Rico, oh I was in that a lot. ‘We’re going to do a *parranda.*’ And that ended at 6 in the morning, at 7 in the
morning, at 8 in the morning, at 10 in the morning. And it means a lot to you. Nowadays they don’t do it like they used to because people are afraid in Puerto Rico now. “Here comes la parranda!” But now they don’t celebrate it like they used to, because now there are gunshots and there’s so much revenge. But I loved the parranda, with all the food and the drink and then they would make a big pot of soup. Ave Maria, how nice! And then I would go with my husband and then he would take his instrument and then they would play and there would be so many people because my husband’s family was as big as mine. (G7)

Another informant lamented other losses of Puerto Rican culture through the lack of knowledge of the youth of traditional songs and dances, el danzón, both here in NYC but especially in Puerto Rico.

I really like the traditions and sometimes it makes me sad when I see other countries with their flags and colors well maintained, but over in Puerto Rico no more and other Puerto Ricans have lost their flags and colors. They don’t know what the le lo lai is. They don’t know what a danza is.... We don’t know anything. It is a tragedy (K3).

This informant attributed this cultural loss of the le lo lai and danza, Puerto Rican musical and dance traditions, respectively, to parents not sharing these traditions with their children any longer, “The family must be more united. Because it is through the traditions of the grandmother that you have the best possibility…” (K3). One key and one general informant spoke of being regular salsa dancers and frequenting salsa clubs when they were younger and dancing all night long. One of these informants shared that she no longer had the stamina to dance but she recounted the names of clubs and salseros (salsa singers) from the 1980s and 1990s. Another informant reported that she did not dance too often in NYC but liked to go to the clubs when she visited Puerto Rico and was looking forward to a new club opening in Manhattan. Other informants revealed that they often listened to music and even danced in their homes but were reluctant to go out without a partner or friends to accompany them. Music and dancing held cultural significance for many of the informants. With the changes in their self-care, dancing became a form of physical exercise for their health and music became a means of relaxation.
Political and legal factors. The discussion of political factors varied among the informants. Some of the informants were very connected to the political climate of their communities, NYC, the US, Puerto Rico and globally. Their awareness of the power of politics to impact their lives and that of others was tangible and these women were empowered by their active participation in the political process. In contrast, other informants expressed frustration about their interactions with political leaders in their communities when trying to access services.

The two… in my neighborhood they’re no good…. We, I had it with them. I tell you, ‘How dare you? You’re Hispanic and you can’t help Hispanics.’ You know…Okay I went, two friends of mine a gentleman and a lady, ‘cause they needed like some support, to see what they needed because they’re elderly, a senior citizen program and stuff. And she came out and said, ‘Listen I cannot help you.’ And I said, ‘And you want my vote?’ (K2).

One general informant, who identified as Black Puerto Rican, specifically discussed that President Obama, as the first African-American president, and Mayor Bill De Blasio, whose nuclear family is biracial, brought important and new perspectives regarding race into the political arena. However, for the most part the informants did not speak of politics beyond its impact on their own lives.

Political events at the time on both the municipal and state levels had an impact on the lives of the informants and other people living with HIV. Multiple hospitals had closed in the preceding fifteen years, many of which provided care to people from lower socio-economic groups and some of them were at the forefront of HIV care at the beginning of the epidemic.

The thoughts I have is that it really sucks. I told you I…. (Laughter) They’re closing our clinics, XX is one of the ones on the line for being closed down for years. Quality of service you get is not the same…A lot of clients that I know they used to go to XX, they shut XX down. (K5).

One general informant expressed her belief that these hospital closings were politically motivated because the state failed to provide financial assistance and support to these facilities.
Five of the general informants needed to change the location of their HIV care because of these hospital closings.

Four key and eight of the general informants expressed uncertainty regarding the impact of the Affordable Care Act on HIV/AIDS services. Those informants (two key and four general) who also worked at AIDS Service Organizations (ASO) shared what they were being told by their employers and how they were being instructed to answer questions from clients. More questions were raised than were answered. However, it was still early in the implementation of the ACA to know the effect on ARV medication coverage. While the informants all received their medications through Medicaid, there could be some future changes to coverage with the Medicaid expansion.

The four key and four general informants with extensive ties to Puerto Rico and whose families owned land, were very concerned about the worsening financial situation there, which resulted in increasing taxes and restrictions on leasing homes.

The government denied the loans and the economy began to break. Then there is all of the crime, the jobs. Many don’t go to school. The education system, the kids don’t go, and the government doesn’t make them. You can’t do anything if you don’t have the will. The parents don’t take them to school. There are some mothers that don’t care about that. It is the economy and the jobs (K3)

How the price of food is going up and water, and electricity and everything. And I worry because I have family there. You know up to now, things weren’t so bad, and my family is okay, and people have to eat and all that (G2).

But I see a lot of corruption and so much money is being stolen. I see that, and I say, ‘My God, what is going on in Puerto Rico?’ (G7)

Some of the other informants (two key and three general) were not fully knowledgeable about the political relationship between Puerto Rico and the US (e.g., the definition of Puerto Rico’s commonwealth status) and voiced a lack of understanding of the difference in taxation, representation, financing of the health care system and the availability of community-based
resources there. In contrast, for all informants, there was an understanding of the benefits of their American citizenship here on the mainland and the flexibility of travel between the US and Puerto Rico.

Some of the informants had legal issues that they shared with the researcher. Three informants (one key and two general) had been jailed due to drug trafficking activity as noted previously in this chapter. Other informants were involved with the family courts, either as children when their parents were divorcing or as adults when they were fighting for child support payments from the fathers of their children. Two informants (one key and one general) relinquished custody of their children to family members when required for legal purposes. Two key and two general informants had frequent interactions with the police and the legal system due to the verbal and physical altercations that occurred on a regular basis with their family members. Besides these informants, the others did not report any legal concerns.

**Economic factors.** Finances were a concern for many of the informants. All the informants lived on budgets, whether their income came from benefits or salaries. The four key and seven general informants who were unable to work were dependent upon disability payments, the supplemental nutritional assistance program (SNAP) and subsidized housing. Even with these benefits, some of the women found it necessary to supplement their income by working “off the books.”

The restaurant wants too much, you know. I mean they pay you well but I’m not going to kill myself. I work(ed) 12 to 14 hours a day, 6 days a week… I don’t have a job. I get a check once a month and I’ve got to pay bills and I barely make it with this damn check. What I would make in one month, I used to make in one week working in a restaurant, you know and I’m like ‘What? Are you kidding me?’ and that got me into a severe depression. I can’t do this, you know and then I figured it out…That I had to do side jobs or get a job off the books because that’s the way it is. Because you gotta do what… you gotta do (G10).
Some informants had been put in the position of needing to pawn their jewelry for cash. “I pawn my jewelry... because I had problems with my food stamps. I’m not going to starve,” (G10). The plan was to obtain the money to buy back the jewelry before it was placed for sale to the public. She then, showed the researcher which pieces of jewelry she had just retrieved.

The past work history of the informants reflected the level of education they achieved earlier in life. The informants who completed high school (two key informants), some college credits (five general) or a college degree (two general) worked in clerical positions or in the service industry as counselors and four of them were still working at the time of the interviews. The four key and five general informants who had less than a high school education or a GED, had worked in factories making candles, clothing or jewelry, or were in the culinary industry and were more likely to no longer work. Some informants were unpaid for their labor as housewives and caretakers of family members. As discussed previously, some informants were involved in drug trafficking as their source of income.

Informants carefully considered the pros and cons of their housing options and for some the choice came down to finances as described by one general informant.

They offered me an apartment from the M... They have a doorman, they have a gym, and they have landscaping on the rooftop. But I pay $600 a month and that would come out to $1000 a month and I don’t. First of all, you’ve got to earn between $21 and $24 thousand and I don’t earn that. So, when I applied they said I would have to pay more. So, I would have to pay at least a $1,000 a month because $600 plus my bills, my phone and cable. Now I’m paying $245 there I don’t have to pay electricity, so I have to weigh it out: Do I want to live in luxury? Yes, I would love to live in luxury but then I would be tight. And here financially I’m good. I can go shopping I can go away to vacation (G11).

As this informant stated it was more important for her to have financial security in a place where she knew how to safely live than to risk financial insecurity for amenities. Another general informant noted that a change in her income would result in a corresponding change in the rent. In subsidized housing, the tenant would be responsible for all utilities, except for water usage.
Informants who lived in subsidized housing were concerned about their utility bills and often were actively seeking ways to cut payments by removing unnecessary services, such as cable and internet.

There are times when I have to go…. because the telephone with the cable they were charging me $117 and so I went, and they lowered in to $54. That was last month and now this month it came out to $98. So, I said, ‘Come here, the girl told me that I was going to pay this much and now it’s $98.’ I said, ‘Next month it’s going to be more.’ And so, I went. My girlfriend advised me to turn in the box and get an antenna. So, she says, ‘It is the same, there are the same channels and you can see the same movies’ (G7).

Finances also impacted the living arrangements of some of the informants. Three general informants reported that their adult children live with them; and two of them have their children’s families (spouses and children) sharing the living space, too. In each of these circumstances, the primary reason for these living arrangements was financial. In these cases, it was the children who could not afford to live on their own and their mothers had space in their apartments for them. “I pay all the bills; take care of them when they’re sick. But it’s vice-versa because they take care of me too. They take care of me, and I boss them around” (G4). Each of these informants spoke of a loss of some privacy but also were happy to have their children close and to be able to help them out.

Other informants also reported living with family members on a temporary basis when finances were limited; or, they were in transitions. Two general informants reported that family members would come to them when they needed money to support a drug habit. They wanted to be helpful to their family but not in that way. Finances could also get in the way of informants and their families. One general informant reported not seeing her children and grandchildren for over four years. Neither, could she afford the plane tickets, nor her children get the time off from work long enough to validate the cost of the tickets.
No, not every year, when there is not enough money for every year. I don’t have the benefit of doing that. I went some years in a row, when I was working. But now no because I have obligations for myself. Paying my rent, my phone bill, the cable bill, you know. But when I have, well you know I take out my time (G2).

**Educational factors.** As noted previously, the informants had varying levels of education. There was no noted pattern in these differences based on where the informant was raised. Three key and one general informant did report that their pursuit of education was not supported by their parents. The parents of two key informants allowed them to not complete their basic education, i.e., drop-out of school: to get married as a teenager (K5); or, to not have to manage another delinquency report in middle school (K1). Some parents and spouses were very supportive of the five general informants who continued their schooling, but it was their own decisions to further their educations. All the informants encouraged their own children to complete their schooling and expressed great pride in their children’s academic and professional accomplishments. “And my son, he studied 2 years in college for law and now he’s going to go back and finish his bachelors” (G10).

Two of the key and four of the general informants did not complete high school and expressed regret over this situation. Even though two did eventually complete a GED, there was a sense that this was a lesser alternative, especially because they felt it limited their employment options afterwards. A few of the general informants were unable to work in the fields in which they received degrees or certificates. The reasons included: drug use (G7), health reasons (G1) and for one informant (G5), it was the scheduling of the HIV clinics in Puerto Rico that prevented her from working in her field.

But I could never work in that because of my illness in Puerto Rico. You know it’s not like here you can see the doctor in the afternoon, over there it’s in the morning and you can’t miss days. So, I had to work in a Home Depot thing like a buildings store because I could switch my hours and go see the doctor (G5).
These informants expressed regret that they did not have the chance to live up to their potential in their work lives.

Many informants spoke of taking classes to improve their knowledge and/or gain new skills. One general informant completed a few certificates in various office skills. The two key and four general informants who worked at ASOs, also reported frequent attendance at training sessions to broaden their skill set in working with people living with HIV. One general informant shared that she received scholarships from the ASO, “They have scholarships here every 6 months and every time I apply for it, I get it” (G11), to take policy development classes at a local college. The two key and six general informants who were raised in Puerto Rico and mostly spoke Spanish all reported taking classes in English once they arrived here in NYC. However, they reported that they did not do well in class and they believed that they could not speak English well.

Folk Care Maintenance and Illness Prevention

The informants discussed many activities to maintain health and prevent illness. Some of these practices were ones that they used throughout their lives and were recommended for everyday symptoms like headaches, or nausea for use by anyone. Other remedies were specific to improving immune function, reducing stress and encouraging general wellbeing.

General health practices. The informants all discussed their activities to prevent getting ill. They spoke about general preventative care practices such as getting an annual flu shot, staying up-to-date with other vaccinations, washing their hands, and staying away from sick individuals, including children and grandchildren. Getting enough rest each day and reducing stressful situations also helped them to stay healthy. Surrounding themselves with caring and loving individuals, defined as people who put their health and wellbeing first, was another
strategy discussed by the informants. Another strategy was distancing themselves from those individuals whom they loved but whose behavior made them feel at risk for excessive stress, substance use, etc., “I left them without regret as they say when I knew that one was drinking. I knew that he drank but I did not know that another one was doing drugs. And I said, ‘I prefer to leave’” (K6).

**Herbs, teas and other home remedies.** Some of the informants discussed herbs, teas and other remedies to be used to treat ailments. These were practices that they were raised using. One key and one general informant provided detailed strategies for managing migraines, when sentinel symptoms begin to reduce the severity or duration of the episode. Another general informant elaborated on the detailed juicing activities she engaged in to reduce allergies, including discussing the pricing and values of various juicing machines. These and other informants (two key and one general) shared that they were taught to recognize plants with healing properties as children both in Puerto Rico and in NYC.

You went in the backyard. We took everything from the plants in the backyard. And the backyard there is a plant there that they even have it here when you walk by (G5). They frequently shared remedies with others and knew what ingredients could be exchanged for another when not available.

Some of the herbs/teas discussed were: **hierba buena** (spearmint) tea for stomach issues; nawnee juice for immune health; menthol for opening sinuses (can be used for congestion and headaches); **manteca de ubre** (a pomade with menthol, camphor, pine and cedar oil) for headaches; Echinacea flowers for colds; **raíz de magüey** (century plant root) for eye inflammation; **té de tilo** (linden flower tea) to calm a cough; onion tea for infections; black or herbal tea with lemon and honey and sometimes a shot of liquor (any type was equally effective) for sore throats; and general herbal teas available for various ailments at health food stores.
Information on any of these herbal remedies could be readily accessed via the internet. The informants who used more elaborate herbal remedies relied on various sources: friends and relatives, herbalists and the internet, for information.

Quite a few of the informants, one key and eight general, discussed herbal remedies for other activities, such as spiritually purifying their homes and bodies, providing protection from or removing the effects of the trabajos (bad intentions) of others.

Well I have these things that you always put by the door, these little cubes and you can buy them in the 99-cent store, they’re called alcanfor (camphor) and I always have a cup in the corner and I put a few in there and that’s good for the sinuses because it smells (G5)

These products usually included flowers, and agua florida (perfumed water). These recommendations were made by espiritistas or santeros and the products were acquired locally in a botánica or in other stores, like pharmacies or health food stores.

**Comparison of Health Care Systems of Puerto Rico and United States**

Eight of the informants (two key and six general) had experience with the health care systems in both in the US and in Puerto Rico. Nearly all this subset experienced HIV care and/or substance use recovery care in both locations, as well. These informants indicated that they preferred to receive their HIV care and/or recovery care in the US. This held true even though they preferred the lifestyle in Puerto Rico. Two of the general informants had been invited to relocate to Puerto Rico by family members,

Benefits, they don’t give you benefits. My cousin she asked me if I wanted to move in with her. She has a house, it has 2 bedrooms, but I don’t want to move there (G1), but they declined these offers.

These informants reported that healthcare is funded and organized differently in Puerto Rico. Two general informants disclosed that they could not hold a job in their desired fields and receive HIV care, “When you work, it is really difficult to do this treatment and it wasn’t easy to
start the treatments” (G6), because of the need to spend the whole day at a clinic for one visit. As presented previously, one general informant (G5) took a retail position, so she could easily schedule a day off from work when she needed to go to the clinic, because of the option of weekend shifts. For these informants, the need to take a day off from work often meant a loss of the day’s pay.

Other informants, two key and three general, discussed the differences in the insurance coverage in Puerto Rico which did not provide the same level of services, including medication coverage. This was discussed for care of other health conditions as well. These informants who cared for loved ones in Puerto Rico reported having to pay for medical supplies out of pocket, “I didn’t know that it would take more than a week to get her out. It’s a whole process to pay for the oxygen tank,” (K3) that would have been covered here in the US. Another key informant obtained medication in NYC for her mother in Puerto Rico, when she could not afford the medications.

She became diabetic and all the meds that she needed, one was $8 a pill. So, there was some medicines I was able to get for her and send to her to help her out and now she’s here. She has her own services (K4).

One general informant (G9) seriously considered relocating to Puerto Rico after her diagnosis, but her child had special needs and resided in a home.

I tried to go back to Puerto Rico after I received my diagnosis, I went there and I asked my sister to look for a spot for him there and one of the young men who was helping me on the telephone asked me how things were over here, and he told me that if he is here to stay here because there is not even a third of what is here. Someone who works in that field told me that (G9).

Her decision to stay was also based on the presence of her other children in NYC who also assisted in managing her son’s care.

One salient area of differences in care between the US and Puerto Rico was in substance use treatment and rehabilitation. The informants who received substance use treatment reported
there were limited resources and facilities in Puerto Rico. As shared by a key informant, the rehabilitation facility she attended in Puerto Rico was connected to the church and did not provide information on safer sex practices nor continued treatment when she was discharged.

I had decided that I wanted to be well and because he was with me, they didn’t have too many classes about using condoms because they did tell us that if he didn’t use a condom that we could reinfect each other (K6).

This informant experienced a few relapses when she returned to the same environment. Her family later suggested that she come to the US to receive better substance use and HIV treatment. She disclosed that the new environment gave her the setting she needed to maintain her recovery and even though she missed her family, she had no plans to return to Puerto Rico.

Caring Beliefs, Expressions, Patterns and Practices

Caring was reported by all informants to be an important factor in the maintenance of wellbeing and health. Yet, many of the caring beliefs and practices shared by the informants focused on helping others, family members, like parents, siblings, partners, friends and neighbors. Cultural traditions of *personalismo* encouraged these outward expressions of hospitality and each of the informants discussed these activities throughout their lives. Informants recounted stories of their family members taking in a child or extending a place for them to stay, as described by this informant who was cared for by her aunts during her mother’s treatment for mental illness.

Her sisters kept me and my sister and my two brothers with my aunt because BCS [Bureau of Child Services] at that time wanted to take us away. They said, ‘If they keep those kids away from T, T *se muere* (will die) and we can’t allow that’ (G11).

They shared instances when they reached out to others by caring for children, family, friends and even strangers. As one key informant described

They young that’s why it’s important to bring this out, you understand. That’s why when I go… and I see them talking, I stick to their level because I been there and done it. You
understand, and I know what it’s like you could do life. I know what is dealing drugs; I know what is gang banging fighting; cut all that, I know all that. That’s why I bring it to them on the table because I don’t want them to go what I went through (K5).

This care could be direct: money, a meal, or words of advice. When the caring actions were provided to loved ones, it was often a healing experience for the informants. It was also reported to be a desired activity to engage in during times of illness and active dying. Another way Puerto Rican people demonstrated caring acts, as stated by the informants, was being present during illness or other difficult times.

A very strong caring belief voiced by all the informants was women as caretakers. They felt that this was an expectation of their Puerto Rican culture. For the three key and three general informants who felt that they did not receive caring from their mothers in their childhood or as adults, there was anger in their voices, “My mother didn’t do nothing. Jesus Christ. My neighbor did more for me than that lady,” (K2) and they expressed feelings of loss. For the three key and nine general informants who described caring mothers, there was much gratitude, even when these mothers tried to impose their beliefs, like religion, or women’s and men’s roles, on them. One general informant expressed her love for her mother when considering losing her to death, “I don’t know how I’m going to deal with that. That’s my moms. She’s been my backbone. With all her sxxt and all her stuff, she’s always been there for me” (G3). This concept of the woman as caretaker was important to the informants and they expressed true regret when they did not exhibit those behaviors, as with the two key and two general informants whose drug use interfered with raising their children when they were in rehabilitation or incarcerated. They also saw it as their responsibility to care for their children now, such as in preparing them for life by instructing them on how to care for themselves.

Oh, yeah, my story, my life is an open book when it comes to my children. You know because a lot of times people will disclose the things that go on in their lives with the hope that their children will learn from the things that they’ve done (G12).
All the informants expressed a desire and a need to share their stories to educate others, children specifically, about how to protect themselves from HIV. During the screening process, they all stated that they would participate in this study because this was an important message for them to share.

The examples of caregiving men were rare and vital among the informants’ fathers, as discussed previously. In addition, two key and six general informants described caregiving actions from their sons, “He’s always on top of me. He doesn’t want to lose me. ‘You’re all I have. Yeah. You’re all I have’ (G11). The descriptions of the sons of the one key and one general informant who were uncaring, included references to their own troubles and these mothers were trying to help them through these issues, so they could become more caring.

There’s something wrong with him mentally. I can’t help him pero (but) I’m his mother. You know how Puerto Rican parents are. So, I’m the mother, you know but I’m like, he’s 30 years old, ‘Get your life together. You know I’m not going to be here forever’ (G3).

This, however, was not the case for uncaring fathers or partners. The informants were not interested in helping their fathers become better caregivers. For the fathers of the five key and one general informant, who were strong caregivers, their actions often overshadowed those of the mothers even when they were caring, too. These caring men, father and sons, offered advice on achieving wellness and living with HIV and accepted the caring actions of the informants. These informants reported these reciprocal caring relationships as important for overall well-being.

**Caring behaviors.** The informants described caring behaviors as demonstrating an outward demeanor of love and acceptance. This was expressed by and to family and friends of informants by being present and available to each other, as well as meeting certain needs. Caring could also be shown to others outside of their networks, when presenting a friendly smile and
kind words to people in any setting. The informants desired these behaviors from others and wanted to demonstrate them as well.

Beliefs regarding care of others included the need to demonstrate caring to those who ask whether in need, or not. Three key and five general informants shared their own stories of giving their time, money and food to family, friends and neighbors when specifically asked or when they were made aware of the need. Two key informants reported their observations of their parents engaged in these behaviors during their childhoods and they were proud of this history. One informant (K1) discussed her mother’s efforts to care for their friends in the neighborhood. As a result, they called her, “Ma,” too. Another key informant revealed that during her childhood, her father often gave food to the “drug users and alcoholics” in their neighborhood rather than money. She hoped to be able to do similar things herself in the future, “I wish that I had money, so I could help them” (K5). Demonstrating caring behaviors was also problematic for informants when others took advantage of them. One informant’s wellbeing was affected and her trust in others damaged by a boyfriend, “he betrayed me really bad. And I, um, didn’t trust nobody” (G10). She felt she could not help others because she needed to protect herself.

Care was described in many ways by the informants and while the informants did not have any issue with discussing care as they provided it to others, parents, children, spouses and partners, they often needed time to ponder how care had been provided to them by others. The informants’ descriptions of the care that they received as children were readily offered, such as recollections of extreme illness, injury, and recovery. In addition, experiences with needing to care for themselves included details of the remedies used at home. However, they needed prompts to recall and define the caring they received in their recent past from loved ones.
All the informants discussed their efforts to not need care from others, to not become dependent. They discussed working hard to not get sick or take care of things for themselves. Three key informants and eight general informants described accepting help and care from selected individuals, such as partners, or children. Speaking about her fiancé, one key informant described how involved he was in caring for her when she was ill. “Hell yeah, don’t let me be sick. I’m telling you he’ll pick me up and take me to the hospital” (K1). The children who provided care were often the only children of the eight general informants and/or the child mature enough to be self-sufficient and reliable. The people who these informants turned to for help were aware of their HIV status and prepared to be able to safely provide physical care, if needed. One key informant described her request to her professional care givers to assure her family was educated to care for her.

‘I need you to prepare my family, educationally about this. Not me, from somebody else because it can’t be from me.’ Even though I graduated, [meaning, she had learned everything required] I did whatever, but it’s good from another source (K5).

For the informants who had not revealed their HIV status to family members, they described different circumstances in which they would reach out to different people to meet different needs.

I want to say something so that you understand more clearly. I have my aunt and we talk but I don’t put my issues on her. I don’t talk about my health, and I didn’t do that with my mother either. To keep her (my aunt) quiet, I ask her how her kids are (K4).

As described by this key informant, she deliberately does not share any information about her health with the aunt who helped her get settled in New York City. This situation resulted in her controlling her family’s ability to help her when she needed assistance.

**Protection.** All the informants described their beliefs about care as protection demonstrated through personal care; care for parents; and, care by parents. Protection of self was deemed necessary by four key and five general informants to reduce stress by limiting
exposure to stressful situations and the people causing them. One general informant discussed purposefully limiting her interactions with people in general because she felt that people were often looking for what they could get from her, “It’s like that when my brother comes to talk to me, he wants something I know he wants something” (G10). She cared for herself by controlling her exchanges with him. Protection was reported by all informants as required for their physical health and was discussed as part of their self-care practices: “When someone is coughing at my side, I don’t stay there, you know. So, I will move myself in a way that I don’t offend them” (G2). These protective self-care practices included medications, nutrition, exercise, spirituality, infection control, safer sex, stress reduction and environmental modifications.

Informants also shared examples of being protective of their mothers during incidents of IPV when they were children.

My father punched her in the face. And I’m there and I loved my father, but I said, ‘no la toque’ (don’t touch her) and I’m behind her and he hit her that one time and that’s how come they broke up (G3).

Other examples of protecting parents include providing care to parents during illness. Protection for children was demonstrated by preparing children for an independent life in which they could protect themselves. All the informants with children spoke about providing them with advice for life decisions, and unconditional love but this did not preclude the need to address problematic behaviors, by setting limits on interactions that were deemed by the informants as seeking enabling behaviors from them.

The effort to prepare their children for independence was linked to informant reports of instances when they felt that they had not received protective caring actions from their own parents. Such as, not guarding them from themselves and self-destructive behaviors, like drug use or dropping out of school: “My parents didn’t know any better,” (G11); or, from the behaviors of others, as in sexual abuse, “they were not really protecting me like they were
supposed to,” (K4), during their childhoods. Their disappointment continued well into adulthood and they believed this failure to protect them led to the behaviors that were their risk for HIV exposure and infection.

**Caring during illness.** All the informants shared similar cultural practices when someone was ill. These activities included visiting the ill person in their home or in the hospital; saying prayers for them; bringing them needed items; preparing meals for them, especially homemade chicken soup (*sopa de pollo vivero*), which must always be made with a freshly slaughtered chicken to achieve its greatest effect; accompanying them to appointments and assisting them with legal papers. Several of the informants (four key and six general) took on the responsibility of caring for other people whom they deemed were in greater need than them. A general informant (G8) reported that after the interview she would be going to visit her friend and neighbor who was dying of cancer and she shared what foods she was planning to prepare for her.

That’s the problem that I have right now with my friend. Sometimes I go and call her, and I say, ‘M, you want me to bring you something to eat? Do want me to cook for you? Something to eat?’ You see the person with that chemotherapy cartridge and they don’t eat because they’re throwing up. So, I went last Sunday, and I made a bread pudding and I brought her a piece. And she said that she didn’t want to eat, and when I go to see her, I want to bring her something, you know. Bring something, I spent some time with her and I said, ‘Anything you need, I’ll cook it, you just call me. I’ll buy it, or I’ll cook it in the house,’ I told her. When I leave here, and I go to see her and how she is doing, if she’s in the house, or if she wants me to do something for her, I’ll do it. That is one thing that worries me because there are times when I am not well, and I get down and my defenses go down and then I get nervous. You know what it is to worry about someone else.

She also revealed that since she lived in elder housing and she was one of the youngest residents, she had cared for a few of her ill and dying neighbors before. She shared felt that she was good at being a caregiver. Another general informant (G6) shared the story of a young man she befriended sitting in a waiting area who had AIDS and no family. She became his caregiver and
assisted him until his death. He used a wheelchair and when the elevator in his building was not functioning, she would carry him down and up the stairs.

I met a young man down there and we became friends and I cared for him like he was my son. He was sick, and I was taking care of him because he had no family. He had gotten out of jail and he had no family, he had lymphoma, and they gave him chemo and then he couldn’t walk. He was young and then he died downtown. That was traumatic for me when this boy died. You would have thought that he was my own son. I cared for him because I felt so bad for him that he had no one.

Other activities included creating an environment conducive to healing, such as providing a place to stay; taking off from working to provide direct care or providing distractions; and offering prayers and friendly visits.

**Folk beliefs on death and dying.** As noted previously, all the informants expressed concern regarding their dying because of HIV disease. Informants’ general perceptions about death were framed through their previous experiences with death and their own sense of mortality with HIV. Death was unavoidable, yet, some did not want to discuss it in detail while others communicated that death would mean “peace” (G4). A few informants discussed their preferred way of dying, such as, in their sleep (K2); and some others shared experiences of being near death in the past and not wanting it just yet (K4; G3). Some informants described death philosophically as “not really being the end,” and discussed what their death would mean to others or what the death of someone they loved had meant for them. Some thoughts, as articulated by the informants were: death was unfair when it took away a child or a loved one (K2; K3); welcome when it ended suffering (G4; G6); yet, fair when the person had wronged them, “God’s in charge. He don’t make mistakes” (G12). All the informants felt it was important to prepare their loved ones emotionally and practically for their death. One informant who worked in social services spoke about cultural concerns regarding preparing for death.
Some of my friends are taking their parents to get a legal document, what to do with this the insurance, you know, spell it out. A lot of the Hispanic people don’t want to do that because it’s hitting them in the face (G3).

Some of the informants prepared legal documents and made advanced funeral arrangements. A few informants were concerned with how a loved one would manage without them, while another felt that she raised her children well and that they would be okay without her.

I say when my time comes. I’m ready, I’m not scared because I know that no matter what at the end of the day, my kids will be okay and my grandchildren. I did my job. I’m good with that (G4).

Informants with older children who were self-supporting were more likely to respond in this way.

Care for the dying. When a person was dying, a special urgency around visiting, caring and praying for the person presented itself. Especially when the person was a blood relative, parent or grandparent, the efforts to care were increased. For one informant, being able to care for her mother during her terminal illness healed the rift that existed during her youth.

When my mom got sick, we didn’t get along when I was growing up, but when my mom got sick, I was there for my mom. And it’s crazy because everything flipped over (K1).

This mother requested that no one else care for her except her daughter. “Like she wouldn’t want nobody next to her but me” (K1). This opportunity led this informant to discover a skill in caring for others, which then became an employment option for her. A general informant discussed how she cared for her husband’s brothers when they were dying and rejected by other family members. This experience prepared her to eventually care for her own husband, when he was diagnosed with AIDS and eventually died.

My brothers-in-law had it so by the time my oldest brother-in-law. I took care of him and he would stay in my house and I saw a lot of the stuff he went through. So, I was there to help him and so was my husband, so we learned through him. And so, when I found out it was like ‘Okay where do we go from here? What do we need to do to stay healthier?’ (G4).
Another general informant shared how caring for her dying partner demonstrated her devotion to him even considering his betrayal of her trust and giving her HIV. “What matters is that we’re infected, and we have to take care of ourselves. But still regardless of what he did, I still love him” (G1).

Taking time off from work and travelling, even to Puerto Rico, were ways that informants demonstrated caring for their loved ones when they were dying. One key informant disrupted her HIV care here in New York to be with her mother as she was dying in Puerto Rico. Consequently, she had to reveal her diagnosis to receive treatment for a progressive condition. And after the swollen leg, she told me, ‘Relax, I will send you to the emergency room.’ No, I couldn’t stay there like that. ‘You can’t take care of your mother like that with your leg that way.’ My leg was swollen. So, doctor I have this but there is more that needs to be treated. Please don’t tell everyone (K3).

The physician and family friend assured the informant that she would not say anything because of the demands of her profession to maintain confidentiality.

Informants expressed great distress when their efforts to care for or comfort a dying loved one were unsuccessful. An informant was upset that she was not given the opportunity to visit her dying father or even speak with him on the phone. “So, the last time, they saw him, he asked for me I guess maybe he wanted to say bye, but no one called me to say bye” (K4). No one helped her to participate in his funeral services, which occurred out of state. Though she could not verbalize any rationale for these events, she remained saddened and angered by them.

**Caring for the dead and those in mourning.** Caring did not end after the death of a person. In fact, many of the informants spoke about the elaborate ways in which they continued to care for their deceased loved ones and reported a cultural basis to these practices. The communal religious and spiritual practices for the dead have been discussed earlier in this chapter, and these were willingly performed to assure the repose of the souls of their loved ones.
A more intimate practice is the lighting of white candles, either in the home or in church, on their birthdays or anniversaries to guide them to peace. One general informant shared that she lights a candle for her deceased husband when the mood strikes her, “I feel like lighting this candle for my husband. I’ll go buy it and I’ll do it” (G4).

Caring practices for the dead, wakes, funerals were also an opportunity to care for those in mourning. Each informant who shared a story on caring for the dead found solace in those caring practices. One general informant (G6) observed that when she came to NYC for the funeral of her mother who practiced another religion, she preferred the calm and quiet presence of the attendees at the services.

Everything was beautiful, beautiful. And it was about that she was in a better place and she had a good life and she is happy now that she is in the other world. I can say that it was good and that I really liked that part and afterwards we left the cemetery and they had a dinner in the church. A dinner for everyone. That really got my attention, I really liked the way that they did it. That way is good, I will say that to my children, I haven’t done it yet (G6).

Her mother’s funeral brought her such relief that she wanted to give that to her own children when the time for her funeral would come.

Special prayers for others include *el Santo Rosario para los Difuntos*, (the Holy Rosary for the Deceased), a novena or nine days of rosaries after the death of someone in the Roman Catholic faith. Two key informants (K2, K3) spoke of their participation in this communal prayer practice usually conducted in the home, followed by a shared meal that continues for years after the person’s death. Some informants had traveled to Puerto Rico to participate in these prayers on the anniversaries of the death. These reunions allowed mourners to share and relieve their collective grief with the retelling of stories of the deceased, as well as maintain connections to friends and relatives long after the death.
**Diagnosis with HIV.**

All the informants shared their stories of their HIV antibody testing experiences and their receipt of the HIV diagnosis. The reasons they were tested varied but fell into some broad categories. Three general informants were tested because their partner/husband was diagnosed with HIV, “In that time, because my husband, the father of my children, when they diagnosed him, and it was less than two years. And I followed.” (G9). They reported that receiving the diagnosis was difficult for them because they were preoccupied with caring for their partner/husband. Three key informants received a callous, impersonal message, by note or voicemail, telling them they should be tested for HIV from the partner who transmitted the virus to them. After sending the message, these men disappeared.

The HIV I didn’t go looking for it. My husband brought it home and left me a note about it and just disappeared (K2).

Another subset of informants (one key and four general) was tested for HIV because they were ill, “Yes, they took me to the hospital, and I was really sick. So much sweating at night and I lost weight, who knows how much, I had an infection all over my body, everywhere” (G2). One general informant shared her story in which she was tested on a regular basis at her physician’s office after the death of her husband, but it was not until she became ill and was hospitalized that she discovered her own diagnosis.

I had my regular doctor I would go to, and he would test me. He kept telling me I was negative. I was fine, and I caught a cold that wouldn’t go away and these diarrheas that wouldn’t go away. When I went to him, he gave me cough medicine. He said, ‘you’ve got a bug’ I said ‘okay’ so I took the medicine, I went home, and I got sicker…They took me there [hospital] and I found out I was HIV+ (G4).

Two general informants were tested for HIV in settings where HIV testing was required as in incarceration (G7), or application for the military (G10). Each of these informants were aware of their risks but were not expecting a diagnosis of HIV. One key and two general
informants were tested during their participation in rehabilitation programs for drug use, “Because, they told me to in rehab and there it came out” (K6). In these instances, they were educated on risk factors for HIV, leading them to self-identify the need for testing. One key and one general informant learned of their HIV status when they were tested as part of their prenatal care.

I found out when I was pregnant with my second child. They did the test and then called me that there was something wrong with the blood work. They couldn’t tell me on the phone obviously (K4).

For each informant, the experience changed their lives at a fundamental level and gave them a new worldview. It changed their perceptions of who they were; who their partners, family and friends were; and, how they interacted with the world. One informant described it this way:

You know I was humbled and I had to look at the world in a different way, look at life in a different way. And how I appreciate life and I think twice before I do anything like I used to (G11).

**Folk Beliefs of HIV and Expectations of Care.**

All the informants felt that it was possible for them to be healthy while they lived with HIV. This was a change from their initial beliefs about their HIV status. Each of the informants discussed their fears of dying soon after they discovered their HIV status. At that time, the 1980s through the late 1990s, there were still many people dying and very little was known about how to manage HIV disease. “When they gave me the diagnosis, I thought that I was going to die” (G2). They recalled the limited number of medications available early on and how toxic they were.

I lost a lot weight, the medication, they were giving me AZT at that time and it was strong because it built up my T-cells, but it ruined my body, I got anemic and they had to do blood transfusions (G11).

They shared that they felt empowered to have medications available to help them be healthier.

In support of their beliefs of being able to be healthy, each of the informants discussed their
action plans to achieve that goal, including: healthy eating; adequate rest; exercise; prayer; stress reduction; and infection control practices.

Some of the informants continue to engage in “unhealthy” behaviors such as excessive alcohol consumption and smoking, “I started drinking my Xanax and Ambien with liquor and brandy and Viejo [a brand of liquor] and all I found” (K2). One of the key informants (K1) just began a new phase of recovery from substance use. Each of them verbally acknowledged the effect these behaviors had on their immune systems and consequently their health and general wellness. While they did not have any immediate plans to reduce their smoking or drinking, they did speak of needing to make that change in their behaviors, indicating their belief in this change having the potential to benefit them.

Regarding illness and specifically HIV, the informants reported that their infection was due to their behaviors. Even though some of them (three key and seven general informants) did feel that their choices were limited by the deceptions of partners, “I was faithful to this man, I thought he was with me but obviously, he wasn’t” (K4), they did not connect the infection to forces outside of their control. For the two key and three general informants, whose risk behavior was injecting drug use, they acknowledged the risks of sharing injection equipment and revealed that they acquired other infections, such as cellulitis or hepatitis. One key informant (K3) referred to her time as an injecting drug user as a “big mistake,” and expressed shame because she felt that she had not lived up to her mother’s ideals for her. The informants who became infected through sexual activity with an infected partner, expressed regret over not protecting themselves and putting their trust in someone who did not deserve it. Some expressed anger,
The thought of someone having infected me was like, ‘Wow’ and then you know of course the anger that they knew, and they didn’t tell me. You know like ‘God forgive me, I hope they’re dead’ (G12).

while, others disappointment at the actions of their partners depending on whether their bringing HIV into the relationship was due to deceit or neglect.

And then when my husband had it. I took care of my husband and before he died he had...said that he was sorry. He said, ‘he didn’t mean to...’ ‘It’s okay, it’s okay, I’m fine with it’ (G4).

These informants either forgave their partners or chose to move on from those feelings and relationships through group work and/or therapy.

No informants discussed conspiracies to spread HIV among Latinos and African-Americans, though they did observe the limited availability of information about HIV and HIV prevention, specifically designed for these communities.

I took a peer educating program, a training. I took it for that, because there’s a lot of Puerto Rican women that don’t understand the virus that don’t even speak English and they need to get educated because a lot of them don’t even know about what HIV is (K1).

The informants shared their thoughts that making this information more accessible to the Latino and African-American communities would be a way to reduce stigma and get individuals to be more careful with their behaviors (i.e., using safer sex practices and not sharing injection equipment) and therefore reduce new HIV infections. In addition, there were many remarks about the need to increase services for Latinas with HIV.

Help a lot of Latina women because of the fact that the abuse they be going through in all types of ways. The support they do not get out there of HIV and AIDS. There’s a lot of rejection out there you know. Especially single mothers that got kids that have the HIV that it’s hard for them like working and hard for them to go into places, it’s hard for them to have people who understand what they going through of their health problems as well (K5).

Again, the informants thought that these services would assist those already infected with HIV to better care for themselves by participating in groups and making connections to HIV care.
providers. While community programs would assist in HIV education efforts for the public. As discussed previously some of the informants decided to be actively involved with the efforts to expand the provision of services to the Latino community by working for community-based programs.

**Stigma.** Thirteen of the informants (four key and nine general) expressed dismay over the continued stigmatization of people living with HIV. They reported feeling that enough time has passed for people to know that anyone can be at risk based on behaviors; and, that there was not something different or bad about them to put them at risk. They expressed concern that the epidemic will continue as long as the stigma does. They felt that the stigma served to perpetuate ignorance about evaluating and reducing one’s risk.

I think it’s horrible, the ignorance that even in 2014 people will still point a finger and not knowing they, themselves. And it’s funny because I honestly believe that people who judge don’t matter and those that matter don’t judge, and I think a lot of it has to do with the fear. They’re afraid to know their own status, or they know their status and they don’t want other people to know their status. And so, they continuously point the finger at the next individual (G12).

Their disappointment though was greatest when they felt stigmatized by health care providers who they saw as having no excuse for being uninformed or treating a patient in such a way.

The informants also recalled their own participation in perpetuating the stigma of HIV, when they denied their status and refused to connect themselves with HIV support resources and care for fear of identifying themselves with this disease.

Everybody was dying, and it was scary. You know, and I had to go to these places where people were gay to get treatment and I did not feel comfortable. Cause before all of this I never hung out with gay people or anything you know. Now I’m not prejudiced or anything, that’s their problem, but I’m not used to being around that. But I got used to it now (G10).

For this informant and others, these beliefs and actions led to delays in HIV care and/or continuing their drug-use activities. “When I first found out I was in denial for a long time after
that. So, for the first three years I didn’t bother going to the doctors or nothing” (K1), as this informant shared.

**Confidentiality and privacy.** The informants expressed an expectation of confidentiality in all their health-related and service-related encounters. Two key and seven general informants shared stories in which confidentiality and privacy were compromised by providers and other staff members at medical facilities and even in ASOs. One informant (G9) who was a snowball referral shared that she did not like to attend the group meetings because she had issues with her information being shared inappropriately in the past, which she felt made it her harder for her to trust the women in the group.

It is confidentiality. I wanted to talk in the group and be upfront about it with everyone. And that is fine because I want that, but not for other people to say it. I can only speak about my own story and not that of others (G9).

Informants (four key and six general) also shared stories of rumors and gossiping in the groups and workplace in ASOs, which made them feel uncomfortable. Their responses varied from reducing involvement at the location; moving to another organization; or, being more reserved in the setting.

In the healthcare setting, quite a few of the informants shared concerns about the privacy of their health information. These concerns stemmed from the behaviors of the staff and the use of technology. These informants (one key and two general) were not clear about how information was shared and who would have access to the information, fearing that their private health information would become public. One informant (G3) shared that she left a job in fear that she would be terminated because the staff from the human resources department could see the utilization of her health care plan and had made comments to her about the types of doctors she was seeing and what medications she was taking. Since then, she chose to work with HIV service organizations, where she felt there was greater understanding. The informants did expect
that their providers and staff would conduct themselves per the professional code of conduct, even though this was not always the case, as discussed previously.

The informants shared instances about violations of their privacy by personal contacts. One general informant described an incident at work after her ex-boyfriend revealed her status publicly.

They were like, they didn’t want to talk to me and ignoring me and I didn’t know what was happening and then his ex-wife, I was a new cashier, she said ‘Oh I heard you have AIDS. I gotta to go check myself?’(G10).

Other informants, three key and one general, shared similar experiences of having their HIV status announced in the streets of their neighborhoods by an ex-partner. The informants described these experiences as painful and embarrassing at the time. Even though they were not trying to hide their HIV status, they felt that it was their right to disclose.

**Communication.** All informants expected that their providers would be able to communicate effectively with patients. Informants discussed the need to understand what the provider was saying and to have the provider understand what they were saying for their well-being. Some providers were native Spanish speakers or learned to speak the language as part of their professional education. These Spanish-speaking informants expressed appreciation when their providers spoke with them directly or used an interpreter who was physically present during the visit. The importance of being able to see someone’s face and read nonverbal cues was shared by two of the Spanish-speaking key informants. One key informant reported that she greatly disliked the language line services available at her clinic for just that reason and would use her own interpreter.

I don’t like to talk on the phone. She knows that I have a caseworker and many times my caseworker comes with me to the appointment to interpret for me and that is better (K6).
An English-speaking informant discussed the importance of clear communication and comprehension when she was considering participation in a clinical trial. She shared with an attorney she was consulting on another matter, that she was considering participating in a clinical trial and was nervous about what it meant.

That lawyer showed up at my clinic. When I seen her I said, ‘What are you doing here?’ She said, ‘I’m going to talk your doctor. I’m going to address your concerns,’ (G4).

The attorney arrived without warning at the screening visit. The informant did enroll in the study with her attorney’s guidance. The provider would often refer to the attorney’s actions during follow-up visits.

**Barriers to HIV Care**

Most of the informants, four key and ten general, became engaged and retained in HIV care at the time of their diagnosis. This was more likely to occur for the informants who were diagnosed with HIV when they were living in Puerto Rico (one key and two general); diagnosed related to an illness (three general), or pregnancy (one key and one general). Informants who were actively using drugs at the time of diagnosis in NYC (one key and two general) were often lost to follow-up for a period, describing themselves as being in and out of care. Once these informants completed a drug rehabilitation program as part of the recovery journey, they could regularly attend care visits. The barriers identified by the informants included language concerns and delays in care, both non-HIV and HIV related.

**Language.** Two key and four general informants experienced difficulties communicating with their providers because they were not fully conversant in English and their providers did not speak Spanish. Even though one key informant would bring her case worker to medical visits as discussed previously, these Spanish-dominant informants received care predominantly in English. This was the case even though their preferred language was Spanish,
as per their interviews. Most did not utilize the linguistic services available to them. The key informant wanted to be able to “see someone’s face” (K6), because she could not know for sure what they meant. Even after attending a number of English classes since coming to NYC, she still felt she was unable to understand the language. Other informants reported being able to speak when necessary in English, or as one key informant (K3) stated “me defiendo” (I defend myself or I can manage). They did not report if their providers were learning Spanish.

**Delays in care.** Most informants described delays in non-HIV related care when they were referred to providers who were not comfortable providing care to people living with HIV. One informant (K2) related an incident when she needed to have minor surgery and the surgeon she was referred to at a local hospital refused to perform the procedure because of her HIV status. This resulted in a delay in the care she needed until a second surgeon could be found to perform the procedure without incident. Other diagnoses complicated HIV care by reducing the number of drugs that could be used for ART due to interactions, as well as, taking precedence over HIV care management. One key informant relayed a story of her recent relapse in which she stopped taking her ARVs, but she continued to attend appointments with her NP.

But then I relapsed and when I relapsed, and I told her. She said ‘I was just waiting for you to say something. I already knew it.’ She said ‘When you come, you’re quick to go. You would do your thing and bounce. You would even skip blood work. Now you’ve got to take bloodwork before you even see me. Because I knew you relapsed’ (K1).

During that time, she could have experienced a rebound in her viral load and a corresponding drop in her CD4 count. However, this was not the case for her. Another key informant struggled with adherence to her ARV regimen and had a viral load of over 6000 and CD4 count of less than 50. She reported that her provider was concerned but that she had a recent diagnosis of diabetes mellitus and needed insulin. It was too much for her to manage both conditions and that
she would manage “one at a time” (K4). For her, managing her diabetes was more important since she almost died from it.

Like I said especially with this virus alone I messed up lovely when it came to adherence. Call it forgetting about it or unconsciously not talking it or getting my drug holiday like they call it because I would say like ‘Fxxk it, I’m tired of taking the pills.’ Or most of the time forgetful, that’s no excuse but I been there, too. But like I said sometimes you get to the point when you’re so tired and then when the diabetes came, I said ‘Oh God, now more pills to fxxk it up more.’ Excuse my French to mess it up more because with the metformin, another bullet twice a day. I’m like okay, which one is it going to be? Are we doing the virus first or the diabetes. And when they told me officially that I was diabetic, I was not playing with the diabetes, I’m telling you. It’s scary because if you put it in the tubes I will make sure the diabetes is fine because it attacks your organs. I know that HIV does too but not like the diabetes. The last thing I want to go through is dialysis… And I don’t want to see myself in that position so when it came to diabetes I said let me control this diabetes and then I’ll go back to the virus (K4).

Caring Attributes and Actions related to HIV

Overwhelmingly, the informants described more experiences of caring actions and attributes from family and friends as well as from professional care providers and staff at clinics. The most salient episodes occurred during diagnosis, disclosure, care during crisis, and transitions in care. Because of the many times these informants experienced non-caring actions, they were very grateful when they experienced kindness from another.

That opened my eyes because you see she does care. She cared enough to stop even though she was leaving crying. She wrote this note for me. It was like ‘wow’ that was big for me (K1).

However, as their prognoses have improved, and they have lived much longer than they ever expected, they have transformed to expect caring actions and caring attributes from those they entrust with their well-being because they deserve these experiences.

When a caring action was observed or experienced regarding HIV, the informants reported being more comfortable in their interactions with these individuals and better able to fully be themselves and more open to receiving caring from them and others. For example, a
general informant made a choice to reveal her diagnosis to her son’s girlfriend preemptively.

This young woman reacted very positively as a relative of hers had died from AIDS, and she felt strongly it was due to the way she was stigmatized by others.

So, she said to me, ‘Oh you have the AIDS virus?’ and I said, ‘Yes.’ ‘Ay, my cousin died of that, but for me she died but not because of the illness but she died of sadness and depression. Because in the house when she sat down to eat, they gave her disposable plates and cups.’ So, it seems to me that this affected her a lot and I said to her, ‘But you’re not going to do that with me, right?’ And she said to me, ‘I am not going to do that’ (G7).

When this young woman gave birth to the informant’s grandchild, she called her over and handed the infant to her immediately, demonstrating her trust in the informant’s caring for the child. The openness of family to be in direct physical contact with them when HIV transmission was poorly understood was crucial for them to be confident that they would receive care when their condition warranted it. As a general informant shared, “I have always received that from them. They have never rejected me. They have always treated me with caring” (G2).

Non-caring Attributes and Actions related to HIV

Non-caring actions regarding HIV were reported by all informants. Many of these experiences were connected to the stigma associated with their HIV status. Depending upon how someone reacted to their HIV status or how they delivered care related to their HIV status, a single event could result in a non-caring experience. These experiences had been and, for some, remained challenging, forming the basis of how they interacted with others. However, at the time of the interviews, most informants had been living with HIV for many years and were first diagnosed when HIV was still considered a death sentence, and something to be greatly feared. During that period, the informants were more vulnerable when others did not demonstrate caring actions. Certain attributes were associated with professional caregivers who demonstrated non-caring actions.
When informants observed loved ones displaying non-caring reactions to someone else’s HIV status, their responses were either to continue to hide or educate and reveal their own status as a caring action. Many of the informants shared stories in which plastic plates, cups and utensils were provided to them or someone they knew with HIV infection. In another instance, an informant (K2) reported that her mother would enter the bathroom after she used it to disinfect the room, “If I went to the bathroom to pee or brush my teeth. She came after me with Clorox spray, in my house.” All the informants shared that experiences like these were hurtful to them. To reduce stigma within their families, some informants took it upon themselves to educate their family members about how hurtful these actions were, and how they were not based in science. One informant pleaded with her sister to treat her better by respecting her health needs. “’Yeah but you got to stop one thing because you’re hurting my feelings very bad,’ and I got very emotional, ‘and don’t make me never set foot in your house again’” (K5). In situations like these, the informants reported that their family members were responsive to being educated and considering their emotional needs.

**Professional Caring Attributes and Actions.**

Some informants (four key and three general) experienced compassionate caring when receiving counseling, being tested or receiving results. One key informant reported that when the doctor knew she had planned a vacation to visit her mother in Puerto Rico, he told her that there was a problem with the result and the test needed to be redone. He told her to “enjoy her visit with her mother” (K3). The informant reported that she knew that the first result was positive, but that the doctor’s action gave her a little more time before having to deal with HIV.

All the informants had reported they had very good working relationships with their care providers. Each of the informants regularly attended care visits as per the recommendations of
the CDC and Department of Health and Human Services (DHHS), and as indicated by their clinical condition. All informants received their HIV care in clinic settings, rather than in private medical offices. Although, there were changes from time to time in who cared for them (NP vs MD), the informants reported that they were receiving the best care available for them. Their confidence in this sentiment came from the relationships they developed with their HIV care providers. Most of the informants shared that nurses in general did more to care for patients than the doctors did. They reported that nurses were the ones who took the time to explain things and NPs did the same. However, the informants were more concerned about how the provider cared for them rather than what specific education or credentials they had.

When asked to describe the relationship with their providers, the informants all spoke about honesty in their interactions. The providers were up front about any problems and what they thought about it and the women were honest about what they needed. One general informant described her physician as “real” and stated that she trusted her with her life. She was my doctor, as a matter of fact I came to know her through a mother and child study, back in the beginning of the 90s and she was the doctor taking care of the women. So, Yo me encontré con ella (I found myself with her) and I mean she was awesome I mean it got to the point where I trust her with everything. I wanted to make her my health proxy. But that’s against the law. Pero que (but) yeah, really, she helped deliver my son. I mean I can talk with her about anything, anything, anything. I mean yeah you have to put up with the waiting, the this and, the that because she sees a whole lot of people, but I wouldn’t give it up (G12).

Another key informant (K3) who had been cared for exclusively by NPs reported that each of her NPs worked at the clinic for an extensive length of time before moving on or retiring. Before leaving each one said goodbye to her and gave a full report of her care to the new NP. She had not felt that there had been any gaps in her care.

If they were any issues with a provider, the informants felt that they could request a change. One of the key informants who had just switched to a new provider and she reported
that she was still getting used to her, “She’s good but we just started the relationship. I don’t want to leave the clinic because I’ve been there for 14 years” (K4), since her diagnosis. She was planning on remaining open to this new provider who she thought was doing a good job, even though she missed the relationship with her old provider. She went on to describe how her bond with her previous provider at that clinic was established.

You know I was with the doctor for 12 years. We had a bond. He even took care of my kids even though they’re not positive. He was the pediatrician, and the good news is that he left, and he can still see my boys. I can’t see him, but he can still see my boys and we see him in 2 days. So now, I just had them with the last physical at the clinic but now they can go see him and he’s still in their life. He’s a real good doctor and they’re not too many around here and to find a doctor like that and to bond, is good (K4).

She also recalled the caring way that he spoke to her children and her and fondly recalled the gifts that he arranged for her children to receive one Christmas. Per the informants, providers demonstrated caring by checking in with them in between visits, not only to give test results, but also asking them about their families and, considering their needs regarding office visits. One key informant shared an experience in which her provider needed to cancel an appointment due to a family emergency, and she left her a note apologizing attached to her prescriptions, stating she would call her the next day, which she did.

You know it’s important to me... Like the other day, I went, and she had an emergency and, but she left me an envelope. ‘She left what?’ ‘Yeah she left you an envelope.’ She said, ‘You’re the only client she does this for.’ So, she left me a note apologizing, she left me my scripts, she left me my blood work and she left me my next appointment. So, I’m like ‘Holy cxxp!’ That made me feel special (K1).

Another general informant (G10) discussed how her provider referred to a planned change in medications to give her the energy to go dancing again. Other informants focused on the honesty and patience that their providers demonstrated during their visits. By offering them attention and frankness, they felt that they were partners in their health care and not being acted upon or expected to just follow orders.
Being in a partnership in care was a key way to manage ARV adherence, which can be difficult with some regimens involving multiple pills with dosing throughout the day and side effects like lipodystrophy and nausea and vomiting. The informants reported that their providers worked very closely with them to assure that their regimens were the most effective in maintaining undetectable viral loads and keeping CD4 counts above 500 with a minimal amount of side effects and the easiest dosing. The informants reported full discussions of test results and described the efforts of their providers to assure that they understood the results. One general informant (G11) was experiencing lipodystrophy and had been very upset over the way that her body looked with visceral adipose tissue in her torso and a loss of subcutaneous adipose tissue in her cheeks. Her physician was running resistance testing to determine what regimen changes could be made. Another general informant (G4) shared that her provider was considering simplifying her regimen which she started as part of a clinical trial many years earlier. There was some reluctance on his part because the regimen had been so effective for her over the years. The one key informant (K4) with a detectable viral load had been working with her provider to manage one health condition at a time and she was reporting that with the diabetes coming under control, she was preparing to focus on the HIV. A simpler regimen was being used to help her be as adherent as possible. These examples of adherence management demonstrated the caring relationships that the informants had developed with their providers.

When necessary, informants needed to change their care providers or the location of their HIV care over the years. Only two general informants (G4, G12) remained with the same provider of care throughout their HIV care since diagnosis. Reasons for changing providers included staffing changes; changes in insurance coverage; or, changes of residence. Two key
informants (K3, K4) reported that their new providers were well-informed about them, having received detailed reports from the previous provider.

Four of the informants (one key and three general) relocated from Puerto Rico to NYC for care and services. Each informant reported satisfaction with the care they received and one (G6) shared her experience by describing the detailed efforts of the clinic staff in Puerto Rico who sent all her records and scheduled her first appointment for her in NYC.

By the grace of God that they gave me ones like that. And so, that’s how I arrived, with everything done and I had already spoken with the staff and everything was calm and when I got here, I didn’t even dare to go to the hospital. But since they already had my address and my telephone numbers, they called me. And I said, ‘No I will go tomorrow, I’m going’ (G6).

When this informant missed her appointment, the clinic staff in NYC contacted her promptly to reschedule.

The main caring attribute described and desired by the informants was compassion. This was a preferred attribute of the professionals they worked with as well as of their friends and family. Each of the informants spoke of the need for professional caregivers to be compassionate and caring to clients.

And I was like ‘Wow you do care.’ You know because doctors usually… they don’t … Listen take what you want and get paid and keep it moving. But not her (K1).

Caring was defined as being approachable:

Caring comes in different forms. In the hospital setting; being gracious; being ‘Hi, How, you doing?’ It goes a long way (G3);

and, open to discussions and negotiations about care. Compassion was evident when a provider was patient:

They meet my needs and everything; they work with me…They go step by step, baby steps (G5);

or, tough:
She’s raw. She doesn’t sugar coat it. *Yo soy cabecidura.* (I’m stubborn) (G12)

with the informants regarding their care, depending on what the situation warranted.

Another caring action of professional caregivers was providing care per standards and requirements. This included both clinical and ethical aspects of care. When describing care providers, the informants were pleased to report that they were receiving the highest level of care, in their opinion. This included an ARV regimen that controlled their viral loads and caused their CD4 counts to rebound to normal levels. One of the general informants (G1) reported being impatient with waiting for her CD4 counts to recover after being lowered because of chemotherapy treatments yet she reported that she understood the need to be on pneumocystis prophylaxis in the meantime:

I was undetectable and over 500 and radiation and especially the chemo brings them down. I’m still undetectable though, but my T-cells and I’m on Bactrim because of it. I feel like I’m going backwards (G1).

She knew that this was the standard of care for her clinical presentation. Another informant reported (G11) that she was very dissatisfied with the side effects of her ARV regimen because she had lipodystrophy. However, she was confident that her provider could find an appropriate regimen that would reduce the lipodystrophy and at the same time maintain her excellent viral load control and high CD4 count, because she has experienced resistance and mutations.

But I don’t know I just don’t want to deal with side effects again. So, we’re going to talk about in August because I said I would think about and let her know (G11).

While being able to practice within the recommendations was very important, as noted above, the informants consistently reported that a provider’s compassion and willingness to see them as partners in their care, was central to their relationship and goal to maintain their health and wellbeing.
Professional Non-Caring Attributes and Actions.

All the informants shared experiences of non-caring in their interactions with professional caregivers, both nurses and physicians. These non-caring experiences were not limited to the early years of the HIV epidemic but included more recent encounters as well. However, nurse practitioners and other providers specializing in HIV care did not demonstrate non-caring behaviors as described by the informants. The initial reaction of the informants was shock that a provider would speak or behave towards a patient in ways that revealed a lack of knowledge and compassion: two characteristics that they expected from them. Even many years after the incidents, the informants continued to be deeply hurt by these episodes and remained cautious of all interactions with providers. This caution explained the surprise that the informants expressed when they encountered a provider who was caring.

Diagnosis was a particularly difficult time for informants to experience non-caring actions from providers. A general informant (G12) reported being told she had HIV after testing during her pregnancy. The nurse who gave her the results told her, “How dare you do this!” The reaction of this nurse shocked and shamed her, causing her to seek care elsewhere. Another informant recalled being told shortly after she tested positive that she should never have children.

The doctor told me I could never have kids and all this sxxt, so I said, ‘Who the fxxk are you? How are you going to tell me that?’ And I never went back. When I got pregnant from my son. I didn’t go back either and then my son was born with it and then when he was 11 months old, it went away (G10).

The informants found comments like these to be particularly hurtful and demeaning because what they were being told made them feel that they were bad people and bad mothers. For a key informant, a provider in an emergency department violated her privacy by asking about her HIV status in the presence of her father. When she denied being positive because her father was
there, the provider then performed an HIV antibody test with her father still in the room without any pre-test counseling.

He starts doing the rapid test and he put the timer and my father’s looking at the timer and he’s looking at me and I’m like shaking, I’m sweating I start crying and I say, ‘Look stop the timer, I’m positive’ (K1).

No support was given to her or her father after the disclosure and it took some time before the father could control his emotions.

Some informants reported that the rotations of medical students and interns through the infectious disease clinics led to non-caring experiences, causing them to leave a practice. One general informant reported being tired of telling her whole history to yet another medical resident or intern and after being seen by another physician she left that clinic, never to return.

And it was kind of hard because I was going from one doctor to another and I was explaining. And after a while it gets tedious explaining. I’m not saying now, but you go to a different doctor and even though they have your medical record you know they… especially a new doctor, you have to explain and I’m like ‘why are you asking?’ They want to make sure that you know but the last one…she was uncompassionate, so I left (G1).

Non-HIV care providers were more likely to demonstrate non-caring actions towards the informants. These actions either occurred directly in the informant’s presence or when the informant was believed to be unable to hear the comments. There were inappropriate comments regarding the informant’s HIV status, and not providing appropriate care, such as, standing at an excessive distance when examining someone’s mouth or refusing to perform a procedure.

I went to get a colonoscopy one time and I think the nurse thought that I was fully under. And she told the other nurse that was there ‘Oh put the mask on and stuff because she’s HIV+.’ And as I heard that, and I started to comment but then the nurse commented for me. She said, ‘You’re being very discriminating. You’re lucky she’s under and I know how to take universal precautions, so in case you didn’t know because that’s one of the things that they teach us’ (G4).

I had a doctor tell me I had a lipoma and he said, ‘Yeah you need surgery, but I can’t perform surgery on you.’ And I said, ‘Why not?’ and He said, ‘Because you’re HIV
positive.’ And I said, ‘Excuse me?’ And he said, ‘I have interns, and should they have an accident, I’m not going to risk my interns’ life and have them get infected’ (K2).

More important to these informants than their hurt feelings, was the violation of the standards of care that they expected to receive. These informants were upset that these health care providers who were supposed to be educated in the care of people living with HIV and general infection control practices were providing a different and lower quality standard of care to them because of their HIV status.

When informants encountered professional care providers who exhibited non-caring attributes, they were described as “not compassionate” (G1) and they made assumptions about the informants. Providers who were not compassionate and did not pay attention to personal details or important factors in their lives, like children, even if their care met requirements and standards, would prompt the informants to leave that care setting and not return as reported by two key and seven general informants. One informant (G1) stated that she would not confront a provider but that she just would not go back, and she provided an example of when she did that in the past.

Because I’ve seen doctors when I wasn’t comfortable, and I never saw them again. I won’t say I don’t like you, I just won’t come back. Because I don’t want to insult that person’s education, profession (G1).

When informants discussed the assumptions made by providers, two key and three general informants used words like discrimination, or prejudice. They relayed stories of the assumptions being made about them and how they acquired HIV and what that said about who they were as individuals. The informants reported that these experiences including being told how they should live their lives, e.g. not having children while having HIV (G10); and whether they are contagious. One general informant shared a particularly painful experience.

When I was having my daughter and I was in the delivery room. A nurse came in and said, ‘how dare you?’ This was in XX Hospital. ‘Knowing what you got, how dare you?’
You know I’m in labor to deliver for 13 hours and you know that’s still with me. What she did and she’s a health care provider. What she did has scarred me for the rest of my life (G3).

**Living with HIV through caring**

For some informants (three key and eight general), the reality of needing to change their lives to survive and “be there” for their children and other family members was immediate. These informants entered care upon diagnosis and reported a strong support network in their adult children. For the other three key and four general informants, the transition to living with HIV was difficult. After an intense period in which they thought they would die, they were eventually able to shift to caring for themselves, which included rehabilitation from drug use, and starting HIV care. For all but one key informant, their HIV care became a primary focus of their self-care. This included changes to diet, activity and rest, mental health and spiritual health, in addition to taking ARV medications regularly, attending provider appointments and engaging in wellness activities. The one key informant who had not put her HIV care first, had other health conditions, which were a greater threat to her health and she opted “to do diabetes first, and then HIV” (K4).

For all the informants, living well with HIV, was not something that they did just for themselves but rather something that they were meant to do for others. They shared a firm belief that they were meant to be survivors, to be role models and to help others learn how to protect themselves from HIV.

You know I didn’t ask for this. It was brought to me. It was given to me. But I gotta use it as a blessing. In the beginning, it was a denial to me but it’s a part of my life. And today I…. it saved my life. So, I like to take it and help somebody else with it because I know what I went through and that I could have did damage to myself if I had waited any longer to start treatment (K1).

They did this by becoming active in their communities as either members of groups and helping others; becoming peer counselors and being willing to speak to anyone anywhere (on the street,
in the subway) about HIV prevention and testing; working for ASOs doing extended outreach activities, policy development and running support groups. On a more intimate level, the informants took it upon themselves to educate family members: parents, siblings, children, grandchildren and great-grandchildren, of the need to practice safer sex and protect themselves from HIV infection.

I have a nephew and he lives in Florida and he was messing with a lot of girls and my sister was scared. So, I said, ‘Listen boy, do you know what HIV is?’ and he said, ‘Yeah’, and I said, ‘How do you know the difference?’ and I had to laugh, and he said, ‘Titi (Auntie), when they got a whole bunch of bumps on their butt, then they have HIV.’ So, I said ‘Really, then you have to come to New York and tell me if I have a whole bunch of bumps on my butt, because I’m HIV+.’ (G4).

They also educated their family members on how to protect themselves from HIV in the home safely when cleaning and cooking, without perpetuating stigma.

My mother raised my cousin and my cousin was an addict and she, when she found out about HIV and my cousin would come to the house, ella separaba los platos (she separated the plates); and when I sat down with her to tell her I told her, ‘Y no quiero que tú me haga lo que tú hiciste a él, porque esta es mi situación’ (‘I don’t want you to do to me what you did to him, because this is my situation’) and she stood quiet. And she did that not knowing the only way you can get this, and I had to educate her, and I asked her to get tested. And she did (G3).

They identified these actions in which they exposed their diagnosis as their duty to correct misinformation in their loved ones and teach them the appropriate way to protect themselves and others. The informants stated they believed it was “God’s will” that they were still alive and able to be independent. They each stated they had a purpose they needed to fulfill.

All the informants shared that their ideas regarding caring changed once they knew they had HIV. This included becoming more accepting of caring from others, even though this was often difficult for them. They were also more willing to proactively care for themselves, in addition to taking their medications regularly. They also shared that they were more willing to demonstrate caring towards others, as described above.
Self-care. All informants engaged in several self-care practices with the purpose of regaining and/or maintaining their health. These practices included protecting themselves from infections; practicing safer sex; protecting themselves emotionally; reducing stressors to enhance their mental and physical health; changing their diets; and, maintaining their recovery from drug and alcohol abuse, “After this last relapse I learned. I learned a lot like I can’t stress over nothing. I can’t. Because stress will take me back out there” (K1). These activities were reported by the informants as essential for their health. They described a deep understanding of their power to control their health journey, knowing that HIV would accompany them throughout their lives, but they would decide if HIV or they would take the lead. As one informant revealed,

I have a companion with me that will be with me for the rest of my life. I have to accept it. I have to know it...I have to do my part if I want to live. I have to take care of myself, take my medicine. As I do it, my medicine works. I don’t drink, I don’t smoke, I don’t use drugs, I don’t have random partners. I take a lot of care of myself. You know, because before I didn’t take good care of myself but now I do. I am not slacking off. (G2)

Nutrition. The informants all reported changes to their diets since becoming HIV positive. These changes reflected an understanding of the effects of the ARVs and HIV on cardiac health and the risk for the development of diabetes and other end stage organ diseases (kidney or liver). Some of the informants admitted that their diets were “not good” in the past but improved. The informants recounted that most of the foods they grew up eating were often fried and high in carbohydrates. While many of the informants reported that these types of foods were favorites in their youth, they needed to reduce their intake of these foods to prevent the development of complications while managing their HIV disease. The informants discussed these foods now as treats that they would permit themselves for celebrations or holidays.

Nearly half of the informants (four key and three general) had weight issues in the past and a few were still overweight (two key and one general), while another key informant was
obese. No BMIs were measured. They discussed their struggles with their weight in the past. Two key informants had gastric bypass surgery to treat their obesity. They now reported eating smaller more frequent meals, which they also found helpful with managing medication regimens. The obese informant was trying to lose weight, so she could qualify for gastric bypass surgery. When discussing ways to maintain health, each informant listed healthy eating first among their actions to stay well.

Dietary changes included reducing the intake of red meat, pork, and/or fried meats; increasing the intake of fruits and vegetables and water. Informants were eating smaller and more frequent meals, to better regulate blood sugars and accommodate medication schedules.

I can’t give myself the treats that I used to before. Now that I have diabetes and HIV. Well the diabetes, you have to control with portions of everything that you eat, and you have to eat more vegetables and natural things (G2).

They were also reducing their consumption of refined sugars, and white bread, rice and potatoes, in favor of brown rice and other whole grain foods. One informant’s dietary changes were specific to reducing her migraines (K5) and another, her allergies (G10).

**Personal care.** Each informant discussed her self-care practices, especially hygiene. They all shared that they preferred to perform their own bathing and cleaning of their bathrooms.

I clean my bathroom, and keep it as clean as I can, and I always have soap in the kitchen, soap in the bathroom and every time I wash my hands (G7).

A few expressed being nervous when someone needed to clean a bathroom after their use and explained how they taught them to use chlorine-based products to assure disinfection of the area. One key informant (K5) described how she felt she was very dirty after discovering her HIV infection and she showered often, up to four times daily at the time. She had since returned to her usual routine, which included showering twice daily during the summer months.
The researcher observed that each informant was well dressed and groomed for the interview meetings. Each woman’s hair was well combed and when removing a hat, they spent time checking their hair. Their clothing reflected their own personal style. Some informants dressed practically in pants, simple tops and comfortable shoes. The five general informants who worked in an office setting had a more professional casual style to their outfits. The three key and five general informants who were coming from a group meeting were dressed more casually. It was apparent that each of the women paid great attention to their appearance. Some informants remained concerned with how they looked, especially if they had a physical concern, (e.g. excess skin after significant weight loss). These informants initiated discussions about their appearance and reported they dressed to camouflage those areas, because presenting their best look was important.

**Safer sex practices.** All the informants had sexual relationships since discovering their HIV status. Each informant described the use of barrier protection for sexual activities. Included practices were the use of condoms, dental dams for oral sex and female condoms. They also reported the use of birth control methods to reduce the chance of pregnancy while still menstruating, such as, oral contraceptives, as well as intrauterine devices and tubal ligations. Quite a few of the informants, three key and six general, had partners who were also HIV positive. These women shared the importance of continuing to use barrier protection because of the risk of other sexually transmitted infections or reinfections with HIV. All the informants were very knowledgeable about up-to-date information about the benefits of an undetectable viral load for reducing the risk of HIV transmission. They reported using that information as a strategy for negotiating sexual activity, if their partners were not as adherent with their medication regimens.
Some of the informants (five of the key and eight of the general) revealed that some of their partners were reluctant to use condoms from time-to-time.

Then my husband and I had stopped having sexual relations without condoms, then I didn’t even want to have sex with him because sometimes he didn’t want to put one on and I, ‘No, you have to put one on if you want us to have sex, because I have faith in you’ (G7).

These situations were very stressful for the informants and they often enlisted the assistance of their providers in explaining the seriousness of not using condoms during sexual activity. The informants were particularly distressed when the partner was HIV negative. The informants were very concerned about transmitting the virus to someone else. Each one was proud to say that they had not knowingly transmitted the virus to anyone, especially loved ones and their children.

Three key and two general informants continued to be very connected to their sexuality and discussed this at length during the interviews. These discussions also highlighted the complexities of their relationships, as the informants (K4) shared their struggles with disclosure and trust with partners. “At the end of the day all positive women and all people are just scared of that rejection” (K4). These discussions occurred more often with the younger informants (less than 50 years), while many of the older informants (two key and six general) shared that they were no longer interested in sexual relationships. The effort in negotiating new physical relationships did not seem worth it or necessary, “I don’t want to complicate life anymore” (G9), but they were looking for companionship, “I’m concentrating on healing and just looking for a companion” (G1). Overall, personal relationships, especially with family members, were given more value than sexual ones, by these informants.

Every action was about protecting themselves. Safer sex practices, “Well, by not having a partner, I am protecting myself” (G6); and avoiding people who were ill, “Wash my hands a
lot. If people are coughing, I try not to be around them because I get sick easy” (G10) served to reduce stressors on their immune systems from outside. Whereas eating well, exercise and reducing stress by avoiding stressful situations and praying could build-up their immune systems from within. Emotional protection was different for each of the informants and more about honoring all the personal work they did to survive drug and alcohol abuse, physical, emotional and sexual abuse and HIV.

**Disclosure as self-care and protection.** The informants who disclosed their HIV status reported they initially did not want to share their diagnosis with anyone because they did not want to believe it and hoped there had been some sort of mistake. They had difficulty when they were ready to share their HIV status because of a fear of rejection. Informants reported that they often were forced into situations where they had to disclose because they were becoming ill, were hospitalized; or, needed to explain the many medications they were taking.

Even though none of these informants reported being rejected for their HIV status by a loved one nor demonstrating rejection when they discovered a loved one’s diagnosis, some informants remained fearful. One key and four general informants had not told certain family members. Another key informant told none of her family members about her HIV status because she would then need to reveal her risk behavior (injecting drug use).

I didn’t want my mother to know that I was using drugs here and she never knew that I came out positive. Once, twice, three times I was at the point of telling her I was positive, but I couldn’t do it (K3).

A few of the general informants, all of whom came to the US as adults, had not told their adult children still living in Puerto Rico, to not disturb their lives, “I see them there so nice and full of life and happy with their lives, that I say, ‘Why would I ruin the lives of my children?’” (G6).
Another informant shared that her fear of experiencing rejection from her children because of a lack of knowledge, kept her from disclosing her status to them.

I asked them to respect what is mine. I will tell them when the day comes that I can, and I could say it but in Puerto Rico, they have nothing, they don’t have the training nor the awareness of all that we have here against the illness. So, you know, I am afraid of being rejected by them. Now you know why I want things that way, that’s why (G2).

Disclosure was also an issue when an informant was starting a new relationship. A key informant reported that she was working on addressing her hesitancy to bring her HIV status into a new relationship because of her continued fear of rejection. She recounted a recent exchange with her therapist:

‘Does he know yet?’ ‘No, I’m not there yet.’ ‘He has the right to know.’ ‘He has the right to know when I’m ready to tell him.’ And I’m not going to lie, she said, ‘Well what about the day you have sex?’ I said, ‘When the time comes maybe I’ll disclose, maybe I’ll tell him to put a condom on.’ Wow, is this the time to tell? Is this the best time? What is right?’ At the end of the day all positive women and all people are just scared of that rejection, you know and I’m like he’s going to slap me down or insult me (K4).

The relationship ended without her disclosing her status. In instances like these, there were no plans to reveal one’s HIV status any time soon.

**Care from others and care for others.** The informants shared some of their ideas regarding the care they receive from others. “Overcare,” “caring from a distance” and “tough love” were terms that the informants used to describe their interactions with loved ones.

“Overcare” described the excessive attention paid to an informant’s HIV status, specifically her numbers, viral load and CD4 counts. Three key and six general informants restricted how often family members could ask about their numbers because in their opinion these numbers did not express everything about them, “I got HIV and she’s going to remind me every day. No, let’s talk about something else” (K2). “Caring from a distance” explained a strategy that informants used to keep those, they love and care for and are the source of stress for them, outside of their immediate circle until they could remedy the situation.
I’m not going to keep on stressing over it because I’m the one that hurts. Because she just sits back and smiles about it, you know. So, you know what, if I’ve got to love you from a distance then that’s what I gotta do (K1).

The two key and four general informants were still aware of the wellbeing of these loved ones but did so without direct involvement. As difficult as this was for them, especially when it was a child or someone in great need but unwilling to do the work, they found it necessary and resolved to stand firm for everyone’s benefit. This was like the “tough love” actions when one key and one general informant asked a child to leave the home, “My stress level has been down a little, and I do miss him, but he was fxxxxing up my mind,” (K2), because destructive behaviors were impeding the informants’ protective self-care efforts.

All the informants described in detail the need to be their own caretakers. Many of them acknowledged that they had not cared for themselves in the past by getting involved in drug use (three key and six general informants), or misplacing trust in their partners (three key and five general informants), “It happened to me when I fell in love with this one person when I was 23 and that person was the worst thing for me, changed me and turned my world upside down” (G11), but now with HIV they had to care for themselves. One general informant referred to the day that she received her HIV test results as a “birthday” or “anniversary” for her. A day to be celebrated because of how it changed her life, “It’s like a birthday of having life” (G12). Honoring that new life meant living differently now for their health and wellbeing through dietary changes; exercise; smoking cessation; substance/alcohol abuse recovery; safer sex practices; medication adherence; engagement in health and mental health care; stress reduction behaviors; prayer, etc. While they may have engaged in some of these practices before they knew of their HIV status, their value became imperative afterwards. Being adherent to their care plans, meant seeing each day as a new opportunity to be healthy.
Tomorrow’s not promised to us. I could be here today and gone tomorrow, so and I try to make the best of my life now even with the virus. Even with the stigma sometimes (G3).

**Patterns and Themes**

An in-depth analysis of the findings presented above revealed sixteen patterns and six major themes presented in Table 4.4.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Patterns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal Theme I</td>
<td>Patterns within Universal Theme I</td>
</tr>
<tr>
<td>For Puerto Rican women living with HIV, the diagnosis is life changing and empowering</td>
<td>1. For Puerto Rican women, an HIV diagnosis lead to a change in worldview</td>
</tr>
<tr>
<td></td>
<td>2. For Puerto Rican women, an HIV diagnosis gave rise to empowering lifeways</td>
</tr>
<tr>
<td>Universal Theme II</td>
<td>Patterns within Universal Theme II</td>
</tr>
<tr>
<td>Puerto Rican women living with HIV experience a myriad range of emotions</td>
<td>1. Puerto Rican women living with HIV experience several fears</td>
</tr>
<tr>
<td></td>
<td>2. Puerto Rican women living with HIV move through various expressions of grief</td>
</tr>
<tr>
<td>Universal Theme III</td>
<td>Patterns within Universal Theme III</td>
</tr>
<tr>
<td>Puerto Rican women living with HIV value care and caring practices directed towards self and others</td>
<td>1. Puerto Rican women living with HIV desire and engage in self-care practices</td>
</tr>
<tr>
<td></td>
<td>2. Puerto Rican women living with HIV desire and exhibit caring practices for others</td>
</tr>
<tr>
<td>Universal Theme IV</td>
<td>Patterns within Universal Theme IV</td>
</tr>
<tr>
<td>Caring expressions and practices of Puerto Rican women living with HIV are deeply influenced by kinship, social and cultural factors</td>
<td>1. Puerto Rican women living with HIV view family members and significant others as motivational forces and sources of strength for self-care and care for others.</td>
</tr>
<tr>
<td></td>
<td>2. For Puerto Rican women living with HIV, mothers are role models for caring and caregiving practices and fathers and sons are emerging as protectors, advocates and caregivers.</td>
</tr>
<tr>
<td></td>
<td>3. Puerto Rican women living with HIV value family unity and reciprocity of care (<em>familismo</em>), through caregiving; and, emotional, financial, residential, and educational supports.</td>
</tr>
<tr>
<td></td>
<td>4. Puerto Rican women living with HIV foster caring for others as an expression of <em>personalismo.</em></td>
</tr>
<tr>
<td>Universal Theme V</td>
<td>Patterns within Universal Theme V</td>
</tr>
<tr>
<td>Spiritual and religious factors play a significant role in the care of Puerto Rican women living with HIV</td>
<td>1. The worldview of Puerto Rican women living with HIV embeds a variety of spiritual and religious beliefs.</td>
</tr>
<tr>
<td></td>
<td>2. Puerto Rican women living with HIV rely on diverse spiritual and religious practices to maintain health and prevent illness.</td>
</tr>
<tr>
<td></td>
<td>3. Puerto Rican women living with HIV use spiritual and religious practices to protect themselves and others from harm.</td>
</tr>
</tbody>
</table>
Puerto Rican women living with HIV reported differences and similarities in professional care in NYC and Puerto Rico.

Patterns within Diverse Theme I

1. Puerto Rican women living with HIV identified language, educational, economic and political factors as barriers to receiving and/or understanding professional care.
2. Puerto Rican women living with HIV identified caring and non-caring attributes and actions of professional care providers in NYC and Puerto Rico.
3. Puerto Rican women living with HIV reported diversities in desires for integrative care that accommodates generic/folk care practices.

These patterns and themes will be discussed in more detail in the analysis of the findings in the following chapter.

**Chapter Summary**

This chapter presented the findings of this ethnonursing study. Beginning with a brief explanation of the location of the interviews and how the informants were encountered, the demographics of the key and general informants were described, and differentiation was noted along the following lines: key and general informants; ACT-2 and snowball referrals; informants born in Puerto Rico and NYC; and English and Spanish speakers. The categories of the findings were identified, and the supporting data were presented. Finally, the themes and patterns that emanated from the findings were listed.
Chapter V
Discussion

Chapter Introduction

This chapter will provide an analysis of the findings of this ethnonursing study exploring the cultural needs of Puerto Rican women receiving HIV care from nurse practitioners (NPs) and other health care providers in New York City, using the ethnonursing research method (ERM). A brief introduction of the purpose and goal of the study and the rationale for the chosen method will be introduced and followed by a presentation of the themes and supporting patterns of the findings in Table 5.1. Then, for each theme, the patterns will be discussed and supporting data from the findings provided. The themes and patterns will be examined further in relation to the literature review first presented in Chapter Two. In accordance with the Culture Care Theory (CCT) (Leininger, 2006; McFarland & Wehbe-Alamah, 2015), recommendations will be made for the culture care decision and action modes for the care of Puerto Rican women receiving HIV care from NPs and other healthcare providers. In addition, specific recommendations will be presented for the use of the Culture Care decision and action modes in HIV care practice known as the HIV continuum of care (CDC, July 2017). Recommendations based on the implications of the analysis of the findings for this ethnonursing study will be made for theory, research, practice, education, administration and policy. The limitations and strengths of this study will be discussed. Finally, some closing thoughts on the study will be shared.

Summary Review and Key Findings of the Study

By identifying gaps in the HIV care of Latinos in the US, the researcher has explored this domain of inquiry for many years as a nurse in direct care, through health education projects and through the development of certification standards for nurses and advanced practice nurses.
Understanding the disparities in HIV/AIDS in the Latino community; the differences among the individual Latino cultures; and, the tendency of researchers to group racial and ethnic peoples when conducting research, this researcher sought a method that would specifically explore perspectives of cultural groups. Using the CCT and the ERM, this researcher chose to focus on a community that at the beginning of the AIDS epidemic over 35 years ago experienced distinct health disparities resulting in increased exposure to and infection with HIV. Puerto Rican women living in New York City (NYC) experienced higher rates of HIV infection, AIDS and HIV transmission to their infants than other Latinas (Selik, Castro, Pappaioanou & Buehler, 1989). According to the CCT, understanding the culture care needs of a community can assist health care providers to deliver care that is desired by the members of the cultural group. The way to explore this domain is by using the ERM, which was specifically developed by Leininger (2006; Wehbe-Alamah & McFarland, 2015b) to discover, describe and interpret the culture care values, beliefs, expressions and needs of the people by focusing on the emic (insider) perspectives of the culture of interest, in this case: Puerto Rican women living with HIV in NYC. In addition, this researcher was familiar with the delivery of HIV care by nurse practitioners, and other health care providers, and the professional make-up of the care team, including nurses, social workers, mental health care providers, nutritionists, etc., in the clinic setting. The research questions that guided this study were developed using the CCT and ERM and further delineated the areas of data required to develop a holistic view of influences on care and wellbeing for Puerto Rican women living with HIV in NYC.

Six key and twelve general informants participated in this ethnonursing study after consenting to be interviewed by this researcher in an office space of a local AIDS service organization (ASO) where many of them received services. While six of the informants were
initially identified as key informants and were to be interviewed a second time because they received their HIV care from nurse practitioners at the time of the interviews, there were three additional informants whose knowledge of the domain of inquiry was substantial. Consequently, they were also interviewed a second time for a total of nine informants interviewed twice to confirm initial findings from the first interview and provide opportunities to further clarify comments; add new information or thoughts on the study. Half of the informants were interviewed in Spanish by the bilingual researcher. Demographic findings of interest regarding these informants, at the time of the interviews, were: (a.) they had been living with an HIV diagnosis for a minimum of 15 years; (b.) they were all actively retained in HIV care, meaning they attended provider visits at the recommended frequency for their diagnoses; and, (c.) except for one informant, all reported adherence to their medication regimen and had undetectable viral loads.

The patterns discovered through the findings revolved around five universal themes and one diverse theme which highlighted the similarities and differences among the informants. The universal themes revealed the impact of HIV on the lives of Puerto Rican women, the experiences of caring, and the factors (kinship, social and cultural factors, spirituality and religion) influencing those experiences. The diverse theme described the varied experiences of professional care from the providers they encountered while living with HIV, in NYC and in Puerto Rico. Table 5.1 outlines the universal and diverse themes and patterns discovered and applicable to this ethnonursing study’s first four research questions.
Table 5.1
Universal and Diverse Themes and Patterns for Puerto Rican Women Living with HIV in NYC

<table>
<thead>
<tr>
<th>Theme</th>
<th>Patterns within Universal Theme I</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal Theme I</td>
<td>1. For Puerto Rican women, an HIV diagnosis led to a change in worldview</td>
</tr>
<tr>
<td>For Puerto Rican women living with HIV, the</td>
<td>2. For Puerto Rican women, an HIV diagnosis gave rise to empowering lifeways</td>
</tr>
<tr>
<td>diagnosis is life changing and empowering</td>
<td></td>
</tr>
</tbody>
</table>

| Universal Theme II                              | Patterns within Universal Theme II                                     |
| Puerto Rican women living with HIV experience a | 1. Puerto Rican women living with HIV experience several fears        |
| myriad range of emotions                        | 2. Puerto Rican women living with HIV move through various            |
|                                                | expressions of grief                                                  |

| Universal Theme III                             | Patterns within Universal Theme III                                   |
| Puerto Rican women living with HIV value care   | 1. Puerto Rican women living with HIV desire and engage in            |
| and caring practices directed towards self and   | self-care practices                                                   |
| others                                         | 2. Puerto Rican women living with HIV desire and exhibit caring       |
|                                                | practices for others                                                 |

| Universal Theme IV                              | Patterns within Universal Theme IV                                   |
| Caring expressions and practices of Puerto Rican| 1. Puerto Rican women living with HIV view family members             |
| women living with HIV are deeply influenced by   | and significant others as motivational forces and sources of        |
| kinship, social and cultural factors             | strength for self-care and care for others.                         |
|                                                | 2. For Puerto Rican women living with HIV, mothers are role          |
|                                                | models for caring and caregiving practices and fathers and sons      |
|                                                | are emerging as protectors, advocates and caregivers.                |
|                                                | 3. Puerto Rican women living with HIV value family unity and         |
|                                                | reciprocity of care (familismo), through caregiving; and,            |
|                                                | emotional, financial, residential, and educational support.          |
|                                                | 4. Puerto Rican women living with HIV foster caring for others as    |
|                                                | an expression of personalismo.                                      |

| Universal Theme V                               | Patterns within Universal Theme V                                   |
| Spiritual and religious factors play a significant | 1. The worldview of Puerto Rican women living with HIV               |
| role in the care of Puerto Rican women living with | embeds a variety of spiritual and religious beliefs.                  |
| HIV                                             | 2. Puerto Rican women living with HIV rely on diverse spiritual      |
|                                                | and religious practices to maintain health and prevent illness.      |
|                                                | 3. Puerto Rican women living with HIV use spiritual and religious    |
|                                                | practices to protect themselves and others from harm.                |

| Diverse Theme I                                 | Patterns within Diverse Theme I                                     |
| Puerto Rican women living with HIV reported     | 1. Puerto Rican women living with HIV identified language,           |
| differences and similarities in professional    | educational, economic and political factors as barriers to           |
| care in NYC and Puerto Rico.                    | receiving and/or understanding professional care in NYC and Puerto   |
|                                                | Rico.                                                                 |
|                                                | 2. Puerto Rican women living with HIV identified caring and          |
|                                                | non-caring attributes and actions of professional care providers in  |
|                                                | NYC and Puerto Rico.                                                |
3. Puerto Rican women living with HIV reported diversities in desires for integrative care that accommodates generic/folk care practices.

Universal Theme I: For Puerto Rican women living with HIV, the diagnosis is life changing and empowering.

The first universal theme emerging from the findings of this ethnonursing study was *for Puerto Rican women living with HIV, the diagnosis is life changing and empowering*. Two patterns supported this first theme: *for Puerto Rican women, an HIV diagnosis led to a change in worldview; and, for Puerto Rican women, an HIV diagnosis gave rise to empowering lifeways.*

The changing of a life and worldview is not an event but rather a process that must be examined through a lens that looks backward and then forward. The informants wanted this process to be understood by the researcher, therefore, they shared their pasts, their presents and their hopes for the future. They reported the behaviors, relationships with loved ones, and self-care practices that put them at risk for HIV infection. They recounted the events that led them to be tested for HIV infection and how they were informed of the diagnosis. They described their reactions to that diagnosis and their feelings in the immediate aftermath. Each informant’s journey was different from diagnosis until the time of the interview, and yet for each one, it resulted in a transformation of perceptions of identity and the power to confront a deadly illness.

In describing this impetus for the first pattern, *for Puerto Rican women, an HIV diagnosis led to a change in worldview*, informants repeatedly used terms like, rebirth, change, birthday and starting new. Receiving an HIV diagnosis was a turning point for these women, a realization that their previous lifeways were not sustainable. Their behaviors had exposed them to, at that time, a fatal illness, in addition, to the other problems with work, finances, education, housing, and family. Most women received their diagnosis at a time when there were few approved and
effective treatments widely available. The following quote supports this pattern by presenting the distinct contrast between expectations at the time of diagnosis and at the time of the interviews:

All the people were dying, all the people. Nowadays, we have a whole bunch of medications as my doctor says you can be reborn and who knows what you can do with your life when at one time HIV gave you death (K3).

In the earlier years of the HIV epidemic the receipt of a diagnosis predominantly brought negative consequences. There were losses of friendships, family and abilities, due to stigma, isolation, physical infirmity and death. Yet as a rebirth, an HIV diagnosis became a reason to celebrate because, it provided the impetus to change one’s life for the better. One informant equated her diagnosis to a “birthday” (G12), in acknowledgment of this start of her new life. It began a journey to wellness that returned her to her family and enabled her to be the mother and grandmother she wanted to be. Not all the informants experienced this transformation on the day of their diagnosis. For others, the transformation would occur later in conjunction with other major life events, such as recovery from substance use. In these instances, the HIV diagnosis directed them to the path of this new worldview. They were not ready to embrace this new worldview at the time because their substance use was still in the way. Only when they were in recovery (Duncan, et al, 2014) could this new worldview and all the associated changes, and empowering lifeways, be fully embraced.

The second pattern of this first theme, for Puerto Rican women, an HIV diagnosis gave rise to empowering lifeways, flows from the first in that if these women did not feel as though they were reborn, they would not have been able to activate empowering lifeways to support their new lives. The empowering lifeways were demonstrated through their self-care practices and taking responsibility for their previous behaviors. They acknowledged the harmful
behaviors that put them at risk for HIV exposure and accepted responsibility for their wellbeing: past, present and future, realizing that creating healthy environments for themselves required self-reliance and survival skills. This was a significant change for the informants, as one general informant shared specifically about her past drug use,

> Remember we’re talking about some 20+ years back and it was hard to come to terms with myself. I didn’t see it as a punishment and you know I take the blame. I made those choices (G3).

By understanding their own roles in the behaviors that put them at risk, they chose to engage in new behaviors or empowering lifeways that would counteract the effects of the virus on their bodies.

The specifics of the activities that the informants for this study used to create healthful environments for themselves varied to meet their individual needs, yet essentially, they achieved similar outcomes because each took control of their environment. As one key informant shared, “I was raised that we gotta be strong and we’re the ones that’s supposed to be. We don’t got time to be sick” (K2). This control was present whether the informants lived alone or with family members. When asked in the interviews, “Who makes the decisions in your family?” each informant stated without hesitation that she made the decisions that controlled her life and her interactions with others. A strong sense of pride accompanied that statement each time and occasionally some informants expressed bewilderment at being asked the question. Their questioning facial expressions implied to the researcher, that there really could not be any other possible answer. However, it is likely that the informants were exhibiting pride that they were now in control and responsible for their wellbeing as opposed to their situations in the past. This pride was also displayed in the way each informant dressed, in her best clothing appropriate for the weather, demonstrating her style and comfort in who she was, a Puerto Rican woman living
with HIV. The researcher was often reminded of the phrase, “You have to dress the part…,” when meeting the informants for the first time and this physical presentation was an empowering lifeway that set the stage for positivity in each interview.

The environmental context of their lives included their experiences of family, kinship patterns, care and self-care patterns and now, HIV infection. Recognizing this became key to their new worldview, as described above. The concept of HIV being a transformational life experience is not a new discovery. Many examples exist of studies where people living with HIV discuss the major transition that was initiated with the receipt of the diagnosis (DeSantis, et al, 2013) and how the passage of time allowed them to change the perception of death to a perception of life and hope (Buscher, et al, 2015; DeSantis, et al, 2013). While some describe it positively, bringing welcome changes in family roles, as reported by MacNeil (1994 & 1996); others like Levya-Moral, et al (2015) described the many losses that can be experienced following a diagnosis of HIV, especially independence and a sense of control over one’s life. Most of this study’s informants had a similar perspective of HIV after their initial diagnosis, yet after living with HIV for a minimum of 15 years at the time of the interviews, they had survived long enough to see the changes in the management of the disease, and the results of their empowering lifeways, leading to better prognoses for them. This could account for the more positive outlook on the life-altering nature of an HIV diagnosis (DeSantis, et al, 2013) at the time of the interviews. This finding was similar to the findings of a mixed methods study of long-term survivors of HIV disease where the women who were also living with HIV for more than 15 years demonstrated better scores on wellbeing and self-management than women who had been living with HIV for a shorter time (Webel, et al, 2016).
Universal Theme II: Puerto Rican women living with HIV experience a myriad range of emotions.

The second universal theme emerging from the findings was Puerto Rican women living with HIV experience a myriad range of emotions became apparent through the stories that the informants shared with the researcher. The patterns supporting this theme were *Puerto Rican women living with HIV experience several fears*; and, *Puerto Rican women living with HIV move through various expressions of grief*. The informants were very open with their feelings and this researcher was personally moved by each palpable expression of emotion, at times crying with them. However, to preserve objectivity, after these interviews, as time permitted, notations about the exchange’s effect on the researcher were made in her journal before leaving the site. This was in addition to the usual notes on observations of the informants during the interview and one to two major topics discussed. Later, during transcription, further notations about any emotional pauses in the interview or nonverbal communications were made for the transcript. The researcher reflected upon these notes while analyzing and writing the findings.

The first pattern for this universal theme focused on *Puerto Rican women living with HIV experience several fears*. Table 5.2 provides a listing of some of the fears that were more frequently shared by informants during their interviews.

**Table 5.2**

Examples of fears of Puerto Rican women living with HIV in NYC

<table>
<thead>
<tr>
<th>Fear</th>
<th>Example from Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dying</td>
<td>I was afraid of dying alone. (G2)</td>
</tr>
<tr>
<td>Disappointing loved ones upon discovery of risk for HIV</td>
<td>When one person starts to talk about oneself then you see. I didn’t come out about it. I didn’t want my mother to know that I was using drugs here and she never knew that I came out positive. Once, twice,</td>
</tr>
</tbody>
</table>
three times I was at the point of telling her I was positive, but I couldn’t do it. (K3)

<table>
<thead>
<tr>
<th>Disclosure of HIV status</th>
<th>At the end of the day all positive women and all people are just scared of that rejection, you know and I’m like he’s going to slap me down or insult me or want to get out and if he tells me to get out. (K4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leaving their children</td>
<td>I want to leave them as adults. I don’t want to leave them as minors, not in nobody’s house bothering no body and them having pity for them or living off of them because they can get a check. (K4)</td>
</tr>
<tr>
<td>Separation from loved ones</td>
<td>‘I could never do that I would get disowned. My family would take my kids away.’ (K1 discussing another woman’s fears)</td>
</tr>
<tr>
<td>Transmitting HIV to a loved one</td>
<td>Then my husband and I had stopped having sexual relations without condoms, then I didn’t even want to have sex with him because sometimes he didn’t want to put one on and I, ‘no, you have to put one on if you want us to have sex. (G7)</td>
</tr>
<tr>
<td>Relapsing into substance use</td>
<td>The fear is because I like it. Because, you know I’m a functional addict. (K1)</td>
</tr>
<tr>
<td>Intimate Partner Violence</td>
<td>I was in domestic violence very bad. And it traumatized me in a way. Because I wouldn’t be sitting here talking to you, because I would have been thrown off the roof a long time ago. And I would’ve (had) blown my face away with a gun because that was what he was going to do. (K5)</td>
</tr>
</tbody>
</table>

The fears that these informants experienced were not isolated experiences. There was frequent and consistent overlay in their discussions with this researcher and as such any efforts to neatly separate each fear were (a.) difficult to accomplish; and, (b.) not true representations of their lives at that time. Following is a brief discussion of each fear listed in table 5.2:

*Dying.* When they received their diagnosis of HIV, the informants were fearful of dying, “because during the 80s, the whole world was dying” (K6). Each informant described their fear of the diagnosis because of its association with death. This was mostly because they first learned of their condition when the epidemic was still brand new; when HIV still meant severe illness, pain, isolation and death. They had personally witnessed or learned, either through the media or gossip in their social circles, how others had died tragically and surely that was to be their fate as well. HIV was something to be feared and they were afraid. As another informant shared after
her diagnosis following a serious illness, “I thought I was going to die. When they gave me the diagnosis, I thought that I was going to die” (G2). This was the initial fear they experienced, before they considered other reasons to be fearful related to HIV or being afraid of the consequences of their impending death from HIV.

Disappointing loved ones and disclosure of HIV status. Once they settled into an awareness of having HIV, the common fear was centered upon revealing their diagnosis. Besides revealing the diagnosis, they were afraid of disappointing loved ones because disclosing their HIV diagnosis meant revealing their risk behaviors and bringing shame on themselves (Ortiz, 2005; Rivero, 1994; Roldan, 1999) and as a result many of them did not disclose their diagnoses for quite some time. Stigma, due to not conforming to societal expectations, such as not using drugs; not having multiple sex partners or a partner with multiple sex partners (Gagnon, 2015), was a powerful reason to delay disclosure or be fearful of it happening outside of one’s control. Two key informants described their reasons for being fearful of disclosing to their parents,

My father, I couldn’t tell him because my father would die with feeling and emotions (K5);

and,

No, I just never told her. I passed so much time not being able to say it. But now? Understand that I don’t want to say anything (K3).

They feared being a disappointment to the parents who had so much faith in them. This led informants to keep the secret of their HIV status from family (parents, siblings and children), even as they started care. They developed elaborate stories to explain away their ailments and need for medical visits. One informant “camouflaged” (G3) her HIV disease as another immune condition. She disclosed that she knew everything there was to know about it at the time to
support and maintain the lie. At the time of the interviews, some of the informants had still not disclosed their diagnosis to family members for fear of disappointing them or “disturbing” (G5) their lives.

*Leaving their children and separation from loved ones.* They were also afraid of leaving their children before they could care for themselves and not be a burden to others; or, be taken advantage of by others for the social security payments to be received. For the informants with young children at the time of diagnosis, there was a fear that they would die before they had finished raising their children to be the adults they wanted them to be. One general informant described her earlier fears of leaving her children too early through death by identifying that the fear was no longer present in her life: “I’m not scared because I know that no matter what, at the end of the day, my kids will be okay and my grandchildren. I did my job. I’m good with that” (G4). Since her children are old enough to manage, she would be ready to die. Being separated from other loved ones, such as parents, siblings and partners was another fear, especially when they were not prepared. A key informant was afraid she would die before completing her living will with her fiancé.

I’m not even ready for something like that. I tried to talk to my husband about death and he doesn’t want to talk about it. I said but ‘Babe we gotta prepare for me’ (K1). He avoided the discussions because of his fear of her dying, while she became more afraid of dying before he was prepared for her death.

*Transmitting the virus to a loved one.* Another frequently voiced fear was transmitting the virus to someone else, particularly a loved one, “sometimes when we don’t have protection, I get scared” (K1). Smith (2015) described women’s assessment sexual risk for HIV when in relationships. Assessments of HIV risk are made for all sexual encounters and the differing perceptions of risk by partners creates fear.
Relapsing into substance use. Informants with a history of substance use were afraid of a relapse by reverting to old behaviors for dealing with their stress of having HIV infection and managing other life concerns Dennis and associates (2015). They described in detail their troubles and journeys into recovery. They first began to use substances for casual reasons but in time the substances were used to escape difficult situations. Even after dealing with the serious issues that lead to a reason to go into rehabilitation like the personal difficulties of losing custody of a child or housing; and, the obstacles they experienced when they stopped using substances, such as, sweating and painful cramps, it was still easy to relapse into substance use. The significant stressors they knew that came with living with HIV made them fearful that relapse would easily happen again. In order to protect themselves from relapse they purposefully stayed away from certain neighborhoods and people, even new loves.

Intimate partner violence. Fear was not a new experience for the informants, as they recounted many life experiences, before knowing their HIV status, when they were afraid for their safety and/or the safety of their loved ones. Some of the informants had not been raised in environments that met their physiological and psychological developmental needs. As children, they witnessed and/or were subjected to emotional, physical and/or sexual abuse at the hands of parents, family members and/or acquaintances caring for them in the absence of parents. These informants experienced continued abuse and neglect when their abuse was denied, further traumatizing them (Grabbe, 2016). Some informants shared their experiences of neglect and abuse.

They treated me bad, they hit me, you know. My stepmother hit me a lot and I had to do all the chores and if I didn’t do the chores, then I was hit hard. I was abused (G8).

For these informants, their experiences of childhood abuse led to similar experiences as adults (Nije-Carr, 2014). They suffered abuse through intimate partner violence (IPV) in their pasts

The second pattern supporting this second universal theme is Puerto Rican women living with HIV move through various expressions of grief. With the receipt of a life-changing diagnosis like HIV, people can experience the emotions associated with grieving. For example, seminal research by Kubler-Ross (1969) identified stages related to grief which are denial, anger, depression, bargaining, and acceptance. Kubler-Ross and other theorists and researchers on grief have described working through the stages and the accompanying emotions as a process, which although mostly directional could result in experiencing multiple emotional stages simultaneously (Rolland, 1987; 1990; Stroebe & Schut, 1999). Fresh personal losses could reignite emotions. Whatever emotion was expressed or recalled by the informants during the interviews, could be as raw as when first experienced, because the informants cried or yelled or even slammed a fist down on the table, as they spoke.

Denial. Denial was the first expression of grief displayed by some informants. The denial was very strongly related to their experience of fear in relation to their diagnosis with HIV. They rejected the diagnosis. These informants described being in shock over the diagnosis, demonstrated by “running away” (K1) out of medical offices where they received their results and for some returning to drug use and relapsing.

Anger. Another expression of grieving by the informants was anger at oneself, and it permeated the interviews. The informants were first, angry with themselves for the personal actions which put them at risk for HIV. These actions included directly injecting themselves
with needles that were shared with others who had HIV. They were also angry with their partners for being unfaithful and carelessly exposing them to HIV and then, shaming them for their trust in these men. One general informant shared her feelings after discovering her partner’s risk behavior:

He never really told me, until I found out after he passed away that he had slept with someone else that had the disease. And I was really angry… His best friend told me because he had a weight on his shoulder, and I became very angry. I actually punched him because I was upset (G1).

Informants also expressed anger regarding their experiences of stigma and prejudice. For some of the informants their HIV diagnoses became neighborhood gossip spread by their partners, fulfilling on of their fears as noted above. Two key informants and one general informant shared stories in which their situations were deliberately exposed in the streets of their neighborhoods in dramatic exchanges with others.

I wanted to tell my father and she just came in the village and said, ‘Oh you know your daughter got AIDS.’ Come on let’s be real and my father went insane (K2).

Anger was also felt when strangers made hurtful comments to them at their places of employment. They discussed being “off guard” (G4) in these settings and not ready to respond. Another setting where they were angry at being stigmatized was in their families’ homes. Having a set of disposable plates, cups and utensils placed in front of them at the meal when everyone else was being served with dishes and silverware or having someone enter the bathroom with a bottle of bleach cleaner after their use were situations described by more than half of the informants. These situations created much anger for them because they felt their own family was shaming them in their “safe places,” and there was no protection for them from the stigma of HIV.
Perhaps the most disturbing situations of prejudice and stigma, and therefore causing the most anger in the informants, were experienced at the medical offices and hospitals where they were receiving care for HIV and other conditions. The informants attributed the stigmatizations from lay persons to ignorance about HIV, “They’ll call you ‘monster’ and say things” (G7), yet they, being more knowledgeable could educate these family members and strangers. However, the statements of health care providers regarding the need to use “more precautions” (G4) or not wanting to put themselves or their colleagues “at risk” (K2) were inexcusable in their opinions. It made them “feel discriminated in that sense if they go to another specialist not an HIV specialist, where they tend to be treated, they notice the way the people back off” (G4). They felt that these health care providers should have known more about this disease than they and in turn should know how to protect themselves to reduce the risk of transmission. The informants were angry at this loss of control because they did not feel they were able to correct these healthcare providers.

The doctor needs to be more concerned about the patient, especially in this field. In this field!?! (Voice rising) (G10).

These instances continued to rouse feelings of anger in the informants many years later.

Sadness. Another emotion connected to grief expressed by the informants during the interviews was sadness. They were sad about their diagnosis with HIV and the losses they had experienced as a result. They mourned the losses from their past and present, and even anticipated losses in their futures. The past losses were a sense of who they once were and their loved ones who had died of HIV: “But it um I still love him, and I don’t think I’m ever going to love anybody, the way I loved him. So, to me that was real love” (G1). Their current sources of sadness at the time of the interviews were the changes to their physical appearance, physical strength; and freedom to work as a result of HIV. One general informant described her feelings
about the amount of money she received from disability payments in comparison to what she earned when she was working full time, as an insult to her self-perception as an independent self-supporting individual.

What I would make in one month, I used to make in one week working in a restaurant. You know and I’m like ‘What? Are you kidding me?’ And that got me into a severe depression (G10).

Feelings of sadness were also derived from being unable to travel or relocate at will: “I had a beautiful life in Puerto Rico” (G5). Their future losses were the plans for their lives (careers and loves) and the time spent with their children and grandchildren. The informants reported that these feelings of sadness had become overwhelming to them and that they had sought out the services of a mental health care provider to assist them with medication and/or talk therapy.

I do therapy and I do mental health. You know, where I could release all that. You know because sometimes emotionally I don’t know what I’m going through (K1).

Each informant continued to receive mental health services, as well as, attend support groups to manage their feelings of sadness and other mental health concerns.

Depression. Sometimes, the feelings of sadness overwhelmed the informants which led them to a sense of a loss of control early in their lives with HIV because they felt unable to determine the course of their existence and became depressed. Their acute awareness of their mortality was the root of this loss of control and other feelings of depression. As they worked through their feelings of fear, anger and sadness in mental health therapy, they found that they gained control and could bargain and act resourcefully to get what they needed and wanted, a feeling of hope that they could have more time with their children and grandchildren, as expressed in this quote from a general informant.

Please, please God let me see my first grandchild and then please, please a little longer… I’ve seen 5 of them! (G4).
**Bargaining.** Most of the informants had children when they learned they had HIV disease and their goals for living with HIV were modest, then. They wanted enough time for those children to grow, become independent, and not need them any longer. Knowing that they needed to take care of themselves, as part of the bargain to reach this goal, they never thought they would live so long and still be in mostly good health. One general informant stated, “I never thought I was going to live to be 30 something years old and now I’m 50” (G10). While another general informant remarked on her amazement of how much she had been able experience as a mother living with HIV: “I already have three great grandchildren. Do you know what that is? Three great grandchildren. And as old as I thought I would be I never thought I would have great grandchildren” (G8).

To achieve these goals and maintain the bargain, they changed their lifeways as described in the second pattern of the first universal theme above and the following quote from a key informant.

That’s what keeps me clean. That’s what keeps me going taking my medication because I want to live. I want to make sure that I get to enjoy and I’m always calling them (K6). Knowing that their good fortune in continuing to live would require something in exchange, the informants concluded and accepted that they needed to give back to others. They became peer advocates, sharing their stories with others and, as many of them expressed, like a general informant, during the screening process, participating in this research study.

He (God) wants me to do this to help you help us. That’s why I kind of joined the ACT2 Project…You know because I want to help people who are HIV+ (G1). Each informant described the ways they helped people, especially newly diagnosed Latinas. Being in better health, i.e. undetectable viral loads with few and manageable side effects from their antiretroviral regimens (ARVs) made it physically easier to be hopeful and helpful.
Acceptance. The actions that the informants took to help themselves and help others are representative of the acceptance, associated with grief, of the new lifeways resulting from the HIV diagnosis. One general informant described HIV as “her companion for life” (G7). This acceptance was demonstrated in the way the many self-care activities that each informant engaged in each day had become routine. Being helpful to others, as described above, also became routine, even for those least willing to help others because of past experiences. “It’s not a ‘what do you want from me situation.’ We’re all there for each other” (G10).

Fearlessness. As the informants journeyed through these emotions (fears and expressions of grief), they could at last be described as fearless in their new lifeways and sense of self as Puerto Rican women living with HIV. At the time of the interviews, not one of the informants described themselves as afraid, even when they were asked their thoughts about death: “I am not afraid of dying. I am ready for it” (G2). Each informant was comfortable with her life choices and had come to understand and exert control over her life circumstances. By understanding their mortality as they faced their fears and expressions of grief, they grew strong and gained control. They did not believe they were invincible, but they certainly knew exactly what they could accomplish, having already accomplished so much. Their source of their strength was their families and themselves, as revealed by a key informant, “That’s how I kept going forward, fighting because I love my children. I want to be who I was before (drugs)” (K6).

Many of the emotions (fears and expressions of grief) experienced by the informants and shared with this researcher were grounded in their cultural beliefs, practices and expressions. The religious and spiritual beliefs of the informants, such as the afterlife, and compensation for life deeds, put a perspective on their HIV diagnosis that ultimately gave them a sense of purpose in their acceptance of their fates, living with HIV. They were then able to channel that purpose
into giving back to the community. Rivera-Casiano’s descriptive study (1994) of stress and coping in Puerto Rican women in Puerto Rico, found similar emotional responses to living with HIV, like fear, anger, and sadness among others. These women, also had developed coping skills and reduced stress through management strategies as part of their life-changing experience of being diagnosed with HIV. De Grezia and Scrandis (2015) described spirituality as an important factor in helping people move through their own needs in relation to a diagnosis with HIV and then being able to help others and then develop resilience (DeSantis, et al, 2013). In contrast, the women in Chase’s ethnography (2011) of Puerto Rican women living with HIV in New Jersey, were unable to effectively develop coping skills that gave them the control they needed to manage their emotional and physical responses to HIV and they did not achieve similar longevity to the informants for this ethnonursing study.

**Universal Theme III: Puerto Rican women living with HIV value care and caring practices directed towards self and others.**

The third universal theme, Puerto Rican women living with HIV experience and desire care and caring practices towards self and others, permeated the findings. The patterns supporting this theme were: *Puerto Rican women living with HIV desire and engage in self-care practices*; and, *Puerto Rican women living with HIV desire and exhibit caring practices for others*. The responses of the informants were grounded in their abilities and actions to care for themselves in the presence of HIV and still care for others. This theme highlighted their identities as proud and strong Puerto Rican women who as survivors of this epidemic could still participate in caring practices for themselves and others.
The first pattern of the third universal theme, *Puerto Rican women living with HIV desire and engage in self-care practices* was described by the informants as necessary for life. As one informant stated:

I have to do my part if I want to live. I have to take care of myself, take my medicine. As I do it, my medicine works. I don’t drink. I don’t smoke. I don’t use drugs. I don’t have random partners. I take a lot of care of myself. You know, because before I didn’t take good care of myself, but now I do. I am not slacking off (G2).

For many of the informants, the initial impetus to care for themselves came from a desire to continue caring for their children, in keeping with the cultural norms of woman as caretaker. However, over time, they saw the need to care for themselves solely for their own survival, “because I’ve got to take care of my health because nobody’s taking care of me” (K5).

The informants developed specific routines to support the patterns of their self-care practices, including the times of day to wake; pray; exercise; eat; attend medical, mental health, social service and support group appointments; and, socialize with family and friends. The specifics of their patterns included dietary changes that were identified by each informant: the elimination or control of substances used (alcohol, and other drugs like cocaine, heroin, etc.); the regular use of prayer and other spiritual practices, like attendance at religious services, “I pray, I meditate” (G12); the regular use of exercise like walking, aerobics and dance, “I try, I try to exercise” (G12); adherence to medication regimens and use of herbal remedies known to not interfere with antiretroviral medications; regular attendance and participation in support groups for women living with HIV; and, the reduction of psychological, emotional and environmental stressors. One informant explained her self-care need to eliminate stressors in the following way:

I’ve been clean 27 years and even some of the people I associate with because some of them relapse and it sounds cold, but I can’t entertain and help you and then I get sucked into the same thing. Some people I have to walk away from (G3).
For the informants who had a steady work history, having a job or a volunteer position was also part of their self-care activities. The routine that a regular job provided, bolstered the management of their other activities of daily living. Being a peer leader and the training and service that corresponded with that work was also identified as a self-care activity. For the informants, whose general health did not permit a regular commitment of that nature, they found other ways to be more involved through being informal leaders in their support groups and the ASOs where they received services: “we volunteer, whatever they ask me to do: sort papers, make folders, whatever” (K3).

The desire for self-care practices that support wellness in Puerto Ricans was identified previously by Higgins (1995) and Fliszar (2004) in their ethnonursing studies of Puerto Rican communities in the US. Self-care practices have also been identified in women living with HIV in a large-scale mixed methods study by Webel, et al (2015). In one of their findings focusing on physical activity as a self-care practice, the participants reported walking to be the most commonly utilized form of exercise for women over the age of 50 living with HIV, as well. This was a commonly reported form of exercise for the informants participating in this study.

The second pattern of this third universal theme is Puerto Rican women living with HIV desire and exhibit caring practices for others and while caregiving practices were a part of their behaviors in the past, this was most often geared towards the care of others as part of their identification of women as caretakers in the worldview within which they were raised. The informants spoke extensively of their caregiving activities towards parents, siblings, spouses/partners and children. The care they gave to others was often at the expense of the care they needed to give themselves, as expressed by one informant, “make sure that they have everything they need, and I do that a lot” (G8). Patterns of caring practices towards others
continued to be motivated by the cultural norms of woman as caregiver and depending upon the relationship were enacted differently. One informant stated, “We’re real good caretakers, especially someone you love. Like, we’ll cater to their every need” (K1).

Patterns of caring for others after an HIV diagnosis were actions to protect by teaching others to care for themselves by specifically protecting themselves from HIV. For example, teaching family members how to safely clean the bathroom to reduce transmission of pathogens and how one might prepare or share food or have physical contact with someone safely. These teaching moments, discussed in detail in Chapter Four, usually surfaced when the diagnosis was newly known or when someone either over or under estimated the potential for HIV transmission. Examples of overestimates of transmission risk were the use of disposable plates and utensils when serving food to the informant or disinfecting a bathroom with chlorine cleaner after the informant’s use. In contrast, examples of underestimates of transmission risk were reports of not needing to implement safer sex practices (Smith, 2015). In some instances, caregiving was also demonstrated through the choice to disclose the HIV diagnosis (Davtyan, et al, 2016). The disclosure was purposefully made so a loved one could protect themselves, as noted above.

Other times the informants purposefully elected to not disclose their diagnosis to family members, such as young children; parents, grandparents or aunts and uncles, especially when elderly, to protect them and spare them the distress of knowing: “They don’t know about my illness. They don’t know, and I don’t want to tell them” (G6). Even when family members, friends and significant others were aware of the HIV diagnosis, some informants limited the discussions of their HIV disease, by restricting the types of information shared with these
individuals and/or the frequency of these discussions. They would direct the conversations away from an excessive focus on their disease process to reduce worry on the loved one’s part.

Like I talk to my dad every other day. And the first thing ‘You took your medicine? You taking care of yourself? You, eating, right?’ I’m like ‘Dad stop asking me I told you already. Yes, yes, yes ask me something else.’ (K1)

This overemphasis on their medical status, for example, CD4 counts and viral loads, also caused the informants stress and they called this behavior “overcare.” These efforts to control information being shared can, therefore, be viewed as a caring action for self and other, the loved one. The loved one may have less worry but at the same time the informant also controls her own sense of worry and distress over discussing her condition repeatedly.

Another caring practice action discovered through this ethnonursing study, was participation in support groups (Webel, et al, 2016) and research studies for the benefit of others (Floyd, et al, 2010). The informants knew that sharing their life experiences with HIV in the support groups and in research would have the potential to benefit others and this served as a motivating factor for them (Davtyan, et al, 2016). The potential to make things easier for a Latina newly diagnosed with HIV by reducing her sense of stigmatization or helping her navigate the clinics; or even prevent a new infection by serving as a reminder to always practice safer sex was a stimulus to action for the informants. One informant explained her reason for speaking with newly diagnosed women:

When they come out positive, they don’t want to eat, they don’t want to drink medications, they want to be in denial over everything. That’s when we gotta like talk to them and tell them the truth (K5).

This third universal theme and the supporting patterns of this study substantiate the CCT meta-theme on generic and professional care discovered by McFarland, and associates (2015, p. 296) “culturally congruent professional and generic care for diverse and similar cultures
influence health, wellbeing and illness outcomes.” Specifically, the first meta-pattern focuses on the contexts of generic and family care patterns; and reciprocal and protective care patterns as influencers of health and wellbeing as demonstrated by the informants. The self-care patterns and the caring patterns expressed towards others described above provide further confirmation of these themes and patterns, as it was through these activities that the informants achieved the wellness they portrayed to others. Maldonado’s (2017) literature review on intergenerational caring in Latinas identified mental health and financial stressors in caregiving of others, which contrasts this theme and supporting patterns. It is likely that this difference stems from the unidirectional emphasis on caring towards other in the studies selected for the review.

**Universal Theme IV: Caring expressions and practices of Puerto Rican women living with HIV are deeply influenced by kinship, social, and cultural factors.**

The fourth universal theme was *caring expressions and practices of Puerto Rican women living with HIV are deeply influenced by kinship, social and cultural factors*. Please refer to Table 5.1 for a listing of the four patterns associated with this theme which are discussed below.

*Puerto Rican women living with HIV view family members and significant others as motivational forces and sources of strength for self-care and care for others* was the first pattern identified, for the fourth universal theme. The informants often spoke of their children and family members (mothers) who needed them as reasons to be well. “You know but at least I want to see (my grandkids), you know, and I want to be around my son a little bit more” (G10). Some family members of the informants engaged in more concrete activities to support their self-care activities, such as providing reminders to keep medical appointments or take medications. The motivational role of family for the informants reinforced the power of familial connections to contribute to the health and wellbeing of family members, starting with the informants and
then continuing to their children and grandchildren as they learned their own protective health care practices, “I always keep a packet of condoms so that I can give them to my grandchildren so they can use them” (G8). Caring practices were also passed from one generation to the next. One general informant shared that she had taught her children and grandchildren to care for others because she had once received caring: “Teach it to, now, my grandchildren, because my kids got all of that. My grandchildren. So, they could do it for somebody else in need” (G4). The motivation that family members of Puerto Rican women living with HIV provided extended to others outside of the family. One key informant repeatedly stated that she was moved to speak out about HIV risk to others because of her young sons.

I’m not here to change nobody or educate nobody. If you want to hear it, I’ll tell you. You take it with you or not. What’s important to me now is that my kids stay safe and protected. It’s not just the virus, it’s not HIV, it’s all these STIs and STDs (K4).

Her efforts to protect her children including teaching them about reducing HIV risk and telling others, as well, about reducing their own risk.

The second pattern discovered was for Puerto Rican women living with HIV, mothers are role models for caring and caregiving practices and fathers and sons are emerging as protectors, advocates and caregivers. The informants relied on their mothers as exemplars for becoming caring Puerto Rican women and mothers. When a biological mother was not an appropriate role model, the informants had stepmothers, aunts and older sisters who could fulfill that role. Being recognized as a caring person like their mothers was an important part of their identity and a cause of pride, as shared below.

I am so much like my mom. I cook like my mom, I clean like my mom, I walk like my mom and I practically look like my mom, just that she was a little heavier (K1).

In turn, they also wanted to be role models to their own daughters, and proudly discussed their efforts to teach them to be independent women who could manage their lives on their own. The
informants were proud to discuss their daughters’ accomplishments as women and as mothers with this researcher. The achievement of having lived long enough to impart maternal wisdom to their daughters spurred a great sense of gratitude in the informants.

Fathers demonstrated caring behaviors towards the informants and these actions were of great importance as a demonstration of love and a source of protection. Some fathers stepped in to provide care to daughters when mothers were unavailable, even teaching them about safer sexual practices:

My father taught me the sex part I learned from my father. He said, ‘You gotta do this, always have your condoms because men could prick the condoms and give you, you know’ (K1).

These fathers went on the offensive, if someone hurt their daughters. These fathers were also very concerned with their daughters’ health once they were diagnosed with HIV. They taught their daughters about herbal remedies and teas to manage the symptoms of their illness. They provided protective care to them.

Sons also assumed a protective role towards their mothers. These sons were raised with their mothers’ health problems and as children came close to losing their mothers to HIV. As adults, they knew extensive details about their mothers’ lives with HIV as reported by the informants. They become supporters of their mothers’ health: suggesting wellness practices, such as exercise regimens and protein shakes. They also advocated when they were concerned that their mothers were being discriminated against or not cared for in a way that they needed. One general informant described her son’s advocacy and protective activities in the following way:

When I’m sick he takes care of me. He goes to the hospital. He don’t miss a day. He argues for me. He advocates for me. That’s what he does. He studies the law, you know. He don’t like people messing with me (G10).
Contrary to cultural expectations of *machismo* and *marianismo*, and as a result of acculturation, these men, the fathers and sons of the informants, have taken on caregiving roles as needed by their daughters and mothers, respectively.

The third pattern supporting this theme is *Puerto Rican women living with HIV value family unity and reciprocity of care (familismo) through caregiving and, emotional, financial, residential, educational support*. Informants discussed ways they relied on their families and their families relied on them as a priority. One key informant declared family caring to be important as follows: “being with and caring for family even when you don’t agree with who they are or what they have done” (K6). *Familismo* was visibly manifested when informants lived with their parents, or adult children and, their grandchildren. Like many families in Puerto Rico’s past and in response to current economic trends, multiple generations lived together, pooling resources and providing familial support. “I was raised united, but we try to keep the family together and anything we can do together we do” (G4). The informants described the unity of their families, without neglecting the conflicts inherent to close and frequent contact. However, they acknowledged and were proud to state that their families would be and had been there for them in times of need. They reciprocated care, especially when living together and shared expenses equitably.

I pay all the bills. Take care of them when they’re sick. But it’s vice-versa because they take care of me, too. They take care of me, and I boss them around (G4).

Financial sacrifices were made when necessary to support family members in need or provide educational opportunities, like private school. Visits, to or from Puerto Rico, were also made to personally check-in with family members, when a phone call was not enough to assure that all was well. Informants described their beliefs and desires for family unity as central to Puerto
Rican identity as the following quote emphasizes: “proud that the family is what makes you Puerto Rican; the unity of the family” (G3).

The fourth theme supporting this pattern *Puerto Rican women living with HIV foster caring for others as an expression of personalismo*. *Personalismo* is the cultural behaviors in public and with non-family members, for example, friendly greetings that could include a hug and perhaps a kiss, that are intended to result in positive interactions. As discussed earlier, many of the informants valued the concept of giving back to others, especially Latinas at risk for HIV and Latinas recently diagnosed with HIV. They saw their actions as vital to crafting a better environment for their own wellbeing in their day-to-day interactions with others, including during professional care encounters and for their children’s future wellbeing. “I have to be grateful. I mean I’m here for a reason” (G10). These women also became politically active by participating in training and lobby days with the ASO to draw attention to their needs and the needs of others like them, thus, finding another way to care for others. Direct outreach was another method of demonstrating caring through *personalismo*, even though some informants found this activity to be difficult, others were inspired by these encounters. One key informant discussed her outreach work at the ASO where she received services.

So, I went out to speak with the Hispanics. I stay here to give help for the AIDS Walk and once a month I help out with the outreach on the corner. The meeting for Latinas and once a month we volunteer and then in March they did the Latinos conference in Albany, which is two days (K3).

The informants served as role models and the cultural values that were discovered in this theme’s patterns were exemplified by expressions of *familismo* within the family relationships and *personalismo* directed towards friends, and strangers.

The fourth universal theme and supporting patterns were similar to the findings of MacNeil (1994 & 1996) who explored the impact of HIV on the lives of women in Baganda.
She discovered the effect of kinship in sustaining caring actions; a sense of needing to survive to secure the future of the family; and changing gender roles to support the family, which correspond to the values of family unity and reciprocity of care (*familismo*); family as a motivational factor for self-care; and, fathers and sons emerging as caregivers, respectively. The findings in the fourth theme of this study also fit with the findings of Higgins (1995), Fliszar (2004) and Martin-Plank (2008) who all discovered the importance of *familismo* to health and wellbeing in the Puerto Rican communities they studied in upstate New York, Philadelphia and western Pennsylvania, respectively. In addition, McFarland, et al (2015)’s metasynthesis findings from ethnonursing research attributed cultural values as expressed through family and kinship influence predictors for health and wellbeing (p. 299).

Maldonado’s (2017) literature review identified various studies that explored cultural norms and values as they related to caregiving for Latinas. However, these studies were focused on the burdens that the cultural norms and values imposed on Latinas as caregivers. This contrasts with the findings of this study which identified more positive aspects of the caregiving relationships the informants developed with family and others in their circle. Perhaps, the difference can be attributed to the informants also being recipients of caregiving versus solely providing caregiving to others. The gravity of having a potentially fatal illness like HIV could be the reason for this reorganization of the caregiving relationships the informants had with others.

This experience, though was not the case for the participants in Chase’s (2011) ethnography, who were inconsistent in activating the culture care values of *familismo* and *personalismo* to their advantage to successfully manage living with HIV, as they struggled to stay away from drugs, support themselves and keep their families together. Even though, from
time to time, some of the informants for this ethnonursing study also experienced difficulties interacting with their family members; had issues with their parents and children; or, did not develop good relationships with some of their providers, they were able to put things into perspective and identify other relationships that were based on positive caregiving behaviors. The differentiating factor, personality, circumstances or something else, for activating *familismo* and *personalismo* for survival was not clear when comparing the women in Chase’s study (2011) and this ethnonursing study.

**Universal Theme V: Spiritual and religious factors play a significant role in the care of Puerto Rican women living with HIV.**

The fifth universal theme identified in this ethnonursing research study was *spiritual and religious factors play a significant role in the care of Puerto Rican women living with HIV*. This theme was also evident throughout the findings as each informant provided details of her religious and spiritual practices. The specific patterns that supported this theme were the *worldview of Puerto Rican women living with HIV embeds a variety of spiritual and religious beliefs*; *Puerto Rican women living with HIV rely on diverse spiritual and religious practices to maintain health and prevent illness*; and, *Puerto Rican women living with HIV use spiritual and religious practices to protect themselves and others from harm*.

*The worldview of Puerto Rican women living with HIV embeds a variety of spiritual and religious beliefs* was the first supporting pattern for this fifth universal theme. For each informant spirituality and religiosity evolved as they matured and was expressed in their worldview accordingly. Their observances as children were based on their parents’ practices and changed over time as they had their own life experiences and exposures to other religious and spiritual practices. At the time of the interviews, each informant reported satisfaction with their
spiritual practices which included a variety of faiths and spiritual tenets interwoven into unique personal belief systems, or worldviews. In line with the ethnohistory of the Puerto Rican people, the informants blended their spiritual and religious practices, too.

Knowledge of other faith practices came from friends and boyfriends they encountered during their teen and young adult lives. This was the case for the one key informant and one general informant who changed dietary practices, like avoiding pork products, after becoming familiar with this practice within Islam. While these informants did not convert to Islam, they identified as Born-Again Christians, they continued to follow the dietary practice, initially out of preference and then later in support of healthy eating. Another general informant who described herself as an observer of many faiths, interwove different religious and spiritual practices of Roman Catholicism, Santería, Espiritismo, Islam, Hinduism, and Native Americans into her day-to-day behaviors. Her clothing and jewelry, necklaces representative of Santería, Native American and Hindu symbols, reflected the many faith practices she followed. Her clothing reflected this statement, she made: “see(ing) God in different forms and I believe that it’s the Higher Power, and I have to respect (G3)”. Whatever the combination of religious and spiritual practices, the informants described it as a foundational part of their being and wellness. One key informant further elaborated on this by saying, “with faith, I can do everything and without faith nothing” (K3). The common thread through all the informants’ religious and spiritual practices was prayer.

The second pattern of the fifth universal theme was Puerto Rican women living with HIV rely on diverse spiritual and religious practices to maintain health and prevent illness. Prayer was the most frequently used and most powerful activity the informants used to express their
faith and give thanks while at the same time invoke assistance with health maintenance and illness prevention.

I always get up every morning and before I open my eyes and get off that floor I say, ‘Thank you God for giving me another day to live’ (G5).

Faith was determined to be a path to healing as one general informant described her faith in her medications and God to reduce her stress and viral load. Prayer was described as a calming and stress-reducing activity. Another general informant described her decision-making process regarding management of her illness which included prayer: “I make my own decisions, or I talk to God about it. I pray on them. I ask Him to guide me” (G1).

Within the belief systems of the informants, healing is embedded within their religious and spiritual practices (Fernandez Olmos & Paravisini-Gebert, 2011). Some had detailed spiritual practices to maintain their health and wellbeing (Donald, et al, 2015), including lighting candles and using floral and healing baths. They also used herbal remedies based in the traditions of Curanderismo and Espiritismo (described in Chapters Two and Four) to manage symptoms of HIV disease and side effects of their ARVs and other medications. Some of these practices were learned when they were children or adults. They could be used effectively without a spiritual or religious focus, but the informants reported choosing to implement the practices fully by including the prayers.

Another spiritual and religious practice associated with wellness was forgiveness. Often associated with the Judeo-Christian tradition, forgiveness is also an important practice in other faiths. It is often believed to benefit for the person being forgiven. Yet, there is evidence (Flasch, et al, 2017) that the greatest benefit is experienced, instead, by the person granting forgiveness, as it releases the emotions of anger and hatred. The informants most often directed forgiveness towards the person who had transmitted HIV to them, such as a philandering
spouse/partner; or, others who had wronged them leading them to the behavioral practices that exposed them to HIV and other hardships. One key informant who provided extensive details of her spiritual and religious practices, explained her decision to forgive and how it was helpful to her spiritual wellness:

That is what I didn’t understand, because you must forgive. I didn’t understand that you forgive for yourself and not for the other person. I said, ‘Oooh, now I understand.’ Because if it were for my husband, no, but to do it right, and for my health and all, well I will forgive. It is okay (K6).

The third pattern supporting the fifth universal theme is Puerto Rican women living with HIV use spiritual and religious practices to protect themselves and others from harm. Many of the spiritual and religious practices were protective in nature and used explicitly for those purposes by the informants. Besides using prayers of thanks and petition, they often used prayers to protect themselves and their loved ones. Protection was desired from the bad intentions of others and this could be achieved through the language of prayers, like “Dios me bendiga” (May God bless me); items, such as, clothing and/or jewelry, “I like to protect myself with Santeria (she shows her beaded necklaces) and that’s for protection” (G3); and actions like, lighting candles or avoiding people, “candles for protection, peace, always peace” (G4). The one key informant and one general informant who tattooed their bodies in memory of their deceased children (a name and a portrait), touched the tattoos when speaking of these children, in a ritual way of blessing them and invoking their blessings of protection at the same time. These actions and prayers seek to bring healing to themselves and others. In this way, the informants become the “wounded healers” of the syncretized Creole religions who by seeking to heal others also heal themselves (Fernandez Olmos & Paravisini-Gebert, 2011).

This fifth universal theme and its patterns supported McFarland and associates’ (2015) meta-theme of social structure “factors including family, kinship, religion and spirituality,
economics, cultural values and lifeways are influencers on culture care that predict health and wellbeing” (p. 298). More specifically the second pattern: “spirituality enabled” them “to experience life with equanimity” (p. 298) connected with the shared experiences of the informants of their own spirituality as Puerto Rican women living with HIV. The equanimity emanating from their daily spiritual and religious practices gave the informants a sense of peace and control to face HIV’s effect on their lives, health and wellbeing.

Diverse Theme I: Puerto Rican women living with HIV reported differences and similarities in professional care in New York City (NYC) and Puerto Rico.

There was one diverse theme identified through the findings of this ethnonursing research study and that was *Puerto Rican women living with HIV reported differences and similarities in the professional care received in NYC and Puerto Rico*. The diverse patterns that supported this theme were *Puerto Rican women living with HIV identified language, educational, economic,* and political factors as barriers to receiving and understanding professional care in NYC and Puerto Rico; *Puerto Rican women living with HIV identified caring and non-caring attributes of professional care providers in NYC and Puerto Rico*; and, *Puerto Rican women living with HIV reported diversities in desires for integrative care that accommodated their generic/folk care practices*.

Some of the informants had spent some of their childhoods and adult lives living in Puerto Rico. Three informants were diagnosed with HIV in Puerto Rico and had received HIV care in the Puerto Rican health care system. They relocated to NYC to receive better care for their HIV disease. Four of the informants who discovered their HIV in NYC, had received invitations from family to relocate to Puerto Rico to be cared for by their relatives there.
However, each was aware of the disparities in care and opted to remain in NYC and receive what they deemed was better quality care. 

*Puerto Rican women living with HIV identified language, educational, economic and political factors as barriers to receiving and/or understanding professional care* was the first pattern supporting the diverse theme. Informants who primarily spoke Spanish had been raised in Puerto Rico and described their struggles to learn to speak English. These women reported at times having difficulty understanding their HIV care providers well, resorting to a combination of broken English (informant) and broken Spanish (provider) to conduct health care encounters with their health care providers. Using a language line was not a viable option for these informants either, because they preferred to be face-to-face with someone.

With a translation service, I don’t like to talk on the phone. She knows that I have a caseworker and many times my caseworker comes with me to the appointment to interpret for me and that is better. I say, ‘Look, I am sorry, but I have her with me.’ And she (the NP) is okay with it because I don’t have confidence in the phone conference. It is difficult (K6).

These Spanish-speaking informants were referred to the study by another informant who ran the Spanish speaking support group at the ASO. One of the reasons they reported choosing to be screened for this study was the ability to be interviewed in Spanish to share their stories. Five informants (one key and four general) who would speak English for their medical provider visits, still chose to be interviewed in Spanish, including one who changed from English to exclusive Spanish in the middle of the interview. During this study’s interviews, to be more comfortable and better understood, these informants chose Spanish over English. Perhaps, this development served as a reflection of their comfort and desire to share intimate experiences with this researcher. This finding could call into question the depth of understanding of both the providers and the informants during their health care encounters. The significance of these
language barriers is informants could refrain or delay sharing health information, if they are concerned that they will not be understood by their providers (Mayo, et al, 2016; Phillips, et al, 2011); they may not understand important health instructions (Mayo, et al, 2016; Phillips, et al, 2011); they may not participate in clinical and biobehavioral research, thus limiting the significance of those findings (García, et al, 2017; George, et al, 2014; Gwadz, et al, 2014). These cultural and language concerns were summed up by one general informant when she shared:

They should try to get somebody from the same culture to attend them for the language barrier. Maybe because somebody with their same culture who has the same beliefs to understand them (G4).

Language barriers were not a concern for the remaining eleven informants who were interviewed in English. However, education figured very strongly into the literacy abilities of the English-speaking informants. The informants completed varying levels of education in the US and only six of them had college experience, with three having completed a college degree. Being able to understand a provider’s questions and instructions are very important to being able to participate in healthcare to avoid lower quality interactions and a decreased satisfaction with decision making (Phillips & Arya, 2016). However, the informants for this study had reported satisfaction with their interactions with their NPs and other providers (Calo, et al, 2014) as demonstrated by infrequent changes in provider, adherence to their ARVs and undetectable viral loads (Brion, 2014; Dawson-Rose, et al, 2016).

The economic and political barriers to care were experienced both in Puerto Rico and the US. In Puerto Rico, there is a deteriorating economic situation perpetuated by the post-colonial relationship between Puerto Rico and the US (Walsh, 2016, July 1); a political environment restricting the ability of Puerto Rico to renegotiate its political status via referendum (Royston
Patterson (2012, November 24); and, a looming debt, incurred by US laws restricting loans restructuring by the government and utilities. With Puerto Rico’s efforts to cut expenses (vital municipal services, pensions, and health care services) and increase taxes, the exodus of the middle class from Puerto Rico to the US has only grown, thereby worsening the economic situation for those remaining in Puerto Rico (Robles, 2017, July 16). Even the US healthcare system’s future is unknown. Efforts to dismantle the Affordable Care Act (ACA) have essentially destabilized the healthcare markets with the proposal of bills to eliminate key tenets of the law, e.g. Medicaid expansion, women’s health and mental health funding (Kaplan, 2017, July 18). Healthcare insurers have begun to withdraw from the markets or increase premium rates. This uncertainty has the potential to affect the range of services offered to all people living with HIV.

These events have exacerbated difficulties with navigating the healthcare system both in NYC and Puerto Rico. However, these circumstances pre-existed for the informants, causing them to either relocate to NYC or opt to remain in NYC to receive desired professional HIV care within recommended guidelines. Another general informant described the differences in care services in this way, “We get all the education here in New York. In Puerto Rico, we don’t get that stuff” (G5). HIV care has been very limited in Puerto Rico due to the high costs of provider visits, diagnostic screening for opportunistic infections and HIV-related conditions, medications, and support services due to the block grant funding mechanism which is currently being proposed for Medicaid funding throughout all 50 states. One general informant explained her rationale for staying in NYC for her and her child’s healthcare needs by stating, “In Puerto Rico, the medical care is poor and there is no help” (G9). Another general informant explained her own reasons for staying in the US even though she had an invitation to return to Puerto Rico:
“My aunt says, ‘Why don’t you come here.’ I would love to go there with them. They don’t know how I would love to but what prevents me is the disease that I have.” (G2). Limited care options are also a concern for substance use treatment (Deren, et al, 2014). There are also less available funds in Puerto Rico for advanced education of nurses, including nurse practitioners, of which there are very few due to lack of full licensing options; and, medical providers to ensure the appropriate training for the advanced practice area of HIV care. The Puerto Rican healthcare system has also been concerned with brain drain to the US (Robles, 2017, July 16) and has restricted health care workers, nurses, from attending conferences, even on the island (D. Suarez, personal communication, July 20, 2012). Informants came to NYC to receive a wider range of services for people living with HIV and easier access to healthcare services, while other informants stayed in NYC to not lose the services and healthcare they were accustomed to receiving.

Notwithstanding, there were still concerns with access to care and receiving the best care in NYC. In New York State, access to healthcare coverage is still closely tied to either employment, income, or diagnosis. Although access to health care coverage improved after the full implementation of the ACA in 2014, the informants recalled the struggles they experienced when they did not yet have an AIDS diagnosis; or, did not yet qualify for disability, as these conditions opened more healthcare coverage/access options before the ACA. At the time of the interviews, all informants had healthcare coverage and no reported problems with seeing a provider to address their health concerns or receiving coverage for medications or substance use treatment.

Moving from Puerto Rico to NYC or vice-versa permanently or for a vacation activated the air bridge in HIV care. Informants recounted instances when their medical information was
forwarded to NYC or Puerto Rico to facilitate the receipt of care in the temporary location. The use of the air bridge in this way had only recently become formalized as many providers did not even know if a patient had moved or was vacationing when they missed an appointment. Before the advent of cellular phones, there was often no way to contact the patient. The air bridge was once vilified as the conduit of HIV transmission between communities in NYC and Puerto Rico (Deren, et al, 2014; Olivier-Velez, 2002), but it then became the conduit by which patients were able to stay adherent to their self-care management plans. One informant described her own experience with the air bridge as follows:

I didn’t know that there was this air bridge and that it doesn’t close. She told me, ‘We will send you to a hospital and we will have you speak with the director of the hospital. All your papers, will be faxed and you won’t have to carry anything. They will give you an appointment, your things, everything’ (G6).

When this general informant relocated to NYC, she had no difficulty in remaining on track with her care. Similarly, informants who had traveled to Puerto Rico for an extended stay had been able to connect with care providers there who were able to communicate with their providers in NYC and assure continued care by having blood work performed locally and medications shipped to their address in Puerto Rico to avoid gaps in care (Lima, 2009). These protocols would be applicable for other communities residing in NYC who return to their home country for an extended visit, as well, though financial and political connections would not as easily facilitate this continuity of care as with Puerto Rico.

The second pattern supporting the diverse theme was Puerto Rican women living with HIV identified caring and non-caring attributes and actions of professional care providers in NYC and Puerto Rico. The caring attributes and actions of the providers also kept the informants adherent to their healthcare encounters and medication regimens (Dawson-Rose, et al, 2016; Gelaude, et al, 2017; Grimes & Grimes, 2013). These attributes and actions were based in the
cultural value of *personalismo*, making them more significant to the informants because this was desired of the provider. While traits like language concordance and even cultural concordance were valued by the informants, they were always quick to point out that there was something more to the relationships they developed with their providers, as the following quotes demonstrate.

I have a good communication with her because the things that I am most concerned with she checks on right away (K3).

She(’s) Puerto Rican and not because she’s Puerto Rican, she’s good at what she does. She’s compassionate, she listens…because some of them don’t even know how to talk to you (G10).

Over the years, you start to see the provider as part of your family. And now if I’m in the office or not and something is bothering me then I don’t have a problem calling her (G12).

These providers demonstrated the caring attributes most desired by the informants. The trust they developed was described as comparable to the trust they experienced with family members. This, however was not everyone’s experience, every time they met a professional care provider.

Informants reported continued episodes in which they or someone they knew experienced non-caring attributes and actions in professional care situations. The informants clearly noted that stigma and discrimination in professional care settings (Chase, 2011; Farley, et al, 2014) discouraged HIV screening in people of color and accessing care within an appropriate timeframe after diagnosis (Chase, 2011; Cook, et al, 2015).

A lot of people don’t get tested due to stigma. They don’t go to doctors due to stigma, because some doctors do treat you, you know, that you put yourself in that predicament and you have to deal with it and there are still some doctors that discriminate against it (G11).

Informants also reported that they and other people living with HIV had received a different quality of care due to discrimination from non-HIV care providers. Experiences of
discrimination due to race and/or ethnicity were reported by one key informant and two of the general informants participating in a second interview but the predominantly reported experience of the informants was different treatment due to their HIV diagnosis.

All this discrimination …in the hospitals… it was many times, you know. It doesn’t matter …you know, it’s like I don’t know. People get jobs and they don’t know how to treat people. It’s like they think you asked for this disease or something. I didn’t ask for it (G10).

Professional care providers could be fearful of making a cultural mistake or care error due to language barriers and cultural misunderstandings and therefore, not provide culturally desired care as found in the grounded theory study on culturally competent care with Hispanics by Sobel & Metzler Swain (2016). Stigma in HIV care could be experienced as symbolic, through stereotyping; structural, through disclosure for risk management; and, episodic, through differences in care by other providers (Gagnon, 2015). The informants for this study had experienced each of these types of stigma with their professional care providers as described in the interviews. For the informants experiencing stigma in Puerto Rico, it was isolated to their diagnosis and their risk factors (Rivero, 1994; Roldan, 1999). Whereas, for the informants experiencing stigma in NYC, it also included their race, ethnicity and language. Gagnon (2015) further noted that coexistence of stigmas is synergistic within the healthcare system. These co-stigmas, then increase the risk of people living with HIV not receiving desired culture care, in addition to needed evidence-based care. In this ethnonursing study, this greater risk was described by the informants diagnosed earlier in the HIV epidemic. However, the availability of healthcare options, i.e. other hospitals, clinics and providers in NYC counteracted the synergy of their experience of these co-stigmas.

**Puerto Rican women living with HIV reported diversities in desires for integrative care that accommodated generic/folk care practices** was the third pattern supporting the diverse
theme. While all informants used spiritual practices for well-being, some also incorporated healing practices that included the use of herbal remedies in their self-care practices. There was a variety of responses regarding how they shared this information with their providers (Julliard, et al, 2008). All informants did share their spiritual practices with their providers and some informants also reported that they no longer used any herbal remedies because they did not want any interactions with their medication regimens (Holtzman, et al, 2013). These informants who had relocated to NYC from Puerto Rico, also did not wish to share with their professional care providers their past use of herbal remedies. Other informants did report sharing information about their herbal and nutritional care practices when asked by their professional care providers. Some informants consulted their providers in advance of using any herbal remedies, while others did research on their own, looking for interactions with their medications on the internet. Like the participants in Martin-Plank’s (2008) study of herbal healing practices of a Puerto Rican community in Philadelphia, PA, they had extensive experiences with herbal remedies in their childhoods in Puerto Rico and NYC.

The informants reported a diversity of experiences with integrative care. Not all professional care providers asked about herbal remedies in a way that permitted expressions of desired care activities. These informants could experience symptoms that may not be well managed by medications and their reticence to use herbal remedies with their ARVs could result in continued suffering. Likewise, if an informant chose to use the herbal remedy there could be an error in care due to a medication interaction, potentially resulting in alterations in drug bioavailability resulting in ineffective or toxic blood levels (Holtzman, et al, 2013; Krentz & Gill, 2016). More in-depth integrative care assessments that include inquiries about generic and folk care practices were desired by Puerto Rican women living with HIV to assure quality care.
Leaving out or hiding information is not always intentional and providers need to ask more holistic, probing questions to discover new information and meanings (Courtney & Wolgamott, 2015). The following quotes from two informants emphasize the need for more time and/or attention during the healthcare encounter to make these important discoveries:

Make sure that they always ask, even when you go there to visit them, that if they’re there for one thing, that if we need anything else because sometimes we forget (G5).

When you sit with someone you have to make them feel comfortable, so they don’t feel shy. You have to start the conversation. It’s always important to hear, not hear, listen and at the same time that the person is talking, you’re hearing them, the inside of them (K5).

This approach to healthcare encounters is important for all persons receiving professional care in any setting. McFarland and associates (2015) identified, through their metasynthesis, a metatheme and supporting metapatterns on culturally congruent professional and generic care for diverse and similar cultures influence health, well-being and illness outcomes that corresponded to this diverse theme describing differences and similarities in desires for integrative care; choices of residence because of differences in care and services between NYC and Puerto Rico; and desires for respect and trust (Earl, et al, 2013) in professional care in NYC and Puerto Rico. The professional care relationships described by these Puerto Rican women living with HIV demonstrated various examples of caring attributes and actions, especially the continuous presence of a professional care giver.

**Culture Care Decision and Action Modes**

Culture Care decision and action modes are the professional care activities, influenced by the cultural data derived from either holding knowledge of the culture or new knowledge that the provider elicits from interviews with the client (individual, family, community). Leininger predicted these modes would become culturally congruent nursing care when utilized in creative ways while working with clients (McFarland & Wehbe-Alamah, 2015). The culture care modes
are not to be confused with interventions, which convey a message of control by nurses and providers, emphasizing a power differential that benefits the nurses and providers. The foundational support determining how the modes are actualized is the cultural data shared by informant clients in a reciprocal relationship with the provider. As a tenet of the Theory of Culture Care Diversity and Universality, the culture care modes must be developed using the ERM and the enablers of the theory, such as Leininger’s Sunrise Enabler to Discover Culture Care (Eipperle, 2015). In ethnonursing studies, the data gathered during the key and general informant interviews informs the recommendations for the modes. In this ethnonursing study, the identified themes and patterns are specific to the Puerto Rican women living with HIV who participated in the interviews and the corresponding modes are also specific to these individuals. Further study with more individuals living with HIV is needed to determine what culture care modes are needed to provide culturally congruent care for these populations.

**Culture care preservation and/or maintenance.** Decisions and actions that maintain and/or preserve the culture recognize that the culture care practices are healthful and should continue for wellness. Preservation means the provider encourages culture care practices by recognizing the value of these healthful practices, while in maintenance, the provider actively assists the client to continue the healthful practices. The provider needs to know what culture care practices for health the client uses, and this information is best obtained during the initial assessment but can also be discovered during later assessments as indicated.

1. *Preserve participation in support groups/talking with trusted others* – For Puerto Rican women living with HIV who have already established a support network, they should continue to utilize those resources to discuss their everyday concerns regarding living with HIV. The stigma that continues to exist in society can mean that these resources are
limited and therefore there should be no messaging that demand changes in sources of support.

2. *Maintain spiritual and religious activities of prayer, protection, meditation* – Spiritual practices, such as prayer and attendance at religious services are an important modality for maintaining faith and a sense of control (protective activities). Meditation and prayer are also known to reduce stress and improve immune system function. The Puerto Rican women living with HIV who participated in this study all shared the importance of their spiritual practices even if they did not regularly attend religious services.

3. *Preserve and maintain familial contact for support and encouragement and reminders for self-care practices* – Family was identified as an important source of support and motivation for wellness for Puerto Rican women living with HIV and preserving these relationships can continue to build upon the support they have had and need. For some, this expanded conceptualization of their relationship, relying on family, may need some encouragement by the provider through providing specific suggestions regarding how family could be more involved, by assisting with reminders for medication and provider appointments or preparing meals that the clients desire, for example.

4. *Preserve and maintain use of herbal remedies, that do not interact with medications, for wellness and managing symptoms into the plan of care* – Puerto Rican women living with HIV in NYC reported using various herbal remedies to attain/maintain wellness and to manage symptoms of HIV disease and/or side effects of medications. The provider should become knowledgeable of the more common remedies and determine the risk of interactions to be able to advise the clients accordingly regarding continued use.
**Culture care accommodation and/or negotiation.** Considered the essence of nursing practice (Eipperle, 2015), culture care accommodation and/or negotiation are the modes where the provider is actively working to understand the details of the culture care practices to better understand how professional practices can be incorporated into the day-to-day existence of the client. Accommodation is the modification of professional care practices to the healthful culture care practices for the clients, while negotiation is the compromise that results from adjustments made to both the professional care practice and the culture care practices to meet the specific needs of the client. In professional caring situations, nurses are frequently the professionals who work directly most often with the clients, best understand the needs of the client, and communicate this information to the care team.

1. *Provide healthcare services in Spanish (or desired language) for all encounters* – Providers should be able to communicate in the languages that the clients speak. The use of interpretation services is recommended in the absence of providers that can speak the language, but this is seen to be a less desired alternative. The existence of language programs designed specifically for health care providers are proliferating in the US under the direction of the Office of Minority Health National Standards for Culturally & Linguistically Appropriate Services. In addition, health care facilities can hire nurses, nurse practitioners and providers who can speak the languages of their client populations to improve patient outcomes (OMH, 2016 September). The informants for this study who were not fluent in English, at times, felt that they were at a disadvantage during healthcare encounters. These informants also did not prefer the use of phone interpretation services.
2. **Include family/caregivers into care by inviting them into the health care encounter**

(familismo) – As discussed in the previous culture care modes that encouraged the family support mechanisms preferred by Puerto Rican women living with HIV, including family/caregivers into the healthcare encounter, while maintaining HIPAA guidelines for privacy, can facilitate reductions in stigma and encourage brainstorming of further ways that family can support the wellness of the client and retention in HIV care.

3. **Apply personalismo into the health care encounter by asking about wellbeing beyond HIV; family; etc.** – Puerto Rican women living with HIV in NYC have identified that they want to develop relationships with their providers that go beyond the health concerns being treated. This means beginning each healthcare encounter by talking with them about their wellbeing in a holistic way using pleasantries, and then proceeding to listen to client needs, such as personal concerns that could impact care. By adjusting their approach to meet the specific needs of the client, i.e. giving them space or providing reminders as the circumstances require, the provider retains the client in care. To do this the provider must be “someone who listens more than what they talk” (G12), and here, listening can also mean watching for signals from the client to advance to next steps in care and acting accordingly, as when a provider told a key informant, “I was waiting for you to tell me, you were using again” (K1). Another way to apply personalismo is becoming involved in assisting with services, such as accessing care programs, “He sent me to (long-term care facility) and they treated me like a queen” (K4). Lastly, personalismo, also means sharing some personal information, in a reciprocal manner. The provider should identify personal information that can be comfortably shared to
foster a more personal connection with the patient. An example would be sharing similar parenting concerns, such as calming a crying baby.

4. **Negotiate healthful dietary practices** – The diet as described in this study included many fried foods that were high in carbohydrates. While being of Latino ethnicity is identified as an added risk factor for Type 2 diabetes, it is often the lower socio-economic status and corresponding dietary choices that better explain this risk (Perez-Escamilla, 2011). Living with HIV is also known to be associated with an increased risk for Type 2 diabetes and cardiac disease, due to the accelerated aging related to chronic inflammation and exposure to ARVs. Dietary modifications requiring reductions in carbohydrate and fried food intake and increased consumption of lean protein and fruits and vegetables are recommended to improve tolerance of medication regimens and slow down the effects of the associated metabolic conditions. Working with the clients to use more healthful preparations of favorite meals, such as baking versus frying meats, can assist with this repatterning process to improve dietary intake. Portion control can also be taught for foods which are consumed in celebration of holidays, e.g. *pasteles* at Christmastime.

5. **Negotiate incorporating exercise patterns into daily routine** – Including exercise activity that increases lean muscle mass can also assist with reducing weight, improving carbohydrate metabolism and reducing inflammatory processes. Providers can work with the clients to identify activities besides walking that can improve cardiovascular health. For lower income clients, this would also include identifying low-cost or subsidized exercise programs at ASOs. The informants reported engaging in exercise to maintain wellness and reduce weight.
6. **Negotiate herbal remedies used for wellness and managing symptoms that cause interactions** – When the risk of medication interactions with herbal remedies becomes a concern, the provider should consider an alternative medication or combination of medications to avoid stopping the culturally-based herbal remedy that provides symptom management. Building upon the knowledge acquired during assessment, the provider would have prior information on herbal remedies used by the client when considering a new medication. Each healthcare visit should include inquiries regarding any herbal remedies, especially after a change in season, when new herbs may become available. The informants for this study reported using herbal remedies recommended by family and others, included those sent from Puerto Rico and other countries.

7. **Negotiate the use of the air bridge** – Many Puerto Rican women living with HIV have extensive familial contacts and networks in Puerto Rico and other locations in the US. Travel to these locations where family lives can result in an extended visit, leading to missed provider visits (Gill & Krentz, 2015). Becoming knowledgeable about travel plans (achieved through **personalismo** – see decision and action mode above) will indicate the need to identify the care, providers, clinics and services, available in the area. If necessary, the provider can provide an earlier refill of medications to ensure uninterrupted access to medications and/or arrange for prescription refills (insurance coverage permitting) or laboratory testing during their time away.

**Culture care repatterning and/or restructuring.** Culture care repatterning and/or restructuring are other modes wherein the provider is actively working to understand the culture care practices, however, the perspective is to identify those practices that are harmful to the client in general or because of specific health conditions. Repatterning seeks to modify the
culture care practices to make them safer for the client. The intention is to continue to identify ways to continue those activities that the client deems are important to their cultural identity in a less harmful or harmless way. In contrast, restructuring seeks to eliminate unsafe cultural practices because there is no identified safer alternative.

1. *Instruct on use of condoms and other safer sex practices* – The use of condoms, male and female, and other latex barriers during sexual contact can reduce the transmission of HIV and other infections between partners. Limiting sexual activity whenever someone is ill and potentially experiencing increases in viral load can also limit exposure to organisms which could trigger immune system activation and further HIV production. A full sexual health assessment by the provider would determine the types of sexual activities the client engages in to provide more specific information on safer sex practice recommendations for repatterning this behavior. The use of condoms, male and female, should be demonstrated on a model with a return demonstration as the preferred assessment of this skill. In addition, opportunities for skill development, for example role playing, in safer sex negotiations, that reflect the expressed gender, sexual and cultural norms of the individual (e.g. sexual orientation, *marianismo/machismo*, etc.,) should be provided in the clinic setting or referrals can be made to programs that would also provide that opportunity. An assessment of gender and cultural norms is needed to determine how this could be approached in a sensitive manner. The informants for this study reported using male and female condoms and avoiding sexual activity to reduce the risk of transmitting the virus. They also shared the difficulties they experienced when negotiating safer sex practices, when their sexual partners did not want to use condoms.
Some chose to end relationships rather than continue to unsuccessfully negotiate condoms.

2. *Assist with disclosure of diagnosis to family, friends and intimate partners* – For those clients who have not disclosed their diagnosis to family and intimate partners, the provider needs to help the client determine when and how to best disclose this information and repattern non-disclosing behaviors. The provider can assist with practicing disclosure using role play and the provider’s office can serve as a setting for disclosure which would also create an opportunity for the loved one to have their questions answered by the provider or other health care worker rather than the client. Privacy and ample time must be provided and the language needs of the loved one must be considered. If an interpreter service is needed, this should be planned for in advance, meaning the interpreter is present upon arrival; and, the interpreter should be familiar with terminology used in HIV care and the corresponding translations. The provider can also assist the client to determine how much information will be shared and in what format going forward to moderate caring behaviors of the loved ones, thus avoiding “overcare” (K2). The informants shared how difficult disclosure was, particularly, their fears of rejection. Some of the informants had no plans to disclose to their families as a result.

3. *Encourage limiting substance use patterns (alcohol, tobacco, drugs), to prepare for enacting discontinuation of use via cessation programs* – Continued substance use can cause damage to vital organs that are stressed by the processing of ARVs (liver and kidneys); increase risk for development of AIDS defining diagnoses (recurrent bacterial infections); accelerate the aging process along with HIV infection; increase exposure to
organisms and the development of comorbid conditions (Hepatitis B, C, etc.); complicate adherence to medication regimens and provider visit schedules. Providers should be working with clients to restructure these substance-using behaviors to limit or eliminate the risks listed above. There must be an understanding that repatterning might be necessary in the interim to reduce substance use (harm reduction) until cessation can be achieved. Referrals to harm reduction and cessation programs should be made to programs that are culturally sensitive and family focused. As discussed by Puerto Rican women living with HIV with a substance use history, their recovery was complicated when the cessation programs available to them restricted their ability to care for children; did not provide them with a full range of services (safer sex information); or were associated with religious agendas (Deren, et al, 2014; Perez Torruella, 2011).

4. **Identify diverse religious and spiritual care practices for maintaining mental/emotional and physical health that can be harmful and repattern to use alternate integrative care practices that are not harmful** – Puerto Rican women living with HIV reported the use of spiritual and religious practices, based in Espíritismo and Santería, which can involve exposure to smoke from incense and burning candles, and handling live animals and raw animal products or animal carcasses during rituals for spiritual wellbeing. Becoming knowledgeable about these practices by speaking directly with the clients and/or their spiritual/religious leaders can open avenues to discussions of ways to repattern these practices into self-care, minimizing exposures to substances that can cause health problems, by substitution with other practices (e.g. pouring holy water over the head versus surrounding the body with cigar smoke, including blowing smoke in the face, to perform a spiritual cleansing). When necessary, some practices need to be restructured
when no spiritually equivalent activity exists. A sensitively administered cultural assessment can appropriately identify activities for repatterning versus restructuring.

5. Engage in activities that encourage increased trust between Puerto Rican woman and providers – Providers must use integrative care to enact culture care practices that will engage people living with HIV to trust providers. Historical precedence in various communities: Latino (birth control pill testing in Puerto Rico), African-American (the USPHS syphilis research program at Tuskegee University), and people living with HIV (delays in acknowledging the epidemic and ARV development) eroded potential trust between Puerto Rican women living with HIV and providers. Only when providers can demonstrate that they can be trusted with the lives of Puerto Rican women living with HIV and others by implementing culturally congruent care practices, and personalismo, will they be willing and able to trust their providers (repattern and restructure).

6. Assist individuals to become active participants (engaged) in care, especially HIV care – Being an active participant in care is new to many people living with HIV who were often not given respect of their opinions, preferences, and their time in clinic settings and their personal and cultural needs during the healthcare encounter. Moving from passive to active participation during healthcare encounters requires that the provider first become knowledgeable about the type of client-provider relationship the client wants (Christopoulos, et al, 2013). Then, the provider can instruct the client about the resources available to assist them to be more actively involved and retained in care. It may be necessary to assist the client to navigate the healthcare system as seeking treatment for HIV could be the first time any healthcare services have been regularly utilized. This can include addressing the structural supports missing in a client’s environment (e.g., regular
transportation to clinic setting, regular meals to take ARVs with food, child care for provider visits, etc.) The informants for this study identified the activities of their care providers that engaged them in care, by demonstrating concern and respecting their needs. The desired behaviors varied from informant to informant but met their changing needs over time. The trust they developed with their providers (see above) through personalismo was key to their engagement in care.

7. Encourage seeking mental health care from a licensed professional – For some clients, a mental health diagnosis is equally as stigmatizing as a diagnosis of HIV. In this case, providers need to work carefully with clients to enable them to become comfortable with using mental health services (re patterning). Ensuring the availability of providers who have an in-depth understanding of the culture of the clients is imperative to the development of rapport, trust, and continued use of services to address mental health concerns that could impact implementation of HIV care recommendations, as noted above. The Puerto Rican community has been stigmatized by the mental health community which deemed their cultural behaviors and spiritual activities to be symptoms of mental illness, requiring treatment including medications and/or institutionalization (Gherovici, 2003; Rojas-Vilches, et al, 2011). Some of the informants had personal experience with these 20th century practices and were victimized by the mental healthcare system.

In these culture care decision and action modes, the provider is actively working with the client on behavior change and will need to provide support to the client through the process (Capili, et al, 2014). Motivational interviewing techniques can be useful through all the modes as they provide strategies for providers to use wherever someone is in the change process (Dart, 2010).
The culture care decision and action modes work to acknowledge and encourage healthful culture care practices and discover ways to modify unhealthful behaviors in a culturally sensitive manner. Providers need to find a way to fit into the client’s world (St. Clair, 1999 in Eipperle, 2015) versus the client fitting into the provider’s world of HIV care to achieve the outcomes of viral suppression and visit adherence. By using the culture care decision and action modes and integrating the generic care needs and professional care needs, providers can connect with clients in a way that builds a trusting relationship which has been identified by Puerto Rican women living with HIV as an important factor for improving patient engagement and retention in care. The provider is also engaging in behavior change, themselves, when they use the culture care decision and action modes, and because this may be a new method of approaching patient care, they will also need to be supported by colleagues who are more experienced in using the culture care decision and action modes with people living with HIV.

**HIV Continuum of Care**

The HIV Treatment Cascade developed from the statistically descriptive findings of the Medical Monitoring Project study of people living with HIV receiving HIV care in major cities of the United States (Blair, et al, 2014, June 20). The cascade of the numbers of people living with HIV; diagnosed with HIV; referred to HIV care; engaged in care; prescribed ARVs; and, virally suppressed provided a snapshot of the status of the epidemic in the US and clearly indicated that there were significant gaps in care across all demographic categories (Bradley-Springer, 2014). By quantifying gaps in care, these findings have become the basis for the HIV continuum of care, reflecting the need for various care activities, organized by categories, HIV care providers and settings can implement to close those gaps in care. Accompanied with the knowledge of the effectiveness of pre-exposure prophylaxis (PrEP) and the philosophy of
treatment as prevention (TasP), the HIV continuum of care delineates a shift in focus from isolating the activities of HIV prevention and HIV treatment to combining them into a new public health strategy (CDC, 2017, July; NYSDOH, 2015, March; Ostmann & Saenz, 2013). Moving from public health programs concentrating on helping people identify their HIV exposure risk and get tested, the new protocols go beyond to working on approaches that will connect the newly diagnosed into HIV care settings and keep them linked and then engaged in care.

Research question five of this study sought to identify what culture care decision and action modes could become a strategy for providers to work with clients to maintain adherence to their medication and treatment regimens (Mignano, 2016). In the interim between the first conceptualizations of this study, its implementation, and analysis, there have been great shifts in the thinking of how providers should be approaching HIV care (Barroso, et al, 2017) as described above. It, then, became necessary to further develop the application of the findings from this study of the culture care needs of Puerto Rican women living with HIV into the culture care decision and action modes and then link them into the HIV continuum of care (CDC, 2017, July) to determine how they could best be applied in the engagement and retention in care and developing integrative care practices for HIV care providers. Table 5.3 provides a mapping of the culture care decision and action modes identified through the findings of this ethnonursing study to outcomes on the HIV continuum of care for use by healthcare providers. These data can be used for the allocation of resources in culturally appropriate ways throughout the continuum of care to create pathways for the individual or community to arrive at their desired outcomes.
### Table 5.3

Culture Care Decision and Action Modes for Use in the HIV Continuum of Care

<table>
<thead>
<tr>
<th>HIV Continuum of Care (CDC, 2017, July)</th>
<th>Culture Care Decision and Action Modes for Puerto Rican women living with HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosed with HIV</td>
<td>Accommodation and/or Negotiation</td>
</tr>
<tr>
<td></td>
<td>1. Provide healthcare services in Spanish (or desired language) for all encounters</td>
</tr>
<tr>
<td></td>
<td>2. Include family/caregivers into care by inviting them into the health care encounter (familismo)</td>
</tr>
<tr>
<td></td>
<td>3. Apply personalismo into the health care encounter by asking about wellbeing beyond HIV, family, etc.</td>
</tr>
<tr>
<td></td>
<td>Repatterning and/or Restructuring</td>
</tr>
<tr>
<td></td>
<td>1. Engage in activities that encourages increased trust between Puerto Rican woman and providers</td>
</tr>
<tr>
<td></td>
<td>2. Encourage seeking mental health care from a licensed professional</td>
</tr>
<tr>
<td>Linked to care (visited a healthcare provider within 30 days of receiving HIV diagnosis)</td>
<td>Preservation and/or Maintenance</td>
</tr>
<tr>
<td></td>
<td>1. Preserve participation in support groups/talking with trusted others</td>
</tr>
<tr>
<td></td>
<td>Accommodation and/or Negotiation</td>
</tr>
<tr>
<td></td>
<td>1. Provide healthcare services in Spanish (or desired language) for all encounters</td>
</tr>
<tr>
<td></td>
<td>2. Include family/caregivers into care by inviting them into the health care encounter (familismo)</td>
</tr>
<tr>
<td></td>
<td>3. Apply personalismo into the health care encounter by asking about wellbeing beyond HIV, family, etc.</td>
</tr>
<tr>
<td></td>
<td>4. Negotiate the use of the air bridge</td>
</tr>
<tr>
<td></td>
<td>Repatterning and/or Restructuring</td>
</tr>
<tr>
<td></td>
<td>1. Engage in activities that encourages increased trust between Puerto Rican women and providers</td>
</tr>
<tr>
<td></td>
<td>2. Encourage seeking mental health care from a licensed professional</td>
</tr>
<tr>
<td></td>
<td>3. Instruct on use of condoms and other safer sex practices</td>
</tr>
<tr>
<td></td>
<td>4. Assist with disclosure of diagnosis to family, friends and intimate partners</td>
</tr>
<tr>
<td></td>
<td>5. Encourage limiting substance use (alcohol, smoking, drugs), to prepare for enacting discontinuation of use via cessation programs</td>
</tr>
<tr>
<td>Retained in care (receiving HIV care)</td>
<td>Preservation and/or Maintenance</td>
</tr>
<tr>
<td></td>
<td>1. Preserve participation in support groups/talking with trusted others</td>
</tr>
<tr>
<td></td>
<td>2. Maintain spiritual and religious activities of prayer, protection, meditation</td>
</tr>
<tr>
<td></td>
<td>3. Preserve and maintain familial contact for support and encouragement and reminders for self-care practices</td>
</tr>
</tbody>
</table>
4. Preserve and maintain use of herbal remedies, that do not cause interactions with medications, for wellness and managing symptoms into the plan of care

Accommodation and/or Negotiation
1. Provide healthcare services in Spanish (or desired language) for all encounters
2. Include family/caregivers into care by inviting them into the health care encounter (*familismo*)
3. Apply *personalismo* into the health care encounter by asking about wellbeing beyond HIV, family, etc.
4. Negotiate healthful dietary practices
5. Negotiate incorporating exercise patterns into daily routine
6. Negotiate use of the air bridge
7. Negotiate herbal remedies and integrative care used for wellness and managing symptoms with interactions

Repatterning and/or Restructuring
1. Engage in activities that encourages increased trust between Puerto Rican woman and providers
2. Encourage seeking mental health care from a licensed professional
3. Instruct on use of condoms and other safer sex practices
4. Assist with disclosure of diagnosis to family, friends and intimate partners
5. Encourage limiting substance use (alcohol, tobacco, drugs), to prepare for enacting discontinuation of use via cessation programs
6. Identify diverse religious and spiritual care practices for maintaining mental/emotional and physical health that can be harmful and repattern to use alternate integrative care practices that are not harmful
7. Assist individuals to become active participants (engaged) in care; especially HIV care

Virally suppressed (HIV is undetectable in the blood)

Preservation and/or Maintenance
1. Preserve participation in support groups/talking with trusted others
2. Maintain spiritual and religious activities of prayer, protection, meditation
3. Preserve and maintain familial contact for support and encouragement and reminders for self-care practices
4. Preserve and maintain use of herbal remedies, that do not interact with medications, for wellness and managing symptoms into the plan of care

Accommodation and/or Negotiation
1. Provide healthcare services in Spanish (or desired language) for all encounters
2. Include family/caregivers into care by inviting them into the health care encounter (*familismo*)
3. Apply *personalismo* into the health care encounter by asking about wellbeing beyond HIV, family, etc.
4. Negotiate healthful dietary practices
5. Negotiate incorporating exercise patterns into daily routine
6. Negotiate use of the air bridge
7. Negotiate herbal remedies and integrative care used for wellness and managing symptoms with interactions

**Repatterning and/or Restructuring**
1. Engage in activities that encourages increased trust between Puerto Rican woman and providers
2. Encourage seeking mental health care from a licensed professional
3. Instruct on use of condoms and other safer sex practices
4. Assist with disclosure of diagnosis to family, friends and intimate partners
5. Encourage limiting substance use (alcohol, tobacco, drugs), to prepare for enacting discontinuation of use via cessation programs
6. Identify diverse religious and spiritual care practices for maintaining mental/emotional and physical health that can be harmful and repattern to use alternate integrative care practices that are not harmful
7. Assist individuals to become active participants (engaged) in care; especially HIV care

The findings from this study and the accompanying patterns and themes created an opportunity for the informants to identify their desires for characteristics and actions of providers and care settings that have helped them stay in HIV care. These informants have worked very hard to overcome their feelings of mistrust of the health care system that stigmatized them for being Puerto Rican women, poor and having HIV disease, as per the stories they shared. This qualitative study using the ERM gave their voice a microphone to be heard in a way that other methods could not. Cook, et al (2015) identified that multiple factors: stigma, access, and belief in the need for care, can impact the decision to engage in care, in a study examining the perspectives of linkage to care for people living with HIV. They concluded that providers should obtain recommendations from clients regarding strategies to address their concerns at each point in the HIV continuum of care. These recommendations could be identified using the CCT and
the accompanying enablers, as in this ethnonursing study. Providers, when working with people living with HIV, could then develop a knowledge base and a set of assessment skills focusing on culture care beliefs, expressions, needs, desires, decisions, and actions, (Castro & Ruiz, 2009; Courtney & Wolgamott, 2015; Eipperle, 2015; Embler, 2014, October 23-24; Gagnon, et al, 2015; Kelly, et al, 2014; Leininger, 2006b; Mattelliano & Street, 2012; McFarland & Wehbe-Alamah, 2015; Mignano, 2016; UNAIDS, 2017).

For over twenty years the AIDS Education Training Centers (aetc.org) have offered preceptorships in HIV care to many providers to prepare them to provide HIV care on their own. Similarly, culture care preceptorships could give NPs and other health care providers the opportunity to observe and practice performing culture care assessments and delivering culturally congruent care. If these NPs and providers are planning to provide HIV care, then they could learn how to apply culture care decision and action modes to support patients at the various points on the HIV continuum of care. The culture care decision and action modes of maintenance and/or preservation; accommodation and/or negotiation; and repatterning and/or restructuring as presented in the previous section, could assist NPs and other health care providers to guide their patient care encounters and interactions as determined by the client’s needs for care (Eipperle, 2015). Furthermore, applying these findings collaboratively through interprofessional team efforts in the clinical setting (Graham, 2015) could establish the preferred long-term patient-provider relationships, as described by the informants. The culturally-congruent, patient-centered relationships (ANA, 2015) the informants developed with their providers, supported their retention and engagement in care and accomplished treatment adherence and viral suppression (for all but one informant), as proposed by the TasP model.
Theoretical Formulations

Multiple theoretical formulations emerged from the analysis of the findings. These theoretical formulations address personal care encounters, including self-care and care for and by others, the professional care encounter, and the social structural environment, including political and economic dimensions. These formulations are: (a.) *interpersonal relationships are very important for engaging Puerto Rican women in HIV care*; (b.) *desired qualities of the health care provider include being knowledgeable about safe HIV care and demonstrations of personalismo*; (c.) *demonstrations of caring expressions for others are vital to prevent the transmission of HIV and to assist people to transition into a life with HIV*; (d.) *desired care environments have spiritual, familial, social-structural, political and economic dimensions to deliver holistic care, including mental health services and complementary healthcare*; (e.) *desire to control chaotic personal situations which threaten self-care and/or overly concerned loved ones who only focus on the HIV diagnosis is a form of protection and self-care*; (f.) *HIV-related stigma remains a significant barrier to care in all settings*. Each of these theoretical formulations is discussed below.

*Interpersonal relationships are very important for engaging Puerto Rican women in HIV care.* Having a caring connection to others (family and loved ones) is a motivation to care for self, but it is also the relationships with care providers (nurses, NPs and other health care providers) that facilitated their work to gain health and wellbeing (Buscher, et al, 2015; Dawson-Rose, et al, 2016; Earl et al, 2013; Eipperle, 2015; Embler, 2014, October 23-24; Gelaude, et al, 2017; Grimes & Grimes, 2013; Kelly, et al, 2014; Mattelliano & Street, 2012; Webel, et al, 2016). These supportive relationships are especially vital because of the continued stigma associated with HIV and the continued perception of death connected to this disease. Strong
interpersonal relationships provide support during difficult times: being close to death with an AIDS complication; being discriminated against by a health care professional, health care worker, acquaintance or family member; managing the day-to-day activities required to live with HIV.

*Desired qualities of the health care provider* (NP, other prescribing provider, nurses, etc.) include being knowledgeable about safe HIV care and demonstrations of personalismo. The specific professional license or certification of the healthcare provider is not of importance, but safe care is essential. Safe HIV care includes treatment of HIV and other AIDS related conditions infections that follows the current state-of-the-art recommendations (Brion, 2014; Calo, et al, 2014; Graham, 2015) and the consistent use of universal precautions as appropriate to the risk of body fluid exposure for their own safety and that of the patients in their care. The provider should demonstrate characteristics of personalismo (Castro & Ruiz, 2009; Sobel & Metzler Swain, 2016) and be more focused on the overall wellbeing of patients rather than meeting targets for completed visits and financial gain. The ways in which personalismo could be demonstrated included expressing a nonjudgmental attitude regarding previous and current life experiences and behaviors (Brion, 2014; Gelaude, et al, 2017; Graham, 2015); expressing caring (Brion, 2014; Embler, 2014, October 23-24) and trusting (Dawson, et al, 2016) behaviors (Graham, 2015) that show a personal interest in patients beyond the HIV/medical conditions, being managed during the healthcare encounter.

*Demonstrations of caring expressions for others are vital to prevent the transmission of HIV and to assist people to transition into a life with HIV.* These expressions of caring included being willing to disclose HIV status and participate in research to disseminate needed information to help people at risk to protect themselves. Additional expressions of caring are
needed when someone is newly diagnosed with HIV, since guidance is required through the transition. The goal is to assist these individuals to cultivate a more positive outlook on the diagnosis and reduce stigma through support. This can help them become connected to care, thereby creating more opportunities to reduce morbidity and mortality and reduce further transmission of the virus through TasP (Cook, et al, 2015; Graham, 205; Kelly, et al, 2014).

Desired care environments have spiritual, familial, social-structural, political and economic dimensions to deliver holistic care, including mental health services and complementary healthcare. The health care and self-care environment is determined by political, social structural, economic, technological and spiritual factors. The variability of the support or presence of these factors facilitated the entrenchment of the HIV epidemic in communities of color creating excessive health disparities. Without the political will to provide funding and program support for addressing the social determinants of health (such as economic, housing and educational factors) that have contributed to the disparities in HIV, there will be little improvement (Chase, 2011; Dennis, et al, 2015; DeVoe, et al, 2016; Mignano, 2016). Informants shared their concerns about their housing, economic and health care access situations, which caused them excess stress impacting their ability to care for themselves effectively and the functioning of their immune systems. The variability of care from one geographic setting to another was a significant issue in that it forced individuals to choose their healthcare over their support systems. Informants relocated to NYC or refused to relocate away from NYC to maintain access to better coordinated healthcare which included mental health and substance use treatment and coverage for ARVs. The use of technology improved access to information for self-care and spirituality provided the calm to combat the stressors previously described.
Desire to control chaotic personal situations which threaten self-care and/or overly concerned loved ones who only focus on the HIV diagnosis is a form of protection and self-care. Controlling the care environment was important finding as many people living with HIV find themselves solely defined by the diagnosis in their interactions with others: healthcare providers, family and friends. Many of their interactions became dominated with the current state of their illness: “How many T-cells do they have?;” “What was their most recent viral load?;” Are they experiencing any symptoms now? How is their appetite? Are they exercising, etc.? This overemphasis on their health status by loved ones was described as “over care.” They expressed a desire to control what was discussed in their interactions with others as result and they developed strategies to limit discussion ranging from failure to disclose a diagnosis to restricting conversations to certain topics (Matchinger, et al 2015; Ortiz, 2005). Another area requiring control over personal interactions was personal chaos created by family and friends. In these cases, creating boundaries and limiting contact, called “loving from a distance” by the informants, was necessary to maintain wellbeing.

Stigma remains a significant barrier to the self-care practices by preventing the implementation of risk reduction strategies and presenting for HIV testing. Stigma, experienced as discrimination from health care workers and providers also impacts the delivery of HIV care by preventing people from fully engaging in care, since there is no trust (Barroso, et al, 2017; Davtyan, et al, 2016; Dawson, et al, 2016; Farley, et al, 2015; Gagnon, 2015; Holzemer, 2017, November 2; Relf, et al, 2005). Many instances of stigma in different settings were shared by all informants making it a pervasive concern requiring mental health care services (Matchinger, et al, 2015) and spiritual/religious practices to overcome. Informants were very concerned that the
continued existence of stigma maintains environments that perpetuate the HIV epidemic, a situation that must be addressed (Gagnon, 2015; Holzemer, 2017, November 2).

**Implications**

The implications of the findings of this ethnonursing research study and its corresponding patterns and themes can be identified in theory, research, practice, education, administration, and policy. The implications will be further explicated in the subsequent sections and there are instances of overlap of the implications’ applicability to multiple areas. This reflects the interconnectedness of these areas as well as the integrative nature of culture care.

**Theory.** The implementation of this study using the ethnonursing research method further builds upon the Theory of Culture Care Diversity and Universality (Culture Care Theory) as intended by Madeleine Leininger when she developed both the theory and related qualitative ethnonursing research method. The findings of this ethnonursing study and the resulting discovery of the five universal and one diverse theme and their accompanying patterns support the tenets of the CCT, specifically, Leininger’s first theoretical tenet: “Culture care expressions, meanings, patterns, and practices are diverse and yet there are shared commonalities and some universal attributes” (McFarland & Wehbe-Alamah, 2015, p. 7)

This ethnonursing study’s patterns and themes also supported another theoretical tenet: “the worldview, multiple social structure factors, ethnohistory, environmental context, language, and generic and professional care are critical influencers of cultural care patterns to predict health, wellbeing, illness, healing, and ways people face disabilities and death.” (McFarland & Wehbe-Alamah, 2015, p. 7). This second tenet of the CCT was demonstrated through discovery of rich data that highlighted past and developing culture care patterns related to HIV diagnosis, and experiences of health, illness and healing in the face of an HIV diagnosis.
The third theoretical tenet that was supported by findings from this ethnonursing research study was: “generic emic (folk) and etic (professional) health factors in different environmental contexts greatly influence health and illness outcomes” (McFarland & Wehbe-Alamah, 2015, p. 7). Puerto Rican women with HIV related rich descriptions of the varying influences of generic and professional care beliefs, practices, and expressions on health and illness. In addition, the longevity of these individuals in living with HIV provided an opportunity to compare their experiences within their environmental contexts at various points of time. The informants contributed profound emic descriptions of their experiences with HIV early in the epidemic, when the disease was considered fatal, through current expectations of minimal risks of virus transmission and reduced numbers of deaths.

The patterns and themes discovered for this community of Puerto Rican women living with HIV in NYC can also be folded into the discovered patterns and themes of other ethnonursing studies guided by the CCT focused on Puerto Rican women and people (Higgins, 1995; Fliszar, 2004; Martin-Plank, 2008) further building the beginning knowledge that is available for this cultural group. Other areas for study using the ERM are HIV care in the US and in other areas of the world (MacNeil, 2002); caring relationships between providers and clients; transnational communities (Andrews, et al, 2010); cultural pain (Anderson, Boyle, et al, 2010; Andrews, et al, 2010), stigma (Anderson, Andrews, et al, 2010; Anderson, Boyle, et al, 2010; Clark, et al, 2010; Holtz, 2010) and cultural distress (Andrews, et al, 2010).

More studies can and should be pursued, using methods appropriate for cultural phenomena (Douglas, et al, 2010), to expand, deepen and enhance health care providers’ understanding of the Puerto Rican women and their families. The experiences of the informants as shared with the researcher revealed women who were deeply connected to their families and
often were inspired and/or supported by their families to continue to live with HIV rather than die (MacNeil, 1996). These relationships and their cultural foundation merit further exploration, as many of the informants connected their familial ties to their Puerto Rican identity. Informants also described their experiences of single parenthood, both before and after their HIV diagnosis, and individual relationships with their own parents. The structures of these families, such as women working outside of the home, encouraged family roles and responsibilities that did not reflect anticipated gender norms. The influence of the social determinants of health, like economics and education; and, illness, including HIV, mental health and substance use disorders, on these family structures need further exploration to better comprehend the cultural expressions of Puerto Rican families.

Further data are needed on cultural pain and stigma and the psychological and physiological presentations of each for individuals living with HIV. The CCT frames these through dimensions of caring and other factors in ways to reveal their complexities and perhaps explain the depth of the associated trauma, that, despite efforts at amelioration, persists. Stigma persists because of intersectionality that layers the stigmas associated with the different subcultures, poverty, substance use, living with HIV, etc., within the community, warranting further exploration. The informants identified professional care givers as well as family and acquaintances as sources of stigma reinforcement. When the professional caregivers stigmatized the informants, this was experienced as discrimination and cultural pain, due to the expectation of knowledge to counteract these behaviors. More ethnonursing and ethno-studies could provide the knowledge to address this concern in educational efforts to develop culturally competent practice organizations (Marrone, et al, 2010 & 2013).
HIV care in the US and across the world is changing as HIV disease has become a chronic disease and the means to reduce and possibly eliminate transmission is available (CDC, 2017, July; UNAIDS, 2017). Better understanding is needed about the culture care needs of the communities most affected by HIV because of the profound influence of social determinants of health and experiences of racism on risk for HIV infection. The CCT can provide guidance using Leininger’s Sunrise Enabler to Discover Culture Care to uncover the socio-structural, biological, political, ethnohistorical, educational and cultural dimensions of desire for HIV care. Exploring specific responses, including stigma, to health conditions that have cultural meaning, like HIV, can develop new knowledge for the CCT, and provide further validation of the underlying assumptions of the theory.

An important finding of this study was the value of caring relationships between providers and patients, which was framed through cultural norms, like personalismo. Future ethnonursing studies can continue to explore caring expressions in varying communities, cultures and health conditions. Discoveries can be expanded and further explicate the attributes and actions that define caring relationships for various cultures, which providers can then use to help them acquire the attributes and take the actions that are desired by their patients. In addition, it could be discovered that different caring professional relationships are desired for different health conditions, which would be important information for any primary care provider.

Research. This study has also identified implications for research development. The ERM was developed specifically for use with the CCT to advance the theory by discovering the evidence-based holding knowledge and the accompanying skills to incorporate culture-specific care (Leininger, 2006 & Wehbe-Alamah & McFarland, 2015). In this study, the researcher shared the cultural and linguistic background of the informants. These shared characteristics
were helpful for fostering trust in the research relationship giving rise to the revelation of sensitive information within a short period of time. This experience could further the depth of discovery of culturally relevant data to develop the CCT. There are differences in cultural and linguistic similarities and it can be expected that a researcher who shares either the culture or the language of the community of interest may have differing experiences while interacting with the informants, such as being unable to understand or express cultural phenomena. Since the researcher is a meaningful conduit of the knowledge in qualitative research, these anticipated differences should be explored. At the same time, there is increased potential for bias when the researcher shares culture or language with the informants. The consistent and transparent use of methods for bracketing bias, including journaling, the guidance of an ethnonursing mentor, and the review of transcriptions and validation of findings by the key informants, are essential (al-Amer, et al, 2014; Wehbe-Alamah & McFarland, 2015b). Lastly the experience of conducting ethnonursing research with individuals from the same cultural background should be explored to discover any concerns, such as over-identification or differing sources of bias, for the researcher.

Other research topics which can be explored using the ERM, as well as, other methods, were identified for further development based on the findings and analysis of patterns and themes of this study. Linguistic congruency became a very important concept within this study, as did professional caring relationships in relation to engagement in HIV and primary care. Integrative care is becoming a norm of desired care from professionals and further research is necessary to better understand the spiritual, herbal and family care practices that individuals use in self-care.

Linguistically congruent researchers have been recommended to expand the participation of non-English speakers in biobehavioral and clinical research (Garcia, et al, 2017: Lopez-
Even individuals with a basic knowledge of English preferred to participate in research using their primary language as occurred in this study. This study could not have been completed without the ability of the researcher to speak Spanish and would have required a complete reconceptualization of the study. The use of linguistically congruent researchers will have two benefits through inclusion of non-English speakers (Wehbe-Alamah, 2005): expanding the findings of studies by diversifying and increasing the participant pool; and, creating new opportunities for lines of inquiry based on these diverse research participants.

Linguistic congruency can impact the delivery of professional care to individuals (Sanchez, et al 2014). Each of the informants shared their experiences of professional care givers (nurses, nurse practitioners, and physicians) who either spoke Spanish or did not and there were variances in the perceptions of the care and the caring professional relationships that resulted. More study should be devoted to the effects of linguistically diverse providers to determine what differences in care result, such as increased errors in care because of misunderstandings during assessments or health teaching on medication administration. Utilization of supportive services, such as interpreters, for everyday care delivery beyond crucial conversations or obtaining informed consent, should be examined to determine the potential for added costs for the care encounter, or errors in care based on the type of interpreter service used (telephonic, video-based, or in person) (Mayo, et al, 2016). Other components in the use of interpreters that merit further investigation are the variations in the experience when there are differences in subcultures, sex, gender, race, economic class between the patient and the interpreter. Lastly, patient preferences for care and perceptions of satisfaction also merit exploration by researchers.
HIV care has entered a new phase in which all activities will be viewed through the lens of the continuum of care based on the treatment cascade. Efforts by providers (nurse practitioners and physicians) and nurses to engage patients into care have begun to take on a new sense of urgency as it has become clear that undetectable levels of HIV viral load results in virtual non-transmission of the virus (CDC, 2017, September). This study has proposed that use of the Cultural Care Decision and Action Modes (McFarland & Wehbe-Alamah, 2015) can create culturally congruent care experiences that will bring people living with HIV into care settings and develop the trust and readiness (Eipperle, 2015) to begin ARV treatment to reach viral suppression, tapping into TasP initiatives (CDC, 2017, July). Studies, using qualitative and/or quantitative methodologies, can explore the CCT’s integration into other aspects of HIV care, such as prevention efforts like promotion of safer sex practices, safer injecting drug use activities and PrEP; and, its effect on the care provided to vulnerable communities at increased risk of HIV infection and disease, exploring the specific caring attributes and actions as desired by these communities.

This study also discovered various spiritual, herbal and family care practices that supported Puerto Rican women through their journeys living with HIV. These practices were grounded in their cultural life experiences. There was variety in the use of spiritual and herbal caring practices, with informants sharing diverse experiences with use and desire to share this information with their providers was related to trust and expectations of the patient role. Further study is necessary to develop better understanding of what these herbal practices are; how and when these herbal practices are used; when and why these herbal practices are stopped; and what situations determine when they share this information with their providers to maintain quality and safety of care. Spiritual practices will also need further exploration to identify the specific
roles they play, especially in self-care, when some religions can perpetuate some of the stigmas experienced by people living with HIV (Anderson, Andrews, et al, 2010). Familial care was vital for Puerto Rican women living with HIV and there was often an expectation that family members be incorporated into their care as determined by the informants. Familial care will vary, and these differences require research for understanding by providers to develop the best practices, Cultural Care Decision and Action Modes, that will respect cultural practices while complying with the legal requirements of privacy and confidentiality.

Another area for research is the care of transnational, air bridge, communities (Andrews, et al, 2010), the variation that exists for Puerto Rican communities and the healthcare they require as they travel from one geographical area to the other. There are various ways in which transnational, air bridge, communities utilize healthcare services. Transnational healthcare services utilization research can determine what services are most likely to be accessed and where that utilization takes place. It is also important to be clear that many of the Puerto Rican communities have family within the US and its territories but with the fragmented and differing services from state to state and state to territory, care can easily be disrupted when people travel to visit family for extended vacations or to care for ailing family members. The trends of utilization and the alternative use of resources will provide vital data for healthcare planning by states and municipalities within the US and its territories, as well as other countries.

Practice. One of the caring attributes that the informants for this study desired was a provider who understood and followed the DHHS Guidelines on HIV Care (Panel..., 2017, October). These guidelines are updated annually and contain current recommendations for the diagnosis and treatment of HIV in the United States. The DHHS also provides guidelines for the care of HIV-related health concerns: care of women desiring pregnancy or are pregnant; infants
and children; and, opportunistic infections. These guidelines are all available at www.aidsinfo.gov. Besides using these state-of-the-art practices, the informants also desired care that would be personalized for them, taking into consideration their specific needs.

The experiences of Puerto Rican women living with HIV indicate that cultural caring practices need to be integrated into the HIV continuum of care. Continuing stigma surrounding an HIV diagnosis; laws governing the sharing of health information; and differences in acculturation require sensitivity to the maintenance of privacy and confidentiality. Although, the patient-centered medical home is an initiative for managing the delivery of primary care services to improve the delivery of care and improving quality and safety (Peikes, et al, 2012), the patient-centered approach and coordination of services are qualities of health care services that correspond to important cultural professional caring attributes desired by the informants. Focusing on the care needs of the patients and assuring the appropriate sharing of information when referring patients to other care providers is congruent with the concept of personalismo and was appreciated by the informants when they were cared for in this way. Integrating culturally congruent caring practices, as required by the Nursing: Scope and Standards of Practice (ANA, 2015) can also reduce or eliminate the experiences of stigma in the health care setting and during patient care encounters due to experiences with social and structural injustice (Davtyan, et al, 2016, Gagnon, 2015).

The informants for this study all reported use of mental health services and acknowledged their previous hesitancy to use these services due to cultural perceptions and a history of negative interactions with mental health practitioners in the past (Gherovici, 2010). Knowing that mental health care is effective in managing the negative effects of experience with stigma (Rojas-Vilches, et al, 2011), practice settings should develop culturally congruent mental
health services accessible through the patient-centered home to facilitate earlier acceptance of care. An example of culturally acceptable mental health services for Puerto Rican women living with HIV was the support group. As part of a complement of services, support groups can provide a setting for discussing the day-to-day experiences of living with HIV within which there is not a concern about disclosure (Matchinger, et al, 2015).

Cultural traditions of *familismo*, and herbal and spiritual traditions were of great importance to the informants of this study as demonstrated by the findings. In the practice setting, providers need to conduct a cultural assessment to obtain information regarding these cultural practices and their meanings for patients, so these might be incorporated into the caring practices of the provider and the care setting. Obtaining this information can be accomplished by designing a patient intake form that would include cultural care information in addition to past medical history questions (Courtney & Wolgamott, 2015). Providers will need to receive education on these practices and how they can be incorporated by patients in their self-care (Courtney & Wolgamott, 2015). Other cultural norms can influence care through conscious and unconscious cultural practices by the provider and/or the patient. Staff educational programs can also raise awareness of these practices and suggest activities to further create a culturally congruent care setting.

Being cared for by a linguistically congruent provider was preferred by informants to ensure understanding between themselves and their providers. This was especially imperative when important exchanges of information needed to occur (Storey, et al, 2014). The use of interpreters, especially language lines, was not preferred. The use of key phrases in the language of the patient were greatly appreciated and providers can learn phrases from cultural/linguistic representatives in the care setting or using medical language services, applications and on-line
learning programs. For example, Canopy Innovations, Inc. (2017) has developed a free application which contains translations of common phrases for use in patient care, organized by language, specialty area and activities with pronunciations of the phrases; and an online medical language program, which is currently available in Spanish.

A lay representative can provide guidance to providers as they navigate culture care awareness and the desires of their patients as noted above. Given the sensitive nature of HIV care practice requiring an understanding of the privacy and confidentiality needs of this community, a lay representative could also be an individual living with HIV. One of the important roles that the informants of this study assumed on their own was as a mentor or guide to other women living with HIV. This role was formalized with training in AIDS service organizations as a volunteer and sometimes as a paid position for some of the informants; and, in the ACT-2 research study as they helped others to learn about HIV clinical and biobehavioral research opportunities. However, this role can also be utilized within the clinic setting. Unlike patient navigators who assist patients to make and keep appointments within accountable care organizations or patient-centered medical homes helping them to become independent and trustful of their providers (Natale-Pereira, et al, 2011), the informants serve as role models for using the healthcare services available to them but also for living well with HIV. In Latino cultures, doña, is a woman who is respected because of her age but more importantly her life experience. A program could be developed to train doñas, culturally and linguistically congruent women living with HIV, to help women newly diagnosed with HIV to become engaged in their care and guide them as they adapt to their new self-care needs and practices.

As presented earlier, intake forms need to incorporate the cultural needs and expectations of new patients. Holistic assessments and intake forms that would be appropriate for people
living with HIV and consider culture care practices would include questions regarding disclosure and inclusion of family members in care discussions dependent upon their awareness of the HIV diagnosis and respective of HIPAA concerns. Other important questions would reflect an understanding of the social determinants of health that are prevalent in the community, such as transportation concerns in (dense traffic areas with unreliable public transportation options); safety concerns in their neighborhoods and buildings; and, economic concerns (Dennis, et al, 2015; DeVoe, et al, 2016; Mignano, 2016). With transnational communities, financial obligations to other households are often difficult to document and create an inaccurate picture of the ability to afford copays or travel expenses related to medical care, resulting in missed visits or unfilled prescriptions, and, therefore need to be part of the assessment. These holistic questions would assist the care team in anticipating concerns or needs of the patient and develop plans to address them in a culturally sensitive way, e.g. scheduling patient care encounters or medication refills around planned travel.

Puerto Ricans and many other Latinos, vary in their phenotypical presentations and identify as various and multiple races, in addition to their Latino ethnicity (Amaro & Zambrano, 2000; Cohn, 2012, August 7; Collazo, et al, 2010; Cresce, et al, 2004; Ennis, et al, 2011). In addition, they may be of various religious, educational and socio-economic backgrounds. As with any diverse cultural group, all providers must be able to approach individuals with their presumptions and biases about diverse cultures and identities on hold to avoid offending a patient in need of services (Kalayjian, et al, 2010). Cultural competency skills should be integrated into all caring encounters by all providers to address these concerns (Leininger, 2006a; McFarland & Wehbe-Alamah, 2015).
The expansion of technology in the healthcare setting has been focused on the integration of the electronic medical record into practice, but this can be expanded into HIPAA compliant telehealth modalities which have been identified as culturally and linguistically acceptable and appealing across generations (text and other social media platforms). These platforms can also be used to maintain contact with members of transnational communities when they are not able to attend a planned healthcare encounter. Health related information and health education messages can be shared between providers and patients through new technologies to reinforce teaching that occurred during the healthcare encounter (Kurth, Chhun, et al, 2016). These health education messages should be able to address the health literacy and cultural and linguistic needs of the community members and can be distributed using online modules; links to government webpages, e.g. CDC; or hand-held tablets in the practice setting or SMART phones using secure password protected sites. The Office of Minority Health’s Culturally and Linguistically Appropriate Services (CLAS), Think Cultural Health modules can provide guidance for these materials as recommended (OMH, 2017 September). Another resource is the National Center for Cultural Competence (NCCC) at Georgetown University, which has extensive resources for the development of culturally congruent organizations in health care and education (NCCC, 2003).

Practice settings should prioritize compliance with accreditation requirements as determined by the accrediting agency in the design and implementation of services to the patient population. Accrediting agencies, including the American Nurses Credentialing Center for Magnet status (n.d.), look favorably on the presence of certified nurses on staff at healthcare agencies. Nursing certification options exist for nurses in HIV care (www.HANCB.org) and transcultural care (www.TCNS.org) and should be encouraged for all nurses working with
people living with HIV (Relf, et al, 2004) and/or people from diverse communities. These nurses can provide the support and role-modeling for other nurses in desired care practices, fostering the concept that all nurses are able to and should be delivering HIV care that is culturally congruent (Bradley-Springer, 2010; Kalayjian, et al, 2010).

**Education.** Transcultural nursing, cultural competence education, (Jeffreys, 2016; Mixer, 2015; Wehbe-Alamah & McFarland, 2015) and HIV care (Relf & Harmon, 2016; Spach, et al, 2016) concepts should be threaded throughout all nursing and other health professionals’ educational programs (academic, staff, continuing and professional association). The ability to provide culturally congruent care for individuals, families, communities and populations in ways that respect their cultural identities and lived experiences; assess and mitigate risk for and manage the effects of HIV disease are essential for nursing and health care practice in the 21st century. It is important that these caring practices are visibly integrated into all aspects of education. There are no settings in which a provider does not care for someone of a culture or subculture different from their own or is at risk for HIV disease. Healthcare profession education must address the multiple domains of learning (cognitive, psychomotor, and affective) in an integrated approach through didactic – classroom, seminar, web-based – clinical and skills laboratory/simulation experiences. These are all opportunities to incorporate transcultural nursing, cultural competence, and HIV care.

**Higher education (academic setting).** The American Association of Colleges of Nursing has prepared a listing of competencies for graduates of baccalaureate (AACN, 2008, October), masters (AACN, 2011, March) and doctoral (DNP) (AACN, 2006) programs in nursing which outline essential areas for learning that contribute to the development of their specific role competencies. The apparent separation into different documents of the cultural
competencies for baccalaureate (AACN, 2008, August) and graduate nursing (AACN, 2009, November) programs perpetuates the impression that culturally congruent practice is additional or optional versus integral and essential for competent nursing care. Nurses pursuing a research doctorate (PhD or EdD) should also receive cultural competence education to prepare them for interactions with culturally diverse research participants and nursing students in their respective roles as researchers and educators. Currently, AACN documents for the nursing research and education degree programs are focused on efforts to diversify the nursing workforce (AACN, 2010, November). While being able to participate in research with or be educated by someone who looks like them is a positive experience, this is only part of the solution. The AACN doctoral education documents do not discuss the need for these diverse doctoral students to receive culturally competence education and programming and this situation should change.

The increasingly complex nature of healthcare requires an interprofessional practice orientation. The diversity in practice focus of healthcare professionals requires a culturally competent approach to collaborative experiences and patient-centered care that extends into education and research, as well. The Interprofessional Education Collaborative (IPEC Expert Panel, 2016) has proposed an outline of practice essentials intended to guide interactions among health care professions to facilitate the delivery of safe patient care. Recognized in these practice essentials are the unique personal and professional practice cultures which may inform interactions in healthcare settings. HIV care has benefitted from interprofessional practice approach (Spirig, et al, 2004) to provide care to people living with HIV from early in the epidemic. The complexity of disease and the many unknowns required these interprofessional exchanges and this practice model has continued in acknowledgement of the need for a holistic approach to care. Integrating culturally congruent practice improves the delivery of care
outcomes (Crespo-Fierro, 1997), and should be interwoven into interprofessional educational programs.

Classroom teaching and active learning strategies should be utilized to help students learn transcultural care and HIV care using multiple domains of learning (Jeffreys, 2016). In didactic learning: case studies, including unfolding case studies, provide opportunities to discover the potential impact of missed opportunities for care that is culturally congruent or grounded in HIV knowledge without being in the clinical setting. Reflective journaling, either shared in safe peer groups in forums available via classroom management platforms (e.g. Blackboard) or with instructors, can also help students to express any concerns they might have with any new experiences or learning. Learner-centered assignments that incorporate viewing movies, and/or documentaries, and reading books, both fiction and non-fiction can provide contextual and historical data on the experiences of various cultures for transcultural learning and the stigma of the HIV epidemic can be more effective for students than a teacher-centered lecture.

Learning modules, such as those offered by the Office of Minority Health (OMH) on the National CLAS Standards (www.thinkculturalhealth.gov) can provide guidance on the expectations of knowledge and practice of cultural competency in the workplace. Students can become familiar with the standards for signage and the availability of interpreters or language lines for patients who do not speak English fluently and the inappropriateness of having family members substitute for the lack of these resources. Other classroom teaching/learning strategies that can be useful include websites, interactive activities, like role-play, written assignments and in class presentations on appropriate topics associated with transcultural nursing care and/or HIV care. Jeffreys (2016) provides a comprehensive book on teaching cultural competence using
various evidence-based strategies in various settings where health professional education occurs and can serve as a resource for many more strategies than are presented here.

Simulations and clinical experiences can develop affective and psychomotor domains of learning, in a more profound manner than in the didactic setting, which is often more focused on cognitive learning. In this way, the cognitive aspects of learning are enhanced (Jeffries, 2005; Ozkara San, 2015). Ideally, simulation experiences would occur before clinical experiences, to provide students the opportunity to “practice” using simulated or standardized patients before interacting with a live patient (Schlairet & Fenster, 2012), especially for sensitive experiences like providing culturally congruent care and HIV care. Use of the Standards for Best Practice: SimulationSM developed by the International Nursing Association for Clinical Simulation and Learning (INACSL) would provide guidance for the creation of an in-person or video simulation scenario (INASCL, 2016) that would closely present the desired learning experience, whether it be a scenario with specific transcultural care or HIV care student learning outcome. In addition, there are criteria for creating a safe debriefing setting for student discussion of the experience that should be followed to maximize the achievement of the cognitive, affective and psychomotor learning outcomes (INASCL, 2016; Jeffries, 2005; Ozkara San, 2015). Direct patient contact in the clinical setting should be carefully selected based on the student’s readiness for attempting the intended learning outcomes connected to the course; the opportunity for close monitoring and support by the clinical instructor and/or the availability of a preceptor to prevent negative experiences for both the student and the patient.

**Professional education.** Professional education programs are another venue to provide learning opportunities for nurses, other health professionals, and ancillary staff in culturally congruent care and HIV care practices. This is especially important for nurses (and
other health professionals) who completed their entry into practice education before the incorporation of the culture care competencies into their education programs (Jeffreys, 2016). Starting with orientation programs, nurses can learn the culture of the hospital and the expectations for practice that include culturally congruent practices and the state of the art of HIV care, through classroom time, lab and simulation experiences and shadowing/observation and precepting time with a more experienced or expert nurse on the unit who has completed these programs and/or trained as a preceptor. The length on an orientation program can vary based on the previous experience of the nurse. In some facilities, there are nurse residency programs which differ from orientation programs, not only in their longer duration but also in the availability of mentoring by the preceptor, trained for this role, and inclusion in leadership activities, such as specialty programs (Cochran, 2017). The nurse residency programs could give new nurses greater opportunities to learn more about the specific communities receiving care at that facility and specialty practice (e.g. HIV care) of a unit before caring for a caseload on their own.

Staff inservices and annual updates are another opportunity to provide learning on specific topics that are universal to the practice setting (e.g. hospital, clinic, home care agency, or public health department) or that are specialized to a unit and tied to the patient outcomes for that area of practice (Jeffreys, 2016). They can cover new learning or provide reinforcement of previous learning. Culturally competent care practices can be important topics when working with new populations. There are also frequent updates to HIV care with changes to ARV regimens and new combination medications to learn (Panel.., 2017, October).

Interprofessional education guided by IPEC guidelines (IPEC Expert Panel, 2016), simulation education (INACSL, 2016) are learning experiences that have been built into staff
education curricula and similar scenarios and programs in culturally congruent care and HIV care can be developed as in academic settings. Some differences would be the opportunity to develop more complex scenarios; the added distractions of necessary patient care during the sessions creating the need to shorten or rush through scenarios, if designated education time is not part of the program design or unit/service practice; and, the potential for leaner over-confidence in foundational knowledge from previous practice or learner under performance due to fear of failure before one’s peers. The staff education specialist will need to assess the learning needs of the attendees to develop plans to avoid any situations that could impede the learning of the participants (Jeffreys, 2016).

**Continuing professional education.** Continuing education programs, including webinars, journal articles and conferences, are another modality for learning about transcultural nursing practices, cultural competence, and HIV care. These programs could be used for professional development in pursuit of certification/recertification or could be required for state licensing purposes, as in New Jersey or Florida, for example. When required for renewing one’s license or certification, there can be identified topics that must be completed to meet the designated criteria. States could require a specific number of continuing education units in transcultural care, because of its importance in delivering patient-centered care; and, HIV care, because of the need to identify people with HIV early for the most effective implementation of state of the art care. As an example, currently, the state of Florida requires nurses to complete one hour of continuing education on HIV every licensing period (two years). This could be replicated with transcultural caring content and HIV care and implemented across all state/territory licensing boards for all healthcare professionals.
The preferred method for implementing continuing education programs is for professional specialty nursing associations to offer the content by their experts (Jeffreys, 2016). The Transcultural Nurses Society (TCNS) and the Association of Nurses in AIDS Care (ANAC) have yearly conferences, present webinars and produce journals which offer articles about research and practice in their respective specialties. The conferences have the added benefit of networking with national and international colleagues which expands learning of diverse practices in the specialty area (Marrone, 2016). Each of these professional associations also offer nursing certification of their specialty knowledge. There are required areas of knowledge in each specialty for which the individual must demonstrate mastery before being granted to ability to use the credential. The examinations are updated as needed to incorporate new specialty knowledge. TCNS offers a basic, certified transcultural nurse credential (CTN-B) and advanced, certified transcultural nurse credential (CTN-A) (www.tcns.org) and a core curriculum for study (Douglas & Pacquiao, 2010). The HIV/AIDS Nursing Certification Board (HANCB) offers the AIDS certified registered nurse credential (ACRN) and the advanced AIDS certified registered nurse (AACRN) (www.hancbnet.org) and a core curriculum for study (ANAC, 2010). Both associations have set out the criteria to meet to sit for the exam and the requirements to maintain certification either by examination or completion of continuing education units within a specified time frame.

Administration. Administration practice enhancements can also contribute to the delivery of culturally congruent care and up-to-date HIV care. Marrone (2013) describes culturally competent organizations in which all employees of the facility exhibit culturally competent behaviors during their interactions with the clients, as well as with each other. Informants reported instances where they felt stigmatized for reasons other than their HIV status
by the actions of the clerical staff and terminated care in those clinics, as a result. These experiences highlight the need for culturally competent organizations, which are exemplified by a respect for diversity throughout the organization. Policies creating an environment of cultural safety should be transparent (Marrone, 2013). The National Center for Cultural Competence’s website (www.nccc.georgetown.edu) provides access to numerous links to resources, websites and documents to guide the development of a culturally competent setting for the delivery of care (2003). These resources can be used to support the promotion of culturally congruent care services in various settings, inpatient and outpatient, from all personnel.

Care delivery models like the patient-centered medical home (Gelaude, et al 2017) foster the collaborative practice that is focused on the unique culture care and HIV care needs of the patient. Integration of the latest guidelines of HIV care (Panel…, 2017, October) and the implementation of electronic health record (EHR) programming that facilitates communication among providers (Gelaude, et al, 2017) and maintains patient privacy and confidentiality as per HIPAA guidelines would provide the state of the art care desired by the informants of the study. If desired, encrypted flash drives can be used to transport health information to providers that are outside of the EHR network. Norms of communication should be established and taught through staff inservices to protect patient privacy (Calo, 2014; Storey, et al, 2014).

CLAS standards should be met by the practice setting and the administration of the facility would secure the signage and interpreter services required to meet the language needs of the clients should professional and administrative staff not speak the language (Sanchez, et al, 2014). Facilities should also ensure that staff is able to communicate health information in the language other than English that they speak (Squires & Jacobs, 2016). The exclusively Spanish-speaking informants had concerns about understanding important information delivered by their
providers who did not speak Spanish. All informants for this study experienced the social determinants of health in ways which influenced their risk for HIV and their experiences of HIV care as do other communities. Healthcare facilities must make it a priority to understand the social determinants of health: education, economic stability, neighborhood and built environment, social and community context, health and healthcare (Healthy People), as they are experienced by their clients (DeVoe, et al, 2016; Mignano, 2016; Sanchez, et al, 2014). Efforts can be made by the facility to address some of those issues by changing hours of operation to match clients’ needs or providing transportation vouchers to the facility for medical appointments.

Policy. HIV is a concern that has international, national, and local perspectives. The UN has directed its agencies to provide international guidance and surveillance on factors related to HIV. The WHO has the Sustainable Development Goals (SDG) which address the many concerns regarding health and the social determinants of health discussed previously with new targets for 2030. For HIV, SDG Goal #3 seeks to eliminate HIV by 2030 (UN, 2016). UNAIDS (2017) has released the 90-90-90 targets which have proposed a set of goals for each country to achieve by 2030: 90% of people living with HIV know their diagnosis; 90% of people who know their HIV diagnosis are on ARVs; and, 90% of people on ARVs are virally suppressed. Holzemer (2017, November 2) has added another 90% target to the 90-90-90. He proposes that 90% of those who are virally suppressed should also report a desired quality of life. The informants for this study reported a generally good quality of life, so they have achieved the 90-90-90-90 targets. However, this is not the case for many people living with HIV and efforts must continue globally to assist all countries to achieve the 90-90-90-90 targets and meet SDG #3’s goal to eliminate HIV.
National policy regarding HIV has become complicated since the start of 2017. A new presidential agenda has scaled back the national office (ONAP, 2015 July) and council of advisors on HIV/AIDS policy for the president emphasizing efforts to address the social determinants of health through diverse government agencies like the Department of Housing and Urban Development (Stevens & Victor, 2017, December 30). The goals of the ONAP (2015 July) were (a.) to reduce new HIV infections; (b.) to increase access to care and improve health outcomes for people living with HIV; (c.) to reduce HIV-related disparities; and, (d.) to achieve a more coordinated response. HIV care continues to be studied and supported through the CDC, NIH, and DHHS, agencies which have other health-related responsibilities and needs to manage. The Healthy People initiative (Healthy People, n.d.) will also continue to study and support HIV care through the Healthy People 2030 goals, which are under development. There are concerns that without a national policy, some states and municipalities will not have the directives or supports to reduce HIV disparities (McCree, et al, 2016). This situation must be closely monitored to avoid increases in current disparities in HIV disease.

New York State has taken on the significant task of developing a comprehensive strategy to “End(ing) the Epidemic.” Launched in 2015, after convening experts in HIV care and the care of the populations at greatest risk for HIV, this plan addresses the many factors that put individuals at risk for HIV and the best practices for providing the care, medications and services that are proposed to control the epidemic and reach the goal of less than 750 new infections annually by 2025 (NYSDOH, 2015 March). A major advance in this bold plan in the inclusion of the social determinants of health for people living with and at risk for HIV. Social determinants health have an impact on all people and, as reported by this study’s informants, include access to affordable healthy food options; safe housing options which reflect actual and
perceived discrimination; safe and reliable transportation modes; access to an education free from bias; access to health and healthcare services, including mental health care coverage, that is affordable and free from bias; economic stability and a safe social and community environment (Healthy People, n.d.).

The informants reported the importance of family caregiving and some were frequent caregivers to others. While none of the informants were homebound, one informant was caring for her elderly father. New York State has a familial caregiving program (NYSDOH, 2016, July) that trains and pays family members to care for individuals who are homebound. This program would support a generic care giving practice that is preferred by Puerto Rican families as described in this study. The Puerto Rican community as a transnational, air bridge, community would benefit from policies which would support their travel to visit and care for family members across state lines and in Puerto Rico (Leff, 2017), such as a single payer health care system or early refills of prescriptions to manage medical care away from their usual location.

Nursing practice regulations at all levels should match the educational preparation required for licensure and certification to permit full practice (Kurth, Jacobs, et al, 2016). This would expand the nursing care including advanced practice, available to people living with HIV. The informants for this study voiced their preferences for all levels of nursing care but were often unable to choose their care providers due to staffing. Efforts must continue to increase the sexual/gender/cultural/racial/ethnic diversity of the nursing profession. Likewise, an increased and diverse representation of people living with HIV and nurses is needed in government, healthcare governance and professional associations to address the lived experiences of all people living with HIV. Licensing, credentialing and accreditation criteria for all healthcare providers, health professions schools, and healthcare facilities should include cultural
competence standards to deliver the culturally congruent caring practices to meet the culture care
needs of all people.

Limitations of the Study

This ethnonursing study of Puerto Rican women living with HIV and being cared for by
NPs and other providers in NYC has limitations. Discussion of these limitations will be
separated by the study design and method, the study population and the researcher.

**Study design.** As a qualitative study using the ERM, that focused on a specific group of
informants, the findings can only be fully applicable to those individuals who participated in the
interviews. The findings which are based on the culture care beliefs, practices and needs of the
informants may not reflect the culture care beliefs, practices and needs of Puerto Rican men
living with HIV, other Latinos living with HIV, and individuals living outside of New York City.
In addition, there would be limited applicability to those individuals who are not receiving HIV
care or even aware of their HIV diagnosis. Since this study was not associated with a specific
clinic or practice setting, the researcher was unable to verify any of the data shared by the
informants, specific to their HIV care, especially regarding CD4 counts and viral loads, identity
of HIV care providers, including their profession, and the visit frequency. Lastly, the location of
the interviews of the study was in an ASO and did not include any sessions in informants’ homes
to permit more opportunities for observation of their self-caring and family caring practices. The
researcher was required to rely on the observations based on phone conversations and the one to
two interviews conducted, as per the ERM (Leininger, 2006a; Wehbe-Alamah & McFarland,
2015b). Most of the second interviews occurred during a different season and the researcher was
able to see the informants dress differently according to the weather but limited new data about
the informants could be obtained because of the controlled setting of the interview room.
Study participants. Half of the informants for this study were participants in the ACT 2 study which was designed to improve the participation rates of African-Americans and Latinos in HIV research and teach recruitment skills to develop a cadre of peer recruiters (Gwadz, et al, 2015). It is unknown if these informants would have participated in this study without having this previous experience. The remaining informants were snowball referrals from some of the first informants. It is unknown if this group of informants would have participated in this study if they had not been actively recruited by the first group of informants. The informants also all had extensive experience with support groups, in which they were encouraged to share their personal stories. The voices of Puerto Rican women living with HIV traumatized by stigma, causing them to remain in the shadows, are not represented here.

The informants, especially the Spanish language dominant women, who had not previously participated in research, were eager to be a part of this study which possibly may have resulted in their telling the researcher what they may have believed she wanted to hear. Some informants expressed that they were “helping” the researcher complete her studies, an example of personalismo. The informants recruited via snowball method were actively recruited by friends and counselors who may have revealed some of their own experiences with the interview, in a sense, priming these informants. Some informants, particularly those who were employees of AIDS service organizations, were knowledgeable about culture care concepts and freely used that terminology during the interviews. Yet, each interview was unique and data saturation achieved through the revelation of the data supporting the patterns and themes discovered.

Some informants reported being very concerned about being seen in the office during the interview or who would have access to the recordings and transcripts, and consequently may have guarded some of their statements. It is also possible that informants were not truthful about
or aware of being cared for by NPs to participate in the study. The researcher found that some of the informants did not know their providers’ credentials and called them “Doctor/a.” This experience was previously reported to this researcher by a colleague (D. Reyes, personal communication, December 2, 2011) and has been repeatedly confirmed by other NPs known to the researcher. However, this study was the first to explore the culture care needs of this cohort and give voice to a community that had often felt underrepresented as stated by each of the informants.

**Researcher.** The researcher is a second generation bilingual Puerto Rican nurse born and raised in New York City, with limited exposure to the island of Puerto Rico beyond touristic experiences, and no experience with the healthcare system in Puerto Rico. The researcher’s first spoken language was English and although she had frequent exposure to spoken Puerto Rican Spanish in home and social settings, she learned to speak, write and read Castilian and Latin American Spanish, starting in middle school and through college. There were times in the interviews when the researcher stumbled over terms, for speaking and understanding, and relied on context and verification with the informant by rephrasing in Spanish when English was not an option for understanding a complex term. The researcher is a clinical nurse specialist in HIV care and certified in advanced HIV care but is not a nurse practitioner working in HIV care. The researcher has observed and worked closely with nurses in the advanced practice role, however it was not possible for her to know all aspects of provider’s side of some of the exchanges described by the informants. Lastly as a Puerto Rican woman raised in the culture, there was a considerable possibility of bias that would have led to overlooking some discoveries because of familiarity with the cultural norms. To address this limitation, the researcher used bracketing and
journaling before and during the data collection and analysis phases and consulted with an ERM mentor who had similar experiences; and, discussions with the dissertation chair.

**Strengths of the Study**

The strengths of this study are grounded in many of the same factors that framed the limitations of this study. In addition, there are other strengths in the opportunities for new explorations in the areas of study brought together by this study.

**Study design.** Using the CCT as the theoretical framework and the ERM to conduct the study provided an opportunity to discover in-depth data for understanding the Puerto Rican culture, the various influences on its development and experience of American colonialism (McFarland & Wehbe-Alamah, 2015). With these data and the enablers of the CCT and ERM, the interview guide provided a medium to tap into a rich data source for the findings of this study. Another strength of using the ERM was the reliance on an ethnonursing research mentor (Wehbe-Alamah & McFarland, 2015b) from the study’s conceptualization, and through its implementation, analysis, and discussion to guide the researcher in maintaining the rigor of the method. An additional benefit provided by the ethnonursing research mentor for this study was her professional experience as a women’s health nurse practitioner, as well as, her expertise in the CCT and use of the ERM and her own experience of conducting an ethnonursing study with a community whose culture, language and religion were similar to her own. She is also the co-author and co-editor of the recent revisions to the theory and the method, and thus, provided other levels of understanding and development to these findings making them applicable to multiple areas of nursing practice and advanced nursing practice. The use of journaling through multiple phases of the study, and enablers to evaluate progress through the research process, as part of the ERM, provided opportunities for bracketing to reduce bias and record personal
thoughts and other notes, such as nonverbal communication to develop meaning and context for the interviews and the findings derived from them.

With the setting of the interviews being at the ASO, there were benefits of being in a familiar setting, as the informants were either all clients of the organization or had participated in another research study being conducted in the same location (ACT-2). In addition, by being unassociated with a specific clinic or practice setting and since no data on their sites of care were collected, this study added a layer of confidentiality. The researcher was not able to report back to their providers and other clinic staff. Therefore, the informants could share their feelings and opinions about their present care settings and providers more openly.

**Study population.** This study provided an opportunity for racially and ethnically diverse women to participate in research. Specifically, being a qualitative study with an emphasis on Latinas, this study demonstrated interest in the stories of the informants themselves. They were not part of a larger study, where their voices would be diluted with other groups. In addition, with the option to be interviewed in a language other than English, enrollment was opened to individuals who are often neglected in research (Garcia, et al, 2017; Lopez-Cordova, et al, 2010) because investigators and research assistants do not speak their language and/or translated surveys, or valid and reliable tools in their language are not available.

**Researcher.** The researcher was especially committed to the community affected by HIV, having cared for them since the beginning of her career. Her shared cultural identity and familiarity with cultural and religious practices provided an essential understanding of the informants which led to a quicker movement to a level of comfort and trust for the informants, deepening the discussions emanating from the interview questions. There was less of a need to explain experiences or ideas because the researcher had learned of them through her own life experience.
experiences. Being able to speak the language and dialect of the informants also expanded understanding and amplified the voice of the informants. It was not necessary to use an interpreter or transcriptionist who may have spoken a different dialect creating barriers during the interview and/or analysis.

**HIV care and the CCT.** The study also provided an opportunity to apply CCT concepts to HIV care. As HIV care providers seek strategies to engage diverse communities of people living with HIV into care to reduce morbidity, mortality and transmission, this study could provide guidance on potential culture care decision and action modes to achieve desired outcomes. The findings of this study could encourage other nurse researchers to explore the desired culture care practices of other communities regarding HIV care and other health conditions.

**Reflections on this Study**

This study brought together two areas of deep interest of this researcher. Cultural awareness was deeply embedded in her early conceptualizations and delivery of nursing care. HIV care was a new and rapidly growing area of nursing and medical practice that formed her initial practice as a nurse. Being a second-generation Puerto Rican American and observing and experiencing directly the impact of HIV on her community and family members was formative. Being able to design a research study that explored the cultural dimensions of caring in the presence of HIV disease was illuminating on both professional and personal levels.

Discoveries were made through all phases of this research study about the Puerto Rican culture; the devastating impact of US colonialism on the Puerto Rican existence; Transcultural Nursing Care, the CCT and HIV care; as well as, what it means to nurse one’s community through a deadly epidemic and gain an insight to cultural sources of the strength to survive. The
opportunity to discover culture care decision and action modes appropriate for HIV care was a meaningful experience which will be exciting to share with colleagues and students. Every exchange with the informants reinforced the ideal of co-participatory community-based research, like the ERM, and the need for culturally congruent integrative care for all underserved populations. The generosity of the informants’ commitment to this study, by sharing their stories in the service of improving the care of Latinas living with HIV, was demonstrated by the richness of the data. This researcher was honored to have learned so much from these women and to provide a conduit for their voices through these findings.

**Conclusions**

This ethnonursing study exploring the culture care needs of Puerto Rican women living with HIV in NYC revealed that their caring beliefs, values, expressions, practices and needs were embedded by the culture of their Puerto Rican female identity and the culture of living with HIV. Their caring expressions and practices were greatly influenced by their family’s roles as motivational forces and sources of strength, and the expressions of *familismo* and *personalismo* they experienced in their day-to-day interactions with others. Living with HIV caused these Puerto Rican women to suffer fear and grief in such a way that they experienced a “rebirth” and their worldview was transformed. Their expressions of self-care evolved to include healthier behaviors. They also wished to care for others in new healthier ways that included protecting others from HIV infection and helping other Latina women, newly diagnosed, to navigate a life with HIV by participating in support groups, engaging in outreach activities and participating in this research study and others. These protective activities reflected their spiritual beliefs.

Social structure factors, environmental context, ethnohistory and language strongly influenced the experiences of these Puerto Rican women living with HIV through creating and
maintaining obstacles to the receipt of culturally and linguistically appropriate health care that met the standards of HIV care in the location they desired and with the respect and understanding they needed to become long-term survivors. By defying the social determinants of health and experiences of discrimination and racism, they became exemplars of life to their families and their communities. Having an HIV care provider who was knowledgeable about the latest HIV treatment; delivered safe care using universal precautions; demonstrated characteristics of personalismo; and, provided linguistically appropriate services was crucial to fostering trust that led to these Puerto Rican women becoming engaged in their care.

The caring behaviors demonstrated by the HIV care providers towards these Puerto Rican women living with HIV in NYC that engaged them in their care was recognized and categorized as culture care decision and actions modes to preserve and/or maintain, negotiate and/or accommodate, and repattern and/or restructure culture care practices. These culture care decision and action modes were mapped to the HIV continuum of care being used by HIV care providers to identify desired outcomes for population HIV care to control the progression of the disease in individuals and prevent new transmissions of the virus. This ethnonursing study’s findings generated implications for the theory of Culture Care Diversity and Universality; research in HIV care, and the work of culturally and linguistically congruent researchers in healthcare; the delivery of culturally-congruent nursing care and state-of-the-art HIV care at the practice and administrative levels; culturally competent nursing and interprofessional education; and the development of healthcare policy that fosters the delivery of culturally and linguistically appropriate and safe care that is accessible and meets the needs of all people living with HIV, no matter where they live.
Appendix A

Table 1

Conceptualization of the Ethnonursing Research Plan

<table>
<thead>
<tr>
<th>Ethnonursing Method</th>
<th>Crespo-Fierro study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider the research site, community &amp; people</td>
<td>New York City: epicenter of the epidemic since its start in 1982; mainland US city with largest number of Puerto Ricans; Puerto Ricans are the largest percentage of Hispanic residents in New York City (27%); the Air-Bridge facilitates travel between NYC and PR, includes movement of HIV infection; NYC offers high quality health care and social services for HIV disease; ACT2 Registry based in New York City and focused on increasing participation of underrepresented groups in HIV/AIDS clinical trials (Puerto Rican women are a subset of this population)</td>
</tr>
<tr>
<td>Address Informed Consent expectations</td>
<td>Dissertation chairperson is faculty at CSI-CUNY where main IRB was filed, special considerations for use of Spanish in addition to English, and potentially disadvantaged population due to language and literacy barriers, health insurance status, and infectious disease; ACT2 Registry investigators are affiliated with NYU; application to NYU’s IRB first per CSI criteria; letter of support from ACT2 Registry investigators</td>
</tr>
<tr>
<td>Explore and gradually gain entry to the setting</td>
<td>Researcher utilized professional contacts with nurse practitioners (NPs) specializing in HIV care in NYC and researchers investigating phenomena related to HIV care to explore options for access to informants; researcher collaborated with ACT2 Registry team to review participant demographic information to determine potential informants; develop script for ACT2 Registry team members to use when contacting potential informants and notifying them of the ethnonursing research study inclusion criteria</td>
</tr>
<tr>
<td>Anticipate barriers and facilitators</td>
<td>Barriers: Researcher not a NP; Potential sites may be unwilling to have a qualitative (ethnonursing) researcher explore culture care</td>
</tr>
</tbody>
</table>
needs of clients; potential informants may be unwilling to share their information regarding HIV care and culture care needs; clinics and NPs may not wish to be observed or participate in an ethnonursing research study. Facilitators: Researcher fluent in Spanish; 2nd generation Puerto Rican.

Select and use indicated enablers

Leininger’s Sunrise Enabler to Discover Culture Care
Leininger’s Stranger-to-Trusted-Friend Enabler
Leininger’s Observation-Participation-Reflection Enabler
Leininger’s Phases of Ethnonursing Data Analysis Enabler for Qualitative Data
Leininger’s Semi-Structured Inquiry Guide Enabler to Assess Culture Care and Health;
Leininger’s Acculturation Health Care Assessment Enabler for Cultural Patterns in Traditional and Nontraditional Lifeways; and
The Life History Health Care Enabler both used to develop semi-structured inquiry guide
The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler

Select informants

a. At least 18 years of age,
b. Self-identified as Puerto Rican (of Puerto Rican origin or background and as being a member of the Puerto Rican culture),
c. Self-identified and born as female,
d. Residing in New York City,
e. Receiving most of their HIV care in New York City from Nurse Practitioners,
f. Primary language is English or Spanish, and,
g. Willing to participate in the study.
Source of HIV infection, staging of HIV disease or ARV status will not be exclusion criteria. A history of untreated mental illness will exclude potential informants.

Develop and continue trusting relationships

Researcher engaged in activities affiliated with the ACT2 Registry; ACT2 Registry staff-initiated contact with potential key and general informants; provided information on support services and privacy throughout the research process; engaged key and general informants to identify likely participants and
<table>
<thead>
<tr>
<th>Collect and confirm data through observations, interviews, participant experiences and other data</th>
<th>verify who else should know the findings of this research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Field notes of observations, journaling, and audiotaping of interviews; coded data and notations to preserve privacy; semi-structured inquiry to guide interviews of key and general informants lasting between 60-90 minutes and conducted in the language preferred by the participants, English, Spanish, or code-switching</td>
<td></td>
</tr>
</tbody>
</table>

| Use computer programs to maintain data from informants while using field journals for reflection on data collection and analysis process and consult with ethnonursing research mentor | NVIVO 10 program from QSR (Qualitative Solutions and Research); handwritten field journals for notes after screening and during and after interviews and data analysis; consultations with ethnonursing research mentor from UM, Flint, co-editor of latest editions of theory and methodology textbooks for CCT; use of evaluation criteria for qualitative ethnonursing research |

| Present and confirm findings with informants | Follow-up interviews with key informants after transcription and translation of interviews to caring patterns are described and themes are identified |

| Inform people in advance of plan to leave the setting | Each contact with key and general informants focused on the research relationship and clearly identified a termination time frame |
## Appendix B

### Table 2

Corresponding Culture Care Theory Category, Domain and Code Number (using The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler (Wehbe-Alamah & McFarland, 2015a))

<table>
<thead>
<tr>
<th>Node Name</th>
<th>Category</th>
<th>Domain</th>
<th>Code Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aftercare</td>
<td>Life Cycle</td>
<td>Life Passages</td>
<td>V. 58</td>
</tr>
<tr>
<td></td>
<td>Cultural and Social Structural Data</td>
<td>Kinship</td>
<td>II. 13</td>
</tr>
<tr>
<td>AIDS Dx</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td>Betrayal</td>
<td>Cultural and Social Structural Data</td>
<td>Kinship</td>
<td>II. 13</td>
</tr>
<tr>
<td>Care and Help</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 23</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Professional Care/Caring</td>
<td>III.24</td>
</tr>
<tr>
<td>Caring from a Distance</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td>Caring Providers</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Care/Caring</td>
<td>III.25</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Human Care/Caring</td>
<td>III.22</td>
</tr>
<tr>
<td>Celebrations</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Material and Nonmaterial Culture</td>
<td>I. 7</td>
</tr>
<tr>
<td>Children Care</td>
<td>Life Cycle</td>
<td>Life Cycle Infancy</td>
<td>V. 51</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Life Cycle Adolescence</td>
<td>V. 52</td>
</tr>
<tr>
<td>Coming to NYC</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Ethnohistorical</td>
<td>I. 3</td>
</tr>
<tr>
<td>Connection to PR</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Ethnohistorical</td>
<td>I. 3</td>
</tr>
<tr>
<td>Culture</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Material and Nonmaterial Culture</td>
<td>I. 7</td>
</tr>
<tr>
<td>Death</td>
<td>Life Cycle</td>
<td>Life Passages</td>
<td>V. 58</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td>Disclosure</td>
<td>Life Cycle</td>
<td>Special Life Cycle</td>
<td>V. 57</td>
</tr>
<tr>
<td>Discrimination</td>
<td>Health Care, Social Structure Institutions and Systems</td>
<td>Ethical Moral Care-Cure Factors</td>
<td>IV. 46</td>
</tr>
<tr>
<td>Education</td>
<td>Cultural and Social Structural Data</td>
<td>Educational Factors</td>
<td>II. 12</td>
</tr>
<tr>
<td>Family</td>
<td>Cultural and Social Structural Data</td>
<td>Kinship</td>
<td>II. 13</td>
</tr>
<tr>
<td>Category</td>
<td>Sub-Category</td>
<td>Domain</td>
<td>Page</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------------------------------------------------</td>
<td>------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
<td></td>
</tr>
<tr>
<td>Father Care</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 23</td>
<td></td>
</tr>
<tr>
<td>Finances</td>
<td>Cultural and Social Structural Data</td>
<td>Economic Factors</td>
<td>II. 11</td>
</tr>
<tr>
<td>Food</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Cultural Foods</td>
<td>I. 6</td>
</tr>
<tr>
<td>Groups</td>
<td>Health Care, Social Structure Institutions and Systems</td>
<td>Non-nursing features</td>
<td>IV. 45</td>
</tr>
<tr>
<td>Having HIV Health</td>
<td>Life Cycle</td>
<td>Special Life Cycle</td>
<td>V. 57</td>
</tr>
<tr>
<td></td>
<td>Care, Cure, Health and Illness</td>
<td>Folk</td>
<td>III. 20</td>
</tr>
<tr>
<td>Herbal Remedies</td>
<td>Cultural and Social Structural Data</td>
<td>Religion</td>
<td>II. 15</td>
</tr>
<tr>
<td></td>
<td>Care, Cure, Health and Illness</td>
<td>Folk</td>
<td>III. 20</td>
</tr>
<tr>
<td></td>
<td>Alternative Care/Cure Systems</td>
<td></td>
<td>III. 30</td>
</tr>
<tr>
<td>Hijos de Crianza</td>
<td>Cultural and Social Structural Data</td>
<td>Kinship</td>
<td>II. 13</td>
</tr>
<tr>
<td>HIV Care</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td>Homelessness</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Environmental Context</td>
<td>I. 4</td>
</tr>
<tr>
<td>Identity</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Material/Nonmaterial Culture</td>
<td>I. 7</td>
</tr>
<tr>
<td>Illness</td>
<td>Care, Cure, Health and Illness</td>
<td>Folk</td>
<td>III. 20</td>
</tr>
<tr>
<td>Illness Care Death Care</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 23</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Folk Cure/Curing</td>
<td>III. 28</td>
<td></td>
</tr>
<tr>
<td>Jail</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Environmental Context</td>
<td>I. 4</td>
</tr>
<tr>
<td>Language</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Linguistic</td>
<td>I. 5</td>
</tr>
<tr>
<td>Legal</td>
<td>Cultural and Social Structural Data</td>
<td>Politics/Legal</td>
<td>II. 14</td>
</tr>
<tr>
<td>Marianismo</td>
<td>Cultural and Social Structural Data</td>
<td>Cultural Values Beliefs and Norms</td>
<td>II. 10</td>
</tr>
<tr>
<td></td>
<td>Life Cycle</td>
<td>Life Cycle Male-Female</td>
<td>V. 50</td>
</tr>
<tr>
<td>Marital Status</td>
<td>Life Cycle</td>
<td>Life Cycle Male-Female</td>
<td>V. 50</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Life Passages</td>
<td>V. 58</td>
</tr>
<tr>
<td>Category</td>
<td>Subcategory</td>
<td>Domain</td>
<td>Page</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Med Adherence</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td>Mental Health Care</td>
<td>Care, Cure, Health and Illness</td>
<td>Folk</td>
<td>III. 20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 23</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Professional Care/Caring</td>
<td>III. 24</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Human Cure/Curing</td>
<td>III. 27</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 28</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alternative Care/Cure Systems</td>
<td>III. 30</td>
</tr>
<tr>
<td>Mother Care</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 23</td>
</tr>
<tr>
<td>Music and Dancing</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Material and Nonmaterial Culture</td>
<td>I. 7</td>
</tr>
<tr>
<td>Neighborhood</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Environmental Context</td>
<td>I. 4</td>
</tr>
<tr>
<td>Non-caring Providers</td>
<td>Care, Cure, Health and Illness</td>
<td>Noncare</td>
<td>III. 26</td>
</tr>
<tr>
<td>Numbers</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td>NY vs. PR</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Ethnohistorical</td>
<td>I. 3</td>
</tr>
<tr>
<td>Outreach</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td>Overcare</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td>Parent Care</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 23</td>
</tr>
<tr>
<td>Politics</td>
<td>Cultural and Social Structural Data</td>
<td>Politics/Legal</td>
<td>II. 14</td>
</tr>
<tr>
<td>Pregnancy Care</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td>Protection</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Cure/Curing</td>
<td>III. 29</td>
</tr>
<tr>
<td></td>
<td>Health Care, Social Structure Institutions and Systems</td>
<td>Inter and Multidisciplinary</td>
<td>IV. 43</td>
</tr>
<tr>
<td>Provider Relationship</td>
<td>Care, Cure, Health and Illness</td>
<td>Professional Care/Caring</td>
<td>III. 24</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Professional Nursing Care/Caring</td>
<td>III. 25</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td>Recovery Religion</td>
<td>Life Cycle</td>
<td>Special Life Cycle V. 57</td>
<td>V. 57</td>
</tr>
<tr>
<td></td>
<td>Cultural and Social Structural Data</td>
<td>Religion</td>
<td>II. 15</td>
</tr>
<tr>
<td>Topic</td>
<td>Domain of Inquiry</td>
<td>Subtopic</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------------------------------------</td>
<td>-----------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Romantic Care</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
<td></td>
</tr>
<tr>
<td>Life Cycle</td>
<td>Life Cycle Male-Female</td>
<td>V. 50</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Life Passage</td>
<td>V. 58</td>
<td></td>
</tr>
<tr>
<td>Safety</td>
<td>Environmental Contexts</td>
<td>I. 4</td>
<td></td>
</tr>
<tr>
<td>Self-care</td>
<td>Cultural Social Lifeways</td>
<td>I. 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Typical Day)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual Health</td>
<td>Cultural Social Lifeways</td>
<td>I. 2</td>
<td></td>
</tr>
<tr>
<td>Sibling Care</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Folk Care/Caring</td>
<td>III. 23</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Life Cycle Middlescence</td>
<td>V. 53</td>
<td></td>
</tr>
<tr>
<td>Spirituality</td>
<td>Cultural and Social Structural Data</td>
<td>Religion</td>
<td>II. 15</td>
</tr>
<tr>
<td>Stigma</td>
<td>Care, Cure, Health and Illness</td>
<td>Noncare</td>
<td>III. 26</td>
</tr>
<tr>
<td>Substance Use</td>
<td>Life Cycle</td>
<td>Special Life Cycle</td>
<td>V. 57</td>
</tr>
<tr>
<td>Technology</td>
<td>Cultural and Social Structural Data</td>
<td>Technological</td>
<td>II. 16</td>
</tr>
<tr>
<td>Transmission</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Environmental Context</td>
<td>I. 4</td>
</tr>
<tr>
<td></td>
<td>Cultural and Social Structural Data</td>
<td>Interpersonal Relations</td>
<td>II. 17</td>
</tr>
<tr>
<td>Trust</td>
<td>Care, Cure, Health and Illness</td>
<td>Human Care/Caring</td>
<td>III. 22</td>
</tr>
<tr>
<td>Violence</td>
<td>Care, Cure, Health and Illness</td>
<td>Noncare</td>
<td>III. 26</td>
</tr>
<tr>
<td>Working</td>
<td>General Cultural &amp; Holistic Domains of Inquiry</td>
<td>Cultural-social Lifeways</td>
<td>I. 2</td>
</tr>
<tr>
<td></td>
<td>Cultural and Social Structural Data</td>
<td>Economic Factors</td>
<td>II. 11</td>
</tr>
</tbody>
</table>
Appendix D

Figure 2

Map of Puerto Rico

https://annexx51.wordpress.com/pr-101/puerto-rico-maps/#jp-carousel-808
Appendix E

Figure 3

Map of Sea and Air Route from San Juan, PR to New York City

Appendix F

Figure 4

Visual representation of the “Three Races, One Culture” of Puerto Rico

https://s-media-cache-ak0.pinimg.com/736x/72/ea/c5/72eac587bd7df271d8aec863cb1339c6.jpg
Appendix G

Figure 5

Leininger’s Phases of Ethnonursing Research Process

1. Identify the general intent of the study developing the domain of inquiry under study, purpose and goal of the study and research questions to be addressed
2. Identify the potential significance of the study to advance nursing knowledge, research, education, and practices
3. Review the available literature on the domain being studied, the culture care theory, the ethnonursing research method, and studies conducted using both theory and method
4. Conceptualize a research plan from beginning to end with the following general phases or sequence factors in mind:
   a. consider the research site, community and people to study the phenomena.
   b. deal with the informed consent expectations and human subjects considerations.
   c. explore and gradually gain entry (with essential permissions) to the community, hospital, institution, or country where the study is being done.
   d. anticipate potential barriers and facilitators related to gatekeeper’s expectations, language, political ramifications, location, and other factors.
   e. select and appropriately use relevant enablers with the research process (e.g. Leininger’s Stranger-to-Trusted-Friend Enabler and Leininger’s Observation-Participation-Reflection Enabler). The researcher may also develop other specific enablers or guides for their study.
   f. develop selection criteria and choose key and general informants.
   g. maintain trusting and favorable relationships with the people while continuously conferring with the ethnonurse-research mentor expert(s) to prevent unfavorable developments.
   h. collect and confirm data with observations, interviews, participant experiences and other data. (This is a continuous process from beginning to end and requires the use of qualitative research criteria to confirm findings and credibility factors).
   i. maintain continuous and on-going active data analysis, reflection and processing using computers, field journals and discussions with research mentor(s). Qualitative data analysis software is a helpful means to process large amounts of qualitative data. Data coding can be greatly facilitated through the use of an adaptation of The Leininger-Templin-Thompson (LTT) Ethnoscript Coding Enabler.
   j. frequently present and confirm findings with the people studied to check the credibility and confirmability of findings.
   k. make plans to leave the field site or community by informing people in advance.
5. Do final analysis and writing of research findings soon after completing the study.
6. Disseminate the research process and findings via publications in appropriate journals and presentations at local, national, and/or international conferences.
7. Help implement the findings with nurses and others interested in findings.
8. Plan future studies connected to this domain or other ones.
9. Mentor other researchers in the ethnonursing research process.

### Appendix H

**Figure 6**

Leininger’s Stranger-to-Trusted-Friend Enabler

<table>
<thead>
<tr>
<th>Indicators of Stranger (Largely <em>etic</em> or outsider views)</th>
<th>Date Noted</th>
<th>Indicators as a Trusted Friend (Largely <em>emic</em> or insider’s views)</th>
<th>Date Noted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informant(s) or people are:</td>
<td></td>
<td>Informant(s) or people are:</td>
<td></td>
</tr>
<tr>
<td>1. Active to protect self and others. They are “gate keepers” and guard against outside intrusions. Suspicious and questioning</td>
<td>5-9/2013 Clinic Network</td>
<td>1. Less active to protect self. More trusting of researchers (their ‘gatekeeping is done or less’). Less suspicious and less questioning of the researcher</td>
<td>10/2013-2/2014 ACT-2 Research Staff</td>
</tr>
<tr>
<td>2. Actively watch and are attentive to what researcher does and says. Limited signs of trusting the researcher or stranger.</td>
<td>3/2014 Front Desk Staff</td>
<td>2. Less watching the researcher’s words and actions. More signs of trusting and accepting a new friend.</td>
<td>4/2014 Front Desk Staff</td>
</tr>
<tr>
<td>3. Skeptical about the researcher’s motives and work. May question how findings will be used by the researcher or stranger.</td>
<td>3-7/2014 Screening</td>
<td>3. Less questioning of the researcher’s motives, work and behavior. Signs of working with and helping researcher as a friend.</td>
<td>Early 5/2014 Snowball Referrals</td>
</tr>
<tr>
<td>4. Reluctant to share cultural secrets and views as private knowledge. Protective of local lifeways, values and beliefs. Dislikes probing by the researcher or stranger.</td>
<td>3-11/2014 Deeply personal matters during interviews</td>
<td>4. Willing to share cultural secrets and private world information and experiences. Offers most local views, values, and interpretations spontaneously or without probes.</td>
<td>3-7/2014 Developed during interview</td>
</tr>
<tr>
<td>5. Uncomfortable to become a friend or to confide in stranger. May come late, be absent, and withdraw at times from researcher.</td>
<td>3/2014 1 informant lost after screening</td>
<td>5. Signs of being comfortable and enjoying friends and a sharing relationship. Gives presence, on time and gives evidence of being a ‘genuine friend.’</td>
<td>3-7/2014 Developed during interview</td>
</tr>
<tr>
<td>6. Tends to offer inaccurate data. Modifies ‘truths’ to protect self, family, community, and cultural lifeways. <em>Emic</em> values, beliefs, and practices are not shared spontaneously.</td>
<td>5/2014 1 informant re: age</td>
<td>6. Wants research ‘truths’ to be accurate regarding beliefs, people, values, and lifeways. Explains and interprets <em>emic</em> ideas so researcher has accurate data.</td>
<td>3/2014 Towards end of each interview and during second interviews</td>
</tr>
</tbody>
</table>

Appendix I

Figure 7

Leininger’s Observation-Participation-Reflection Enabler

Phases:  1    2   3    4

Primary   Primary Primary Primary
Observation Observation Participation Reflection

and Active Listening (no active participation)

with limited participation with continued observations of findings

and Reconfirmation with informants

Appendix J

Figure 8

Leininger’s Phases of Ethnonursing Data Analysis Enabler for Qualitative Data

**Fourth Phase (Last Phase)**
*Major Themes, Research Findings, Theoretical Formulations, and Recommendations*
This is the highest phase of data analysis, synthesis, and interpretation. It requires synthesis of thinking, configuration analysis, interpretation of findings, and creative formulation from data of the previous phases. The researcher’s task is to abstract and confirm major themes, research findings, recommendations, and sometimes make new theoretical formulations.

**Third Phase**
*Pattern and Contextual Analysis*
Data are scrutinized to discover saturation of ideas and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations of data related to the domain of inquiry. Data are also examined to show patterning with respect to meanings-in-context and along with further credibility and confirmability of findings.

**Second Phase**
*Identification and Categorization of Descriptors and Components*
Data are coded and classified as related to the domain or inquiry and sometimes the questions under study. *Emic* and *etic* descriptors are studied within context and for similarities and differences. Recurrent components are studied for their meanings.

**First Phase**
*Collecting, Describing, and Documenting Raw Data (Use of Field Journal and Computer)*
The researcher collects, describes, records, and begins to analyze data related to the purposes, domain of inquiry, or questions under study. This phase includes: Recording interview data from *key* and *general* informants; making observations, and having participatory experiences; identifying contextual meanings; making preliminary interpretations; identifying symbols; and recording data related to the DOI or phenomenon under study mainly from an *emic* focus. Attention to *etic* ideas is also recorded. Field data from the condensed and full field journal can be processed directly into the computer and coded, ready for analysis.

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Project Title: Cultural Care Needs as shared by Puerto Rican Women Receiving HIV Care from Nurse Practitioners in New York City

Principal Investigator: Michele Crespo-Fierro, RN, MS/MPH, AACRN
   Doctoral Candidate
   Graduate Center
   365 Fifth Avenue, Room 3317
   New York, NY 10016
   347 484-6257

Faculty Advisor: Marianne Jeffreys, EdD, RN
   Professor
   CSI, and Graduate Center
   2800 Victory Boulevard, Building 5S Room 108
   Staten Island, NY 10314
   718 982-3825

Introduction/Purpose: You are invited to participate in a research study. The study is conducted under the direction of Michele Crespo-Fierro, RN, MS/MPH, AACRN, Graduate Center, CUNY and New York University College of Nursing. The purpose of this research study is to explore cultural care values, beliefs, expressions, practices and needs of Puerto Rican women receiving HIV care from nurse practitioners (NPs). The results of this study may increase understanding of the values, beliefs and practices related to health and well-being. Audio recordings will be used to transcribe the interviews in preparation for studying, and coding. Photographs of personal objects may be used.

Procedures: Around 18-24 individuals are expected to participate in this study. Each participant will participate in one or two interviews. The time commitment of each participant is expected to be 60 – 90 minutes per interview. Each session will take place in a location agreed
upon which will protect your confidentiality. You may be asked permission to photograph an object that does not identify you.

Possible Discomforts and Risks: Your participation in this study may involve anxiety, stress, or sadness. There is no expected physical discomfort. To minimize these risks you should discuss your concerns regarding continued anxiety, stress, or sadness associated with the interview with a mental health care provider. If you are upset because of this study, you should contact your mental health care provider or the researcher will provide you with a referral for a mental health care provider at a community based organization.

Benefits: There are no direct benefits for participating in this study. However, it may increase general knowledge of care Puerto Rican women and be applied to the education of health care providers.

Alternatives: None applicable

Voluntary Participation: Your participation in this study is voluntary, and you may decide not to participate at any time without prejudice, penalty, or loss of benefits to which you are otherwise entitled. You also may decline to have the interview recorded or object photographs taken. If you decide to leave the study, please contact the principal investigator Michele Crespo-Fierro to inform her of your decision.

Financial Considerations: Participation in this study will involve no cost to you. For your participation in this study, you will receive one round-trip Metrocard and $20 for each interview.

Confidentiality: The data obtained from you will be collected via audio recording, and written document notes and if indicated, photographs of items that do not identify you. The collected data will be accessible to Michele Crespo-Fierro and her faculty advisors and IRB staff at NYU and CUNY. The researcher will protect your confidentiality by coding the data, and securely storing the data. The collected data will be stored in a locked file box in the investigator’s home; no names will appear on any tapes, transcripts, photographs or notes. All consent forms will be stored separately in a safe deposit box. If a transcriptionist is used, a confidentiality agreement will be required to further protect your information.

Contact Questions/Persons: If you have any questions about the research now or in the future, you should contact the Principal Investigator, Michele Crespo-Fierro, 347 484-6257 or m.crespo.fierro@gmail.com. If you have any questions concerning your rights as a participant in this study, you may contact either the University Committee on Activities involving Human Subjects, New York University, 665 Broadway, Suite 804, New York, NY 10012, phone: 212 998-4808, email: ask.humansubjects@nyu.edu; OR Arita Winter – CUNY Human Rights Protections Program Coordinator at the City University of New York, 205 East 42nd Street, 11th Floor, New York, NY 10017, phone: 646 664-8919, email: arita.winter@cuny.edu.
Statement of Consent:

“I have read the above description of this research and I understand it. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions that I may have will also be answered by the principal investigator of the research study. I voluntary agree to participate in this study.

By signing this form, I have not waived any of my legal rights to which I would otherwise be entitled.

I will be given an unsigned copy of this statement.”

Printed Name of Subject ___________________________________ Signature of Subject ___________________________ Date Signed ___________________________

Printed Name of Person Explaining Consent Form ___________________________________ Signature of Person Explaining Consent Form ___________________________ Date Signed ___________________________

Printed Name of Investigator ___________________________________ Signature of Investigator ___________________________ Date Signed ___________________________
CONSENTIMENTO PARA PARTICIPAR EN UN PROYECTO DE INVESTIGACIÓN

Título del proyecto: Las Necesidades del Cuidado Cultural de Mujeres Puertorriqueñas Recibiendo Atención Médica por VIH de Enfermeras Practicantes en NYC

Investigadora Principal: Michele Crespo-Fierro, RN, MS/MPH, AACRN
Candidata Doctoral
Graduate Center
365 Fifth Avenue, Room 3317
New York, NY 10016
347 484-6257

Consejera Facultad: Marianne Jeffreys, EdD, RN
Profesora
CSI, and Graduate Center
2800 Victory Boulevard, Building 5S Room 108
Staten Island, NY 10314
718 982-3825

Introducción/Propósito: Usted es invitada a participar en un proyecto de investigación. Este estudio sería dirigido por Michele Crespo-Fierro, RN, MS/MPH, AACRN, Graduate Center, CUNY y New York University. El propósito de esta investigación es la exploración de los valores, las creencias, las expresiones, las prácticas y las necesidades del cuidado cultural de mujeres Puertorriqueñas recibiendo atención médica por VIH de enfermeras practicantes en NYC. Los resultados de este estudio pueden aumentar la comprensión de los valores, las creencias, y las prácticas sobre la salud y el bienestar. Grabaciones de entrevistas serían transcritas en preparación por la investigación por el estudio y la codificación de la información. Fotografías de objetos personales pueden ser usadas.

Procedimientos: Aproximadamente 18-24 individuos son previstos a participar en la investigación. Cada participante colaborará en una o dos entrevistas. El compromiso de tiempo
por cada participante sería entre 60 a 90 minutos por cada entrevista. Cada sesión tendría lugar en un sitio elegido para proteger su confidencialidad. Se puede pedir permiso para sacar fotografías de objetos que no le identifica.

**Malestares o Riesgos Posibles:** Su participación en esta investigación puede incluir ansiedad, estrés, o tristeza. No hay previsión de ningún malestar físico. Para disminuir estos riesgos **usted debe hablar con su proveedor de salud mental sobre sus preocupaciones de ansiedad, estrés, o tristeza que continúa después de la entrevista.** Si esta disgustada, a causa de esta investigación, usted debe **hablar con su proveedor de salud mental o la investigadora le dará una referencia por un proveedor de salud mental asociado con una organización comunitaria.**

**Beneficios:** No hay ningún beneficio directo. Sin embargo, participar en esta investigación puede aumentar el conocimiento del cuidado de mujeres Puertorriqueñas y sería aplicado a la educación de proveedores del cuidado de la salud.

**Alternativos:** No tiene aplicación.

**Participación Voluntaria:** Su participación en esta investigación es voluntaria, y usted puede decidir de no participar sin prejuicio, ni sanción, ni perdido de los beneficios que tiene derecho de recibir. Usted puede declinar que la entrevista sea grabada o las fotografías de su objetos, también. Si decide a dejar la investigación, favor de ponerse en contacto con la investigadora principal, Michele Crespo-Fierro para informarla de su decisión.

**Consideraciones financieras:** Participación en esta investigación no tendrá cuesta. Por su participación recibirá **un Metrocard de un viaje de ida y vuelta y $20 por cada entrevista**

**Confidencialidad:** La información obtenida de usted sería colocada por grabación audio, documentos escritos, notas y cuando está indicado, fotografías de artículos que no le identifican. La información colocada sería disponible a Michele Crespo-Fierro sus consejeras facultades, y el personal de IRB de NYU y CUNY. La investigadora protegerá su confidencialidad por las siguientes maneras: la codificación de la información, y el almacenaje seguro. La información colocada sería guardada en una caja cerrada en la casa de la investigadora. Ningún nombre aparecía en ninguna cifras, transcripciones, fotografías, ni notas. Todas las formas de consentimiento serían guardadas separadamente en una caja fuerte en el banco. Si esta investigación usa una transcrita, un acuerdo de confidencialidad sería usado para proteger su información.

**Preguntas/Personas de Contacto:** Si usted tiene algunas preguntas sobre esta investigación ahora o en el futuro, usted puede comunicar con la investigadora, Michele Crespo-Fierro, 347 484-6257 o m.crespo.fierro@gmail.com. Si usted tiene algunas preguntas sobre sus derechos
como participante en esta investigación, usted puede comunicar con the University Committee on Activities involving Human Subjects, New York University, 665 Broadway, Suite 804, New York, NY 10012, phone: 212 998-4808, email: ask.humansubjects@nyu.edu; OR Arita Winter – CUNY Human Rights Protections Program Coordinator at the City University of New York, 205 East 42nd Street, 11th Floor, new York, NY 10017, phone: 646 664-8919, email: arita.winter@cuny.edu.

Declaración de consentimiento:

“He leído esta descripción de esta investigación y la entiendo. He sido informada de los riesgos y beneficios envueltos y he recibido respuestas a mis preguntas a mi satisfacción. Además yo estaba asegurado que algunas preguntas en el futuro serían contestadas por la investigadora principal de esta investigación. Yo estoy de acuerdo de participar en esta investigación.

Por firmar esta forma, no renuncio ninguna derecha legal que tengo.

Yo recibiré una copia sin firma de esta declaración.”

<table>
<thead>
<tr>
<th>Nombre de participante</th>
<th>Firma de la participante</th>
<th>Fecha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nombre de Persona</td>
<td>Firma de la persona explicando la forma de consentimiento</td>
<td>Fecha</td>
</tr>
<tr>
<td>Explicando la forma de Consentimiento</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nombre de la investigadora</td>
<td>Firma de la investigadora</td>
<td>Fecha</td>
</tr>
</tbody>
</table>
Appendix M

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

Project Title: Cultural Care Needs as shared by Puerto Rican Women Receiving HIV Care from Nurse Practitioners in New York City

Principal Investigator: Michele Crespo-Fierro, RN, MS/MPH, AACRN
Doctoral Candidate
Graduate Center
365 Fifth Avenue, Room 3317
New York, NY 10016
347 484-6257

Faculty Advisor: Marianne Jeffreys, EdD, RN
Professor
CSI, and Graduate Center
2800 Victory Boulevard, Building 5S Room 108
Staten Island, NY 10314
718 982-3825

Introduction/Purpose: You are invited to participate in a research study. The study is conducted under the direction of Michele Crespo-Fierro, RN, MS/MPH, AACRN, Graduate Center, City University of New York and New York University College of Nursing. The purpose of this research study is to explore cultural care values, beliefs, expressions, practices and needs of Puerto Rican women receiving HIV care from nurse practitioners (NPs). The results of this study may increase understanding of the values, beliefs and practices related to health and well-being. Audio, recordings will be used to transcribe the interviews in preparation for studying, and coding. Photographs of personal objects may be used.
**Procedures:** Approximately 18-24 individuals are expected to participate in this study. Each participant will participate in one or two interviews. The time commitment of each participant is expected to be 60 – 90 minutes per interview. Each session will take place in a location agreed upon which will protect your confidentiality. You may be asked permission to photograph an object that does not identify you.

**Possible Discomforts and Risks:** Your participation in this study may involve anxiety, stress, or sadness. There is no expected physical discomfort. To minimize these risks you should discuss your concerns regarding continued anxiety, stress or sadness associated with the interview with a mental health care provider. If you are upset because of this study you should contact your mental health care provider or the researcher will provide you with a referral for a mental health care provider at a community based organization.

**Benefits:** There are no direct benefits. However, participating in the study may increase general knowledge of care Puerto Rican women and be applied to the education of health care providers.

**Alternatives:** None applicable

**Voluntary Participation:** Your participation in this study is voluntary, and you may decide not to participate without prejudice, penalty, or loss of benefits to which you are otherwise entitled. You also may decline to have the interview recorded or object photographs taken. If you decide to leave the study, please contact the principal investigator Michele Crespo-Fierro to inform them of your decision.

**Financial Considerations:** Participation in this study will involve no cost to you. For your participation in this study, you will receive one roundtrip metrocard and $20 for each interview.

**Confidentiality:** The data obtained from you will be collected via audio recording; written document notes and if indicated, photographs of items that do not identify you. The collected data will be accessible to Michele Crespo-Fierro and her faculty advisors and IRB staff at NYU and CUNY. The researcher will protect your confidentiality by coding the data, and securely storing the data. The collected data will be stored in a locked file box in the investigator’s home; no names will appear on any tapes, transcripts or notes. All consent forms will be stored separately from the data in a safe deposit box. If a transcriptionist is used, a confidentiality agreement will be required to further protect your information.
**Contact Questions/Persons:** If you have any questions about the research now or in the future, you should contact the Principal Investigator, Michele Crespo-Fierro, 347 484-6257 or m.crespo.fierro@gmail.com. If you have any questions concerning your rights as a participant in this study, you may contact either the University Committee on Activities involving Human Subjects, New York University, 665 Broadway, Suite 804, New York, NY 10012, phone: 212 998-4808, email: ask.humansubjects@nyu.edu; OR Arita Winter – CUNY Human Rights Protections Program Coordinator at the City University of New York, 205 East 42nd Street, 11th Floor, new York, NY 10017, phone: 646 664-8919, email: arita.winter@cuny.edu.

---

**PERSON CONDUCTING CONSENT**

I have explained the study to __________________________ (name or pseudonym of subject) in language he/she understands, and he/she has agreed to be in the study.

<table>
<thead>
<tr>
<th>Printed Name of Person Explaining Form</th>
<th>Signature of Person Explaining Form</th>
<th>Date Signed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Printed Name of Investigator</th>
<th>Signature of Investigator</th>
<th>Date Signed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CONSENTIMENTO PARA PARTICIPAR EN UN PROYECTO DE INVESTIGACIÓN

Título del proyecto: Las Necesidades del Cuidado Cultural de Mujeres Puertorriqueñas Recibiendo Atención Médica por VIH de Enfermeras Practicantes en NYC

Investigadora Principal: Michele Crespo-Fierro, RN, MS/MPH, AACRN
Candidata Doctoral
Graduate Center
365 Fifth Avenue, Room 3317
New York, NY 10016
347 484-6257

Consejera Facultad: Marianne Jeffrey, EdD, RN
Profesora
CSI, and Graduate Center
2800 Victory Boulevard, Building 5S Room 108
Staten Island, NY 10314
718 982-3825

Introducción/Propósito: Usted es invitada a participar en un proyecto de investigación. Este estudio sería dirigido por Michele Crespo-Fierro, RN, MS/MPH, AACRN, Graduate Center, CUNY y New York University. El propósito de esta investigación es la exploración de los valores, las creencias, las expresiones, las prácticas, y las necesidades del cuidado cultural de mujeres Puertorriqueñas recibiendo atención médica por VIH de enfermeras practicantes en NYC. Los resultados de este estudio pueden aumentar la comprensión de los valores, las creencias, y las prácticas sobre la salud y el bienestar. Grabaciones de entrevistas serían transcritas en preparación por la investigación por el estudio y la codificación de la información. Fotografías de objetos personales pueden ser usadas.

Procedimiento: Aproximadamente 18-24 individuos son previstos a participar en la investigación. Cada participante colaborará en una o dos entrevistas. El compromiso de tiempo por cada participante sería entre 60 a 90 minutos por cada entrevista. Cada sesión tendría lugar
en un sitio elegido para proteger su confidencialidad. Se puede pedir permiso para sacar fotografías de objetos que no le identifiquen.

**Malestares o Riesgos Posibles:** Su participación en esta investigación puede incluir ansiedad, estrés, o tristeza. No hay previsión de ningún malestar físico. Para disminuir estos riesgos usted debe hablar con su proveedor de salud mental sobre sus preocupaciones de ansiedad, estrés, o tristeza que continúan después de la entrevista. Si esta disgustada, a causa de esta investigación, usted debe hablar con su proveedor de salud mental o la investigadora le dará una referencia por un proveedor de salud mental asociado con una organización comunitaria.

**Beneficios:** No hay ningún beneficio directo. Sin embargo, participar en esta investigación puede aumentar el conocimiento del cuidado de mujeres Puertorriqueñas y sería aplicado a la educación de proveedores del cuidado de la salud.

**Alternativos:** No tiene aplicación.

**Participación Voluntaria:** Su participación en esta investigación es voluntaria, y usted puede decidir de no participar sin prejuicio, ni sanción, ni perdido de los beneficios que tiene derecho de recibir. Usted puede declinar que la entrevista sea grabada o las fotografías de sus objetos, también. Si decide a dejar la investigación, favor de ponerse en contacto con la investigadora principal, Michele Crespo-Fierro para informarla de su decisión.

**Consideraciones financieras:** Participación en esta investigación no tendrá cuesta. Por su participación recibirá un *Metrocard de un viaje de ida y vuelta* y $20 por cada entrevista.

**Confidencialidad:** La información obtenida de usted sería colocada por grabación audio, documentos escritos, notas y cuando es indicado, fotografías de artículos que no le identifican. La información colocada sería disponible a Michele Crespo-Fierro sus consejeras facultades, y el personal de IRB de NYU y CUNY. La investigadora protegerá su confidencialidad por las siguientes maneras: codificación de la información, y el almacenaje seguro. La información colocada sería guardada en una caja cerrada en la casa de la investigadora. Ningún nombre aparecía en ninguna cifras, transcripciones, fotografías, ni notas. Todas las formas de consentimiento serían guardadas separadamente en una caja fuerte en el banco. Si esta investigación usa una transcrita, un acuerdo de confidencialidad sería usado para proteger su información.
Preguntas/Personas de Contacto: Si usted tiene algunas preguntas sobre esta investigación ahora o en el futuro, usted puede comunicar con la investigadora, Michele Crespo-Fierro, 347 484-6257 o m.crespo.fierro@gmail.com. Si usted tiene algunas preguntas sobre sus derechos como participante en esta investigación, usted puede comunicar con the University Committee on Activities involving Human Subjects, New York University, 665 Broadway, Suite 804, New York, NY 10012, phone: 212 998-4808, email: ask.humansubjects@nyu.edu; OR Arita Winter – CUNY Human Rights Protections Program Coordinator at the City University of New York, 205 East 42nd Street, 11th Floor, new York, NY 10017, phone: 646 664-8919, email: arita.winter@cuny.edu.

Persona Conduciendo el Consentimiento

He explicado la investigación a ___________________________________________ (nombre o seudónimo del participante) en el idioma que él/ella entienda, y él/ella consiente a participar en la investigación.

Nombre de Persona
Explicando la forma de
Consentimiento

Firma de la persona explicando
la forma de consentimiento

Fecha

Nombre de la investigadora

Firma de la investigadora

Fecha

CUNY UI - Institutional Review Board
Effective Date: February 04, 2014
Expiration Date: January 17, 2015
Coordinator Initials: AW
Appendix O

Cultural Care Needs of Puerto Rican Women Receiving HIV Care from Nurse Practitioners in NYC
Open Inquiry Guide
Michele Crespo-Fierro, RN, MS/MPH, AACRN

Ethnodemographics

Code Name: Interview Number/Date/Location:

Age: Marital Status:

Place of Birth: Years in US/PR:

Language(s) Spoken: Language(s) Preferred:

Education: Occupation:

Children: Religious Affiliation:

Time since HIV dx: AIDS dx:

Length of time in care: Length of time receiving care from a NP:

Gender, Ethnicity and certification of NP:

Ethnohistory

1. Where were you born? If born in PR, when did you come to the mainland? If born in US, have you ever returned to PR to live? Have you lived anywhere besides where you were born or NYC?

2. Please tell me why you/your family came to NYC or returned to PR.

3. What borough do you live in?


5. Who lives with you in your home? What language do you speak at home?

Kinship/Social Factors

1. What does family mean to you?

2. Where does your family live? How often do you see your family? How do you travel to see them or they to see you?
3. How often do you visit Puerto Rico? Tell me about your visits.

4. How are decisions made in your family?

5. What is your/your family’s typical routine?

6. Who is the caretaker in your family? Who cares for you when you are ill?

7. Who do you turn to for help?

Cultural/Religious Factors
1. How would you identify yourself culturally?

2. Please describe your cultural practices from your childhood? Do you still observe these customs? What customs do you share with your family?

3. Tell me about your favorite foods. What are the cultural/traditional Puerto Rican foods that you eat?

4. What does your faith/religion/spirituality mean to you?

5. How often do you attend religious services? Please describe your spiritual practice.

6. Which religious holidays do you celebrate and how?

7. Tell me about your experiences of being Puerto Rican/Nuyorican?

8. What are areas of concern regarding your culture and the healthcare you receive? Can you describe any examples?

Technology/Educational Factors
1. How do you use technology? How is technology viewed in your culture?

2. How is technology used in the healthcare that you receive? How does technology affect the care that you receive from your NP?

3. Where were you educated? Grammar school? High school? Beyond high school?

Economic/Political Factors
1. What type of healthcare insurance do you currently have? What type(s) of healthcare insurance have you had in the past?

2. If you are currently working, where do you work? What language do you speak on the job?

3. What are your concerns regarding your economic situation?
4. How does your economic situation affect your health and well-being?

5. What are the political factors affecting the safety of your neighborhood? Your health and well-being?

6. What are your concerns about the political situation in the US? In PR? Between PR and the US and how it affects Puerto Ricans in the US and Puerto Ricans in PR?

**Health**

1. What does health mean to you? Tell me about your health?

2. Describe the activities you use to maintain health? Include culture-based practices like food, medicines, herbs that you use to maintain or improve your health.

3. What does illness mean to you? What does death mean to you?

4. Describe any cultural practices to treat illness or care for a dying person? How have they worked?

5. Have you or someone you know ever consulted a curandero/espiritista/santero/botánica?

6. What role does your faith or spirituality have in health, illness, death?

7. What do you share with your nurse/nurse practitioner about your health beliefs?

**Sexual Health and HIV Care**

1. What are your beliefs about sexual relationships between people?

2. Are you currently in a relationship? Tell me about your partner.

3. What methods of birth control have you used in the past? Are using now, if any?

4. Why were you tested for HIV? Who gave you your test results? Where were you when you received the results?

5. What does HIV infection mean to you? Has this changed over time?

6. Who knows about your diagnosis? How did they learn about it?

7. What do other people think about HIV? Puerto Ricans? Is there any difference?

8. Tell me about the HIV care that you have received. When did you start? Has the care you received changed over time?
9. What do you do to protect yourself from infections? What do you do to protect others and partners from infection? What do you do to protect yourself and partners during sex?

Care
1. What does the word care mean to you?

2. What are the characteristics of a caring person? A caring nurse? A caring nurse practitioner?

3. In your culture how do people show care to family or friends?

4. How does care affect your health and well-being?

5. Have your ideas about care changed since discovering you have HIV?

6. Describe how you have been cared for by family/friends or yourself when you were ill in the past? How have you been cared for by family/friends or yourself since your diagnosis? Has anything changed?

7. Describe how you have been cared for by a nurse? By a nurse practitioner?

8. What should a nurse or nurse practitioner know or do to provide you with care that matches your culture?

9. What would you like people to know about caring for someone with HIV?
Appendix P

Las Necesidades del Cuidado Cultural de Mujeres Puertorriqueñas
Recibiendo Atención Médica de VIH de Enfermeras Practicantes en NYC
Guía de Preguntas Abiertas
Michele Crespo-Fierro, RN, MS/MPH, AACRN

**Etnodemográficas**

<table>
<thead>
<tr>
<th>Nombre de código:</th>
<th>Número de la entrevista/Fecha/Lugar:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edad:</td>
<td>Estado civil:</td>
</tr>
<tr>
<td>Lugar de nacimiento:</td>
<td>Años en los EE. UU./PR:</td>
</tr>
<tr>
<td>Idioma(s) hablado(s):</td>
<td>Idioma(s) Preferido(s):</td>
</tr>
<tr>
<td>Nivel de Educación:</td>
<td>Ocupación:</td>
</tr>
<tr>
<td>Hijos:</td>
<td>Religión:</td>
</tr>
<tr>
<td>Tiempo desde diagnosis de VIH:</td>
<td>Diagnosis de SIDA:</td>
</tr>
<tr>
<td>Tiempo en cuidado por el VIH:</td>
<td>Tiempo recibiendo cuidado de una enfermera practicante (NP):</td>
</tr>
</tbody>
</table>

**Ambiente:**

1. ¿Dónde nació? ¿Si nació en PR, cuando vino a los EE. UU.? ¿Si nació en los EE. UU., ha regresado a PR para vivir? ¿Ha vivido en otro lugar (en vez de dónde nació o NYC)?

2. Favor de decirme porque Ud. o su familia vino a NYC o regresó a PR.

3. ¿En qué parte de Nueva York vive Ud.? ¿Vive en un barrio PR o Latino?

4. ¿Tiene Ud. preocupaciones de su barrio? ¿Su casa? ¿Se siente segura? ¿Por qué sí o por qué no?

5. ¿Con quién vive en su casa? ¿Cuál lenguaje hablan en la casa?

**Factores Parentescos y Sociales**

1. ¿Qué significa tiene familia para usted?

2. ¿Dónde vive su familia? ¿Con que frecuencia visita su familia? ¿Cómo viaja Ud. para verla o viajan ellos a ver Ud.?

3. ¿Con qué frecuencia y cómo viaja a PR?
4. ¿Cómo se hace decisiones en su familia?

5. ¿Cuál es la rutina típica de Ud.? de su familia?

6. ¿Quién es la persona que cuida su familia? ¿Quién le cuida cuando está enferma?

7. ¿A quién depende para ayuda?

Factores Culturales y Religiosos
1. ¿Cómo se identifica culturalmente?

2. Favor de describir las costumbres de su niñez. ¿Todavía observe estas costumbres? ¿Cuáles son las costumbres que comparte Ud. con su familia?

3. Dime algo de su comida favorita. ¿Cuáles son las comidas puertorriqueñas que usted come o prepara?

4. Cuál significa tiene su fe/religión/espiritualidad para Ud.?

5. ¿Asiste servicios religiosos? Describe Ud. su práctica espiritual.

6. ¿Cuáles son los días de fiesta religiosos que celebra Ud.? ¿Y cómo los celebra?

7. Favor de decirme algo de sus experiencias de ser puertorriqueña/neoyorquina?

8. ¿Hay preocupaciones entre su cultura y el cuidado de salud que recibe Ud.? Favor de dar un ejemplo.

Factores de tecnología/educación
1. ¿Cómo se usa Ud. la tecnología? ¿Cuáles son las opiniones de la tecnología en su cultura?

2. ¿Cómo se usa la tecnología en el cuidado de salud que recibe Ud.? ¿Cuáles son los efectos de usar tecnología en el cuidado que recibe Ud. de su enfermera practicante?

3. ¿Dónde recibió su educación?

Factores Económicos y Políticos
1. ¿Qué tipo de seguro de enfermedad tiene Ud.? ¿Cuáles eran los seguros de enfermedad que ha tenido en el pasado?

2. Actualmente, si Ud. está trabajando, ¿dónde trabaja? ¿Cuál idioma habla cuando está trabajando?

3. ¿Cuáles son sus preocupaciones de su situación económica?
4. ¿Cómo afecta su situación económica, su salud y bienestar?
5. ¿Cuáles son los factores políticos afectando la seguridad de su barrio? ¿Su salud y bienestar?
6. ¿Cuáles son sus preocupaciones de la situación política en los EE. UU.? ¿En PR? ¿Entre PR y los EE. UU.? ¿Y cómo cree que afecte los PR en los EE. UU. y en PR?

Salud
1. ¿Qué significa tiene la salud para Ud.? ¿Favor de decirme algo de su salud?
2. Favor de describir las actividades para mantener su salud. Favor de incluir las comidas, las medicinas, y las hierbas que usa para mantener o mejorar su salud.
3. ¿Qué significa tiene la enfermedad para Ud.? ¿Qué significa tiene la muerte para Ud.?
4. Favor de describir las prácticas culturales para curar la enfermedad o cuidar una persona que está muriendo. ¿Cómo funcionaban esas prácticas?
5. ¿Ha consultado o ha conocido a alguien que ha consultado un curandero, espiritista, santero o una botánica?
6. ¿Qué papel tiene la fe o la espiritualidad en la salud, la enfermedad y la muerte?
7. ¿Cuáles son las creencias de la salud que comparte Ud. con su enfermera, o enfermera practicante?

Salud Sexual y Cuido de VIH
1. ¿Cuáles son sus creencias de las relaciones sexuales entre personas?
2. ¿Tiene Ud. una pareja ahora? Favor de decírmelo algo de su pareja.
3. ¿Cuáles son los métodos de control de la natalidad que ha usado en el pasado? ¿Está Ud. usando cualquier método ahora?
4. ¿Por qué hizo Ud. la prueba del VIH? ¿Quién le dio los resultados? ¿Dónde estaba Ud. cuando recibió los resultados?
5. ¿Qué significa tiene el VIH para Ud.? ¿Ha cambiado con el tiempo?
6. ¿Quién sabe de su diagnóstico? ¿Cómo lo descubrió?
7. Favor de decírmelo algo del cuidado de VIH que ha recibido. ¿Cuándo empezó de recibir el cuidado de VIH? ¿Ha cambiado el cuidado con el paso de tiempo?
8. ¿Qué hace Ud. para protegerse de infecciones? ¿Qué hace Ud. para protegerse los demás y sus parejas, de infección? ¿Qué hace Ud. para protegerse y sus parejas cuando tienen relaciones sexuales?

Cuidado
1. ¿Qué significa la palabra, cuidado, para Ud.?

2. ¿Cuáles son las características de una persona afectuosa? ¿Una enfermera solicitiva? ¿Una enfermera practicante solicitiva?

3. ¿Cómo demuestra cuidado a familia o amigos, en su cultura?

4. ¿Qué efecto tiene el cuidado en su salud y bienestar?

5. ¿Ha cambiado sus ideas del cuidado desde su diagnosis del VIH?

6. Favor de describir cómo ha sido cuidada por familia/amigos o por sí misma cuando estaba enferma en el pasado. Como ha sido cuidada por familia/amigos o por sí misma desde su diagnosis? ¿Ha cambiado algo?

7. Favor de describir cómo ha sido cuidada por una enfermera. Por una enfermera practicante.

8. ¿Cuáles son las cosas que una enfermera o enfermera practicante debe saber o hacer para prestarle cuidado que corresponde al cuidado de su cultura?

9. ¿Qué quiere Ud. que la gente sabia de cuidar una persona que tiene VIH?
Dear Michelle and Marianne,

Please see newest version of Sunrise Enabler with permission to use in Michelle's dissertation and future publications with following attribution:


Hiba

Hiba Wehbe-Alamah, PhD, RN, FNP-BC, CTN-A
Professor
School of Nursing, University of Michigan-Flint
Phone (810) 766-6760
E-mail: hiba@umflint.edu
PERMISSIONS AGREEMENT

To obtain copyright permission from Jones & Bartlett Learning, including imprints from affiliates and subsidiaries (as listed on the website www.jblearning.com), you must fill out this form completely. This agreement grants nonexclusive, one-time use to reproduce the material in the language specified by the requester. Permission is granted for the material specified, and does not extend to material that is separately copyrighted. This agreement does not include future revisions or editions of the work. Please note that it is your responsibility to ensure that the material you are requesting has not been referenced to another source. If the material has been referenced to another source, you must obtain permission from the original copyright owner. We regret that electronic files of figures cannot be provided. Please allow thirty days for processing.

Requester Information:

Name: Michele Crespo-Fierrez
Street: 545 West 11th Street #51
City: New York
State: NY
Zip: 10025
Phone Number: (917) 475-6610
Fax Number: (_____)-_____ Email: mcrespoferrioz@gradcenter.cuny.edu

Billing Information (If different from above):

Name: 
Street: 
City: 
State: 
Zip: 
Phone Number: (_____)-_____ Fax Number: (_____)-_____ Email: 

I wish to borrow material from the following product published by Jones & Bartlett Learning or Jones & Bartlett Learning imprints:

Title: Culture Care Diversity & Universality: A Worldwide Nursing Theory
ISBN #: 9781284026627
Edition: 3rd
Copyright date: 2015

For text material, list page numbers: Appendix 2A: p. 67-68
Total page count: 2

For illustrations, list table/figure numbers: Figure 3.2; 3.3; 3.6

Found on page number(s): p. 78; 80; 89
Total number of figures/tables being requested: 3

I plan to use this material in the following way (note that multiple uses often incur multiple fees):

Print Book/Publication: 
Ebook: 
CD/DVD: 

Author(s): Michele Crespo-Fierrez
Affiliation: Graduate Center, CUNY
Title: Culture Care Needs of Puerto Rican Women Receiving HIV Care in NYC

Total number of copies to be printed (if print): 10
Estimated number of users (if ebook): 

Duration of use (please include dates): life of edition
Language(s): English

Course Packet: Print: 
Electronic:

College/Company: 

Total number of copies to be printed (if print): 
Estimated number of users (if electronic): 

Page 1 of 2
References


American Association of Colleges in Nursing (2008, October). The essentials of baccalaureate
education for professional nursing practice


American Association of Colleges in Nursing (2010, November). The research-focused doctoral program in nursing: Pathways to excellence.


American College of Nurse Practitioners (n.d.). What is a nurse practitioner?


Silver Spring, MD: Author.

American Nurses Credentialing Center (n.d.) ANCC Magnet Recognition Program®

http://www.nursecredentialing.org/Magnet Accessed on December 29, 2017


of an “Impact of HIV” instrument for HIV survivors. *Journal of the Association of Nurses in AIDS Care, 26* (6), 720-731.


linkage to care among people diagnosed with HIV. *Journal of the Association of Nurses in AIDS Care, 26*(2), 110-126.


Dávila, A. (2001). Local/diasporic Taínos: Towards a cultural politics of memory, reality and


Eipperle, M. K. (2015). Application of the three modes of culture care decisions and actions in


HIV risks, substance abuse, and intimate partner violence among Hispanic women and their intimate partners. *Journal of the Association of Nurses in AIDS Care, 19* (4), 252-266.


govtrack.us (n.d.) Commissioner Jennifer Gonzalez-Colon.


govtrack.us (n.d.) Commissioner Pedro Pierluisi.


studies among African Americans/Blacks and Hispanics: A cluster randomized controlled trial. *AIDS Behavior* DOI: 10.1007/s10461-014-0829-5


Herbst, J. H., Kay, L. S. Passin, W.F., Lyles, C. M., Crepaz, N., & Marin, B.V. (2007). A


International Nursing Association for Clinical Simulation and Learning (2016). *Standards of best*


Kubler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses,*


Martinez, R. A. (2014). “Do they even know that they do it?”: Exploring awareness of Spanish


Mixer, S. (2015). Application of Culture Care Theory in teaching cultural competence and


Washington, DC: Author.


New York State Department of Health (2013, November). HIV Special Needs Plans (HIV SNPs)


Romberg, R. (2003). From charlatans to saviors: Espiritistas, curanderos, and brujos. Inscribed in


language qualitative research. *Qualitative Health Research, 25* (1), 134-144.


Skarbinski, J., Rosenberg, E., Paz-Bailey, G., Hall, I., Rose, C. E., Vlall, A. H., Fagan, J. L.,


Confronting change, challenging tradition: Women in Latin American history. (p. 3-17). Wilmington, DE: Scholarly Resources.


Tejeda, G. (2008, August 5). “We really need to define ‘Hispanic’.” The South Chicagoan.


US Department of Health and Human Services (2011, April). *HHS action plan to reduce racial


CULTURE CARE PUERTO RICAN WOMEN


