2-1-2016

Re-framing Informal Family Caregiving

Magdalena T. Ornstein-Sloan
Graduate Center, City University of New York

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

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

Part of the Health Services Research Commons, and the Human Geography Commons

Recommended Citation
Ornstein-Sloan, Magdalena T., "Re-framing Informal Family Caregiving" (2016). CUNY Academic Works.
http://academicworks.cuny.edu/gc_etds/740

This Dissertation is brought to you by CUNY Academic Works. It has been accepted for inclusion in All Dissertations, Theses, and Capstone Projects (2014-Present) by an authorized administrator of CUNY Academic Works. For more information, please contact AcademicWorks@gc.cuny.edu.
RE-FRAMING INFORMAL FAMILY CAREGIVING

by

MAGDALENA T. ORNSTEIN-SLOAN

A dissertation submitted to the Graduate Faculty in Earth and Environmental Sciences in partial fulfillment of the requirements for the degree of Doctor of Philosophy,
The City University of New York
2016
RE-FRAMING INFORMAL FAMILY CAREGIVING

by

MAGDALENA T. ORNSTEIN-SLOAN

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

Professor Kenneth Gould

______________________________
Date Chair of Examining Committee

Professor Cindi Katz

______________________________
Date Executive Officer

Professor Barbara Katz Rothman

Professor Yehuda Klein

Supervisory Committee
THE CITY UNIVERSITY OF NEW YORK

Abstract

RE-FRAMING INFORMAL FAMILY CAREGIVING

By

Magdalena T. Ornstein-Sloan

Advisor: Professor Kenneth Gould

Informal family caregivers are the backbone of the long-term care system, providing an estimated 80% of the long-term care in the United States. Caregivers provide care to people with disabilities, the ill and older adults, often with little to no outside assistance from the formal long-term care system. Although caregivers receive attention in the academic literature, mainstream media and within public policy and services development, caregiver services continue to remain underutilized. The focus on service provision has various goals, including the desire to lessen the burden caregivers experience by providing services so they can provide care at home longer than they would without these services. Current measurements of ‘caregiver burden’ focus on the proximal tasks caregivers do for care recipients, without recognizing the distal factors of care-giving, such as interactions with the long-term care system (i.e.- in home, direct care service providers, public benefits programs, private insurance companies), as potentially problematic and traumatizing to family caregivers, specifically in relation to increased labor required to obtain and manage services.
Utilizing mixed qualitative methods, specifically autoethnography, in-depth interviews, and participant observation, this research explores the interactions between family caregivers of people with brain injuries and the long-term care system. The resulting microgeographies of the homespace where in-home services are provided are the focus of this research and analyzed within an ethic of care theoretical framework.

Findings suggest several problematic assumptions related to the provision of services especially related to caregiver burden. First, services are developed and delivered utilizing the ideology of the individual, which is in opposition to an ethic of care and fails to recognize the importance of the caregiver/care receiver dyad. Second, there remains a problematic assumption that having formal services in place reduces caregiver burden. Third, current in-home services, while provided in homes and communities, fail to intervene at the household level. When services are provided to people with brain injuries who live with family members, there is an assumption that the family caregiver will continue to provide and maintain the care receiver’s home and relationships. Hence, the family caregiver/care receiver/paid caregiver triads that result from in-home service provision are not recognized as an essential component to the provision of long-term care services. The resulting household negotiations and relational activities of daily living (RADLs) are not recognized as important aspects of caregivers’ lives, or as potential aspects of caregiver burden.

Key words: family caregiving, autoethnography, brain injury, ethic of care, microgeographies of the homespace, system-induced trauma
Acknowledgements

This dissertation was a long time in the making and would not have come to fruition without the support of numerous people. All of whom cannot be mentioned here. The journey through care, which was required in order to survive, thrive and complete the dissertation, was life affirming and life changing. This project began and was formulated while caring for others and was completed while being cared for by numerous others. Thank you to all of the people who care. The world is a better place because of it. Don’t let anyone tell you otherwise!

I would be remiss to leave out all of the people with brain injuries who have trusted, encouraged and supported me through this work and have been my guiding lights. Thank you for letting me in, sharing your joys and sorrows, and cheering me on. This dissertation is dedicated to all the families who are carelessly herded through our medical system. I’ve appreciated the journey with you and look forward to our continued struggles.

This dissertation would not be complete if not for the world’s most supportive committee. Thank you, Yehuda, for encouraging me into the geography program and providing me the support I needed to get acclimated to a new discipline. Ken, first you made me cry, then you wholeheartedly supported my ideas from the very beginning and took me on without hesitation. You were the epitome of reasonableness, when you accepted my use of autoethnography without hesitation. For your support, I will be forever grateful. Barbara, you're the best cheerleader a person could have. Your advisement, dinner parties and index cards got me through!
Carol Levine and Saul Becker, both pioneers in the world of family caregiving, have paved the way for many of the scholars doing work in this field. Carol, you initially used the term ‘young caregiver’ to describe me nearly 20 years ago. You surely set me in motion on a journey that has led me to this place. You have provided consistent support and advice and, in tremendous ways, exposed the struggles of families, while also doing everything in your power to provide them with tangible support through your work at The United Hospital Fund. Family caregivers everywhere owe you much for your dedicated solidarity and tireless advocacy. I am grateful to you for your commitment to this field and support of me over so many years.

Saul, the friendship that evolved out of my research trip to the UK is invaluable. I’ve been motivated by our many conversations and honest discussions about the plight of young carers and how best to support them on their journeys. Thank you for leading the way and exposing the world to the hidden group of caring young people who do so much for so many.

Christine, you are my partner in crime. You got me into this, and without a doubt, also got me through it. Thank you for the ultimate care you took of me, with food and shelter in the final stages of this project. For the encouragement and unflinching certainty that I would get through it and the many, many, many readings of my drafts. Your contributions to this project only made it better. ‘Thank you’ doesn't come close to sufficient here, but will have to do for now. I look forward to our post-PhD life together when we can now, finally, do all those projects and write all those papers that have been on hold for so long. I expect a long future together, and look forward to our time together on the front porch decades from now.
Mark, your skillful and on demand IT assistance was invaluable and kept me sane in otherwise insane moments. Thank you!

Justin, you were a model for the kind of dedicated academic writing needed to get through this dissertation. The balance between writing and being out in the world has come full circle and I’m so glad we became friends and colleagues early in this journey. It has been so much better with you along for the ride! Your encouragement and constant availability to read my chapters meant so much. Thanks to you, Shay and Mooka for providing a writing retreat with a superbly well-stocked library that aided my thought process. And, Elliott, I think she was my defense lucky charm!

My chosen ‘family’ have been my greatest supporters. Andrea, mom’s OLF and my dedicated reader. Together with Lucille, your editing made all the difference. Your many readings and thoughtful feedback were invaluable. Thank you. Carol, you’ve been my constant carer and are a model for knowing what needs to be done and doing it. The world needs more people like you! I hope you know the extent to which your support has gotten me through. Faustina, my care partner and friend, your care for mom and me, and commitment to our lives is beyond measure. I hope you know how grateful I am to you for being with me on this journey of care. Alvaro, your patient love, encouragement and unwavering certainty that I could do this helped propel me forward. I look forward to time together without “having to work on my dissertation” hanging over me- finally!

Finally, I am indebted to my family for the foundation necessary to endure this project. Mom, you are the best human being I know. I appreciate beyond words the love and life lessons you provided me with that developed in me the capacity for caring. You are the easiest person to be with and I aspire to be more like you when I grow up- loving
and content in all I do. Without you, the basis for this dissertation would not exist.

Thank you for being you and for the unconditional love you shower me with. Last, but not least, Gram, who supported my education as the most important thing; I’m sorry you aren’t here to see “Dr. Stitch”, live and in person. It is you who likely planted the seed for all of this.
Preface

This body of work has been in the making for decades, although I didn’t know the extent to which my life providing care to multiple family members over the course of the past 20 years would impact my research so directly.

Throughout my years as a caregiver and particularly when I was a very young caregiver (in my teens and early twenties) the messages I continued to receive were either that I was “such a good daughter” for what I was doing for my family or that I should put family members who needed care in institutions and “go live my life”. While I always felt good about the choices I was making in living my principles by taking care of my family, I also resented these sentiments because I was living my life; it just so happened that my life included people with various degrees of disability who were in need of assistance. I didn’t think that they should have to be institutionalized in order to get the help we all needed.

Very early on in my mother’s medical crisis, I became an advocate for families of people with brain injuries and became involved in various efforts to bring awareness to the fact that here, in the United States, there were young caregivers, kids under 18 who provide significant care to their families, who were and remain unrecognized for the work they do in their families. When I started reading the literature I was struck by the near complete focus on the negative aspects of caregiving. I resented the messages that caregiving is bad for one’s health, the individually-based rhetoric that caregivers must ‘take care of themselves’ and, especially that there was no mention in the caregiver burden literature of the impact of caregivers’ interactions with ‘the system’ in terms of the ‘burden’ they face.
There was a popular discourse that focused on ‘supporting’ caregivers through the development of services, but no one was looking at whether these services were actually helpful. I did a lot to keep my family protected and shielded from a long-term care system that didn’t have our families best interests in mind, took away our personal agency and power with the delivery of services and, often made things more difficult for us, rather than easier. Over the years I often found myself saying ‘this doesn’t need to be difficult.’ I couldn’t fathom how, when dealing with the extremely sad and devastating loss of my mother, as I previously knew her, I also had to continually fight with a system, which was supposed to help us.

The long-term care system is one that each one of us will be enmeshed in, likely at several points in our lives. No one is exempt from the all-consuming nature of it when we, or a loved one gets hurt, becomes ill or ages. My situation, while extreme, is not unique. Mine is the plight of family members who love someone who has been hurt, gotten sick, or old. We are there, day and night. We are the vessels of grief, loss, pain and anger. It is difficult, humbling, rewarding, and heartbreaking and we are often alone as we navigate this purgatory between illness and ultimately death.

Many years ago, when this dissertation was a far off thought I wrote a journal entry after being part of a support team for friends who were participating in a 100km fundraiser walk. Being on this team was a big deal. We were at each checkpoint prior to the arrival of our walkers. We had good, healthy food they liked, changes of clothes, medical supplies, and good cheer to keep their bodies and minds cared for and spirits up, as they were on the walk of a lifetime and needed support to make it through to the end. Of course, it was their effort and perseverance that got them through, but they would not
have been able to finish without major assistance with basic requirements of daily life-food, shelter, and emotional care. As the walk progressed, I remember seeing their bodies and minds change. They became emotionally exhausted and their bodies started to object to the long distance they were walking. Towards the end, sleep deprived and suffering with blisters, I wondered how they would finish and was determined to assist in any way I could to help them finish in the best possible condition, given the extreme circumstances they were faced with. I wanted to help minimize the inevitable suffering resulting from this long trek, which required endurance to complete. In the end, they walked over 60 miles in 36 hours and at the end we were all exhausted, but filled with elation that they had been able to complete it. We did it together. We were there for them because of our dedication to our friends, and the bigger issue they were walking for. They finished, in part, due to our care and support. The following journal entry was written just after the walk. I share it as metaphor for caregiving and the support caregivers so desperately need.

The team did their 100 km hike this weekend. [my friend] and I were their support team and I couldn’t help but feel the similarity between this hike (the length!) and the uphill struggle that is caregiving in today’s world. In thinking about how the medical system treats family members, it is the equivalent of having someone punch the hikers in the face as they were approaching the checkpoints. Caregivers need a REALLY good support team if they are to endure the lengthy and arduous struggle of caring for their ill loved ones. This means listening to caregivers about what their needs are and meeting them, by whatever means necessary. It also means anticipating their unexpressed needs and helping meet them as they arise (or before), if possible.

As much as the hike was similar to caregiving, it was also nothing like it in that the hikers could see an end in sight, even if it was very far away at times. In caregiving there is often no end in sight, and that end means the death of someone very close to us. Is there anything so awful to experience? The feeling that someone must die for this struggle to end?
The team was able to finish the hike, not solely due to our support, but because of their spirit and perseverance. The support helped and made it a bit more pleasant than if they had been completely on their own without friends on their side being there for them, whatever they needed. This is what people need, this is what we all need. Good, supportive people who are compassionate and want us to do and be our best. This is not an easy task in today’s world where we are taught to be independent and that the only one who will take care of us is ourselves. What kind of message is this? No person is an island…

When I first wrote this I envisioned the hikers as the caregivers, and the support team as the system, which instead of being supportive, was just the opposite. As I reflect upon and think about it now, I realize there are multiple metaphors in this story that give it meaning. The hikers could also be the people with brain injuries and the support team, the informal family caregivers. Had the hike gone on any longer, the support team would have needed support. Here is where the metaphor ends.

Caregiving is not a 36-hour sport, but more appropriately often feels like a 36-hour day, much like that hike, but for long periods of time, often years, and even decades. The long-term care system must be a caring and dedicated support team for family caregivers, who are in the trenches, or continuing with this metaphor, on the hike with their loved ones. Separating the care recipient from their caregivers is artificial and impossible if true support is to be provided. This dissertation is an attempt to shed light on how caregivers are routinely ‘punched in the face’ by the long-term care system, with the hope that we can begin to transform it in the same way the hikers finished their walk. One step at a time.

When I was 17 and thrust headfirst into a complicated, life and death medical situation with my mother, I was naïve. I believed the medical system was a place to get help, to provide support, information and comfort to me, and people like me, who were experiencing what would become a continuous battle with myriad systems with one
traumatizing experience after another. Little did I know that these traumas would actually be inflicted by this inescapable system to which my family was now inextricably linked. Now, almost two decades and three graduate degrees later, I know better. I am equipped with life and professional experiences and academic research tools needed to better understand, analyze and critique what I and countless others experience and suffer at the hands of a poorly run medical and long-term care bureaucracy.

This mixed-methods dissertation combines traditional ethnographic methods of in-depth interviewing and participant observation with the newer and more controversial method of autoethnography. As both process and product, autoethnography will be discussed at length in chapters 2 and 3. Chapter 2 contains an in-depth discussion of autoethnography as method and process and chapter 3 provides my personal narrative as an example of autoethnography as product. While autoethnography is an alternative method, the theoretical and methodological underpinnings are the same as traditional ethnography, with findings being grounded in the interview data and a direct result of the research process.

Magdalena Ornstein
January 1, 2016
# Table of Contents

Abstract .................................................................................................................. iv  
Acknowledgements .................................................................................................. vi  
Preface ...................................................................................................................... x  
List of Figures ......................................................................................................... xvi  
List of Tables .......................................................................................................... xvii  
Chapter 1: Introduction ............................................................................................ 1  
Chapter 2: Research Methods .................................................................................. 30  
Chapter 3: Autoethnography: Process and Product .................................................. 51  
Chapter 4: The Provision of Services ...................................................................... 91  
Chapter 5: Responses to Re-traumatizing Services ................................................... 122  
Chapter 6: Microgeographies of Care in the Home ................................................... 140  
Chapter 7: Concluding Thoughts ............................................................................ 174  
References ............................................................................................................... 189
List of Figures

Figure 1: Make up of long-term home care system highlighting ignored relationships in current iterations of “caregiver burden” ................................. 4

Figure 2: Talley & Crews Triadic Model of Caregiving ........................................ 83

Figure 3: Triad Relationship with relational flows of care ........................................ 85
List of Tables

Table 1: Participant Demographics ................................................................. 47
Chapter 1: Introduction

Informal family caregiving is broadly defined as caregiving, which takes place at home or in the community, by friends and family members and often without financial reimbursement. The definitions of what caregiving encompasses are as varied as the people who need and provide care.¹ Every one of us is deeply embedded in various relationships of care that exist throughout our lifetimes, with the nature and degree of caregiving responsibilities being dynamic and ever changing. Mutual care within families is an accepted orientation and activity, however when someone becomes ill, old or disabled, the care provided becomes known as “caregiving” and is rendered distinct from typical care to our families.

With the majority of people needing care being cared for at home, we can assume that most people will be affected by caregiving at one point in time or another. None of us are exempt from the issues discussed in this research. A famous quote in the caregiving world is that “there are only four kinds of people in the world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers” (Carter, 1996). The issue remaining is how we can create supportive environments allowing for caregiving to continue across the age, illness, and gender spectrum while fostering the positive and reducing its negative aspects.

With caregiving situations being as diverse as the people who are involved, and as much as we currently know, there is still much to be discovered about how, why and under what circumstances people engage in various caregiving relationships.

Specifically, little is known about the nature of the relationships between family

¹ For a detailed description of current terms and definitions related to caregiving see Dobbins, 2009.
caregiver/care receiver dyads and the triads which form between these dyads and the in-home, paid care workers who are sent in to assist people through the provision of long-term community-based services. These intricate interactions between family caregivers and the long-term care system are explored here.

Aims

This dissertation seeks to problematize, re-frame and re-theorize the conceptualization of “caregiver burden”, specifically in relation to the omission of positive aspects involved in providing care and the interactions between informal family caregiver/care receiver dyads and family caregiver/care receiver/paid caregiver triads (Abel, 1990; Levine, 2003). This requires an examination of the relationships and interactions between “informal” family caregivers and the myriad service providers as well as other aspects of the long-term care system (including public benefits agencies) in order to gain a deeper and more contextualized understanding of the complex lives of caregivers and those they care for.

This project also seeks to better understand why so many people continue to provide care to their family members without outside assistance although help is available, and why services for caregivers remain underutilized. The hope is this will inform policy and service development and lead to more appropriate supports in the future.

The caregivers interviewed for this dissertation were people who became caregivers after their significant other – spouse, partner, parent, or child -- suffered an unexpected catastrophic medical event, specifically acquired or traumatic brain injury (ABI or TBI). A key point in this research is the traumatic nature of the medical event
that caused the caregiver to step into that role in the first place. Does the nature of these traumatic events impact caregivers in relation to trauma responses they may have in their relationships with the care receivers and health care professionals?

Ultimately, I explore the negative experiences of caregiving that are produced not by the actions of providing hands on care, but by the difficult interactions between caregivers and formal services that have become a taken for granted and unquestioned aspect of their lives as caregivers. This is of particular importance because institutions become conflated with people with disabilities in such a way that the system becomes inextricably linked to the person with the disability, instead of remaining its own entity in need of investigation and analysis. Without this distinction, interactions with services will continue to be conflated with the people with disabilities and there will remain an incomplete and inaccurate definition of “caregiver burden”.

These interactions and relationships are the focus of this research project, as indicated in figure 1 below, which provides a visual representation of these relationships.
This study will contribute knowledge to the current literature on family caregiving and “caregiver burden” as well as community based care for people with brain injuries. Specifically, the questions I addressed in this study are: 1) how are interactions with bureaucracies and formal services systems (i.e., Health Resources and Services Administration (HRSA) programs, Supplemental Nutrition Assistance Program (SNAP), Medicaid/ Medicare; home and community based services; private insurance, etc.) recognized by caregivers as sources of stress in their lives?; 2) why do people continue to
provide care under extremely difficult circumstances?; and 3) what are the contexts of caregiving for people with brain injuries at home in order to deepen the understanding of what would be useful in terms of supporting caregivers so they can continue to provide care for as long as they wish to do so?

**Problem Statement**

“Caregiver burden” is a widely used and taken for granted concept in the wide-ranging literature on ‘informal family caregivers’ as well as in mainstream discourse related to family caregiving. This concept is accepted as a given in terms of the negative experiences caregivers have throughout their ‘caregiving careers’, despite evidence suggesting positive aspects of caregiving (Abel, 1990; Ayres, 2000; Braithwaite, 1992 & 1996; Brown, 2007; Brown &Brown, 2014; Dilworth-Anderson et al., 2002; Fredman, et al, 2015; Marks, 1998). While the term is consistently used as a benchmark of what caregivers face in their day-to-day caregiving and as a guide for the development of caregiver support services, it remains incomplete, as it fails to adequately recognize the positive impacts of providing care, as well as to acknowledge the difficulties caregivers face when interacting with formal service providers.

With an estimated 90% of long-term care being provided at home by informal family caregivers, it is a popular misconception that the majority of people institutionalize the ill and elderly in the United States (IOM, 2008; National Alliance for Caregiving, 2009 & 2015). The vast majority of people who require care are cared for by friends and family at home. Strikingly, it is estimated that 75-90% of family caregivers receive no outside help in providing this care (ibid.). Little is known about the “service mix” that results when care is provided by myriad combinations of informal care and
formal services (Wysocki, et al, 2012). Even less is known about how the variety of service mixes are experienced and negotiated by caregiver dyads and triads.

Literature Review

“Caregiver Burden”

Mainstream literature on the topic of informal family caregiving is steeped in the bio-medical model and rich in a negative discourse of burden, stress, and need (Cannuscio et al., 2002; Schulz & Beach, 1999; Vitaliano et al., 2003). This model is deficit based and has a discourse that focuses on the negative health consequences of caregiving at the exclusion of other possible explanations or outcomes. Caregiver burden has even been utilized as a tool to make caregiving into a diagnosable condition, which suggests that people may need treatment for it (Adelman, et al, 2014).

Caregiver burden was first operationalized in 1980 (Zarit et al, 1980) and remains a highly ambiguous concept, which is widely used to describe the impact of caregiving on caregivers. This burden model has become the dominant and privileged framework used to describe much of what caregivers do as well as how they feel about what they do when they provide care (Chappell & Dujela, 2008; George & Gwyther, 1986; Montgomery et al, 1985). It is used to describe the caregiving situations of people who care for those with a variety of health problems. This includes people who need care due to typical aging processes as well as those who have been injured suddenly through catastrophic accidents, and people with other illnesses and disabilities (National Alliance for Caregiving, 2009).
Measurement

The original instrument designed to measure caregiver burden is the Zarit Burden Interview (ZBI) which focuses on a handful of predictors of caregiver burden, including the caregiver’s response to the care receiver’s symptoms, the social support available to the caregiver, the quality of the relationship between the patient and caregiver prior to the need for caregiving, and the severity of symptoms of the care receiver (Zarit, et al, 1985). The ZBI has been criticized for a lack of theoretical foundation in the development of the instrument (Chou, et al, 2003).

The initial measurement scales for caregiver burden were developed as a result of clinical practice with caregivers of people with dementia. These caregivers were mostly white, middle aged or older women who cared for spouses at home (Zarit, 1980). This is of importance because of the difference between the goals in treating people with dementia as opposed to the rehabilitation goals of people with other illnesses and disabilities. In Alzheimer’s support, it is generally assumed that there will be a decrease in functioning and that there is a family member who is intimately involved in the life of the person and who is providing, as well as overseeing, their care in the community. The goals of this care are not that the person will regain independence, as is the main goal in most other forms of rehabilitation and support, but to keep them safe and enjoy a good quality of life. Family caregivers are acknowledged as an essential part of the care recipient’s care team and, as such, offered support. We will see below how these different goals can impact the way family caregivers of people with brain injuries are treated by long-term care providers.
While the ZBI has shown overall reliability when looking at caregivers with advanced disease states other than Alzheimer’s (including brain injury), this does not address the concerns of omission with the original instrument (Higginson, et al, 2010). The 22-item ZBI fails to ask about or address the complex interactions caregivers have with service providers who work with the care recipient or their struggles with the overall health care system.

Current iterations of caregiver burden exclude important aspects of the caregiving experience, such as: 1) caregivers interactions with formal health and long-term care systems, 2) navigating and applying for myriad social services, and 3) interacting with health insurance companies and non-profit advocacy organizations as well as other difficult aspects of organizing and managing the complexities of care. Some of the components of care that are currently ignored by caregiver burden scales are: 1) advocating to ensure proper and adequate treatment and/or benefits, 2) training and managing home care staff and other medical professionals, and 3) proving/managing/maintaining eligibility for services and the paperwork that accompanies each of these pieces of the care puzzle. While these interactions with the ‘system’ have been recognized as potential sources of stress on caregivers they have yet to receive widespread attention in the academic literature or in practice when measuring caregiver burden (Levine, 2003; Levine 2007). When family/service provider interactions have been examined, the conclusion is that special attention must be given to family care, not just care of the individual (Nolan et al, 1995; Haesler, et al, 2010; Bøttcher Berthelsen, et al, 2014).
Despite the acknowledgement in public discourse that brain injury happens to families and not solely to individuals, in practice, there remains a dichotomy between the person with the injury and the family (Brain Injury Association of America, 2014). While the family experience of brain injury is recognized, the interactions between family caregivers of people with brain injuries and service providers remain limited (Degeneffe, 2001; Sohlberg, et al, 2001; Kreutzer et al, 2002).

Additionally, current research on “caregiver burden” does not connect the micro level experiences of providing care at home with the macro level processes that directly impact caregivers’ daily lived experiences of providing that care. Despite this criticism, these burden scales remain the dominant method for capturing information from and about caregivers and are the basis for Family Caregiver Needs Assessments, which are described below.

The literature on caregiver burden has been growing and evolving from its originally defined uni-dimensional approach to a more inclusive multi-dimensional approach, which recognizes the complexity of caregiving situations (Chou, et al, 2003). Chou, et al provides a helpful assessment of current measures of caregiver burden and provides descriptions of several original scales to measure it. The scales are categorized according to the nature of their dimensionality and range from uni-dimensional and two-dimensional to multi-dimensional. Even with these more inclusive measures, they still ultimately ignore caregiver interactions with the long-term care system as possible contributors to caregiver burden.
Mainstream Discourse

Caregiving can be seen as having both positive and negative impacts for individuals, families, communities and the larger culture in which they are embedded. However, much of the current mainstream discourse around caregiving in the United States focuses on the negative consequences of providing care to family members. Re-framing caregiving to include more than just the negative aspects of providing care has the possibility for broad societal transformation by changing how caregiving is viewed and responded to. The current negative notion of burden placed on caregivers perpetuates the idea that caregiving is bad for one’s social, emotional, economic and physical health. Caregivers are given constant messages that all aspects of their lives, social, physical and financial will suffer; they are even told they are more likely to die than their non-caregiving peers (Schulz & Beach, 1999).

Without critical discussions of the difficulties families experience when interacting with the formal long-term care system or about the intricate and complicated relationships created when in-home services and families collide, caregiving will continue to be viewed and measured simplistically as a burden based on providing hands on care. Even though it has been recognized that disabilities impact entire families, much of the recovery focus is on maintaining independence, rather than recognizing our interdependence with one another (Schumacher, 1996; Brown, 2007). In addition, the mainstream discourse surrounding people with disabilities is steeped in language about individuals’ maintaining or regaining independence This popular discourse is a direct result of the incomplete manner in which “caregiver burden” is currently conceptualized.
and measured, specifically as it omits the positive aspects of care that caregivers identify, as well as the myriad relationships we are involved in.

**Framing Problems with Current Conceptualizations of “Caregiver Burden”**

The framing of social issues are of utmost importance because the ways in which they are framed result in the ways they are responded to. The current framing of informal caregiving serves certain interests, namely the service industry which is supported by the people who need them in order to keep their jobs and maintain their profits. This ‘need’ (by caregivers of services) is a direct result of the current framing of caregiving as negative and burden filled. When caregiving is deemed negative, services respond and change the “environment around the person” so much so, that people become surrounded by a “forest of services” (McKnight, 1995, p. 108). A re-framing of caregiver burden would necessarily explore this new forest, not only the person standing in it.

**Focus on the Negative, Exclude the Positive Aspects of Providing Care**

While the benefits of providing care are continuing to emerge, these positive aspect of caregiving often remain overlooked and only minimally alluded to in the current literature and mainstream discussions around informal family caregiving (Abel, 1990; Ayres, 2000; Braithwaite, 1992 & 1996; Brown, 2007; Fredman, et al, 2015; Jacobs, 2006; Marks, 1998). Recently, there have been more studies emerging documenting positive aspects of caregiving and even benefits to the health and longevity of caregivers (Brown and Brown, 2014; Roth, et al, 2013; Schulz, et al, 2007). However, these positive aspects of providing care and remaining in important relationships remain ignored in discussions surrounding caregiver burden. A communitarian approach to caregiving would broaden caregiving to look at the social costs and benefits rather than
limiting analysis to the costs imposed on individuals. There is an untapped potential to re-frame and explore caregiving as a normal life-course activity that embeds people in their communities and helps build healthy interdependence, similar to the way parenting is viewed.

This approach is in direct opposition to the current individualistic discourse used to discuss the needs of both caregivers and the people with illness and disability they care for. For example, Ayres suggests that caregivers who view caregiving as a normal part of life do not see it as a burden, but as a reciprocal role within the larger context of a family unit (2000). Additionally, caregiving may consist of and be seen by caregivers as positive (Abel, 1990; Braithwaite, 1996; Coristine, et al 2003; Grunfeld, et al, 2004; Reinardy et al, 1999) and even liberating political practice (Kessler, 2005). This side of caregiving needs further exploration in order to gain a more comprehensive understanding of the totality of the caregiving experience.

A recent study of millennial caregivers aged 25-49 found that one third of this generation considers themselves as caregivers (NAC, n.d.). In this study, nearly 50% of caregivers said they were very satisfied with the care they are currently providing to their loved ones. In addition, 13% of these caregivers were unable to identify any negative consequence of caregiving. While not a large percentage, it is interesting to note that these caregivers didn’t focus on the negative, and indicated the development of closer relationships, having a good sense of self and enjoying the time spent with the people they care for as benefits of their caregiving role (ibid.).

In addition to the challenges associated with caregiving, caregivers have also expressed an increased sense of worth, fulfillment, personal growth, and improved
relationship with the person they care for, as well as heightened achievement, as they conquer challenges associated with caregiving that leave them feeling proud of their accomplishments. Women caregivers assert feelings of being better people due to their caregiving, being better attuned to the needs of others, being more socially responsible, and more capable of sustaining intimate personal relationships (Abel, 1990; Marks, 1998). Despite the suggestion that there are positive impacts of providing care in the lives of caregivers, the discourse remains steeped in negativity and focused on burden.

Negative assumptions of caregiving remain the starting point for the questions currently asked of caregivers, thus research is skewed toward the negative with other possible experiences being minimized or excluded. The result is a focus on the individual and proximal level factors that contribute to their ‘burden’, as opposed to exploring the embeddedness of caregivers within the overall structure of the long-term care system and how this structure influences their experiences of providing care (Granovetter, 1985). Until we acknowledge caregivers’ important role in the larger long-term care system, caregiving will continue to be seen as a personal problem, rather than a public issue. Thus, it is imperative that we understand and acknowledge the positive aspects of providing care as well as other factors that may increase caregiver burden so we have a more intricate understanding of the most difficult aspects of caregivers’ lives.

Incomplete Framing of the Issues

Caregiver burden measurement instruments have progressed over more than three decades. These two and multi-dimensional measurement instruments are different from the original ZBI in that they include subjective measures of burden and define caregiving as a dynamic process that is influenced and constructed by larger social processes. Even
though these measures are more inclusive than the original, they still fail to include measures of caregivers’ interactions with formal service providers (Montgomery, et al, 1985; Vitaliano, et al, 1990). In addition, they also fail to capture the positive aspects of caregiving such as personal fulfillment and pride or the ability to successfully overcome challenges which caregivers tend to report (Chwalisz & Stark-Wroblewski, 1996).

Braithwaite (1996) and others caution against the study of caregiving in terms of burden, at the exclusion of other explanations and positive life experiences (Abel, 1990; Brown & Brown, 2014); Chappell & Reid, 2002; Dilworth-Anderson, et al 2002; Marks, 1998). A danger in maintaining the status quo of caregiver burden research is that the “social flesh”, the inseparability of the “corporeality of the body and its discursive construction”, (Braithwaite, 1996, p. 176) remains hidden behind incomplete notions of what it means to provide care in today’s complex social world (Dyck, et al, 2005). The body, as an instrument of providing care, is enmeshed in larger social processes that define and socially construct what it means to provide that care, but with little acknowledgement of the caregiver’s own needs in terms of wanting to provide that care.

There must be an exploration of why people continue to provide care under extremely difficult circumstances that take into account their desires to be available to their family members when alternatives to home care exist.

**The Proximal: ADLs & IADLs**

Activities of Daily Living (ADLs)-bathing, dressing, using the toilet, transferring, continence and feeding and Instrumental Activities of Daily Living (IADLs)-transportation, grocery or other shopping, housework, preparing meals, managing finances, giving medications, pills, or injections, and arranging outside services- the
proximal factors involved in providing care remain the foundation upon which caregiver burden is based (Katz et al, 1963; Lawton & Brody, 1969). Although there have been suggestions to move beyond these tangible activities to an expanded conceptual framework that includes the emotional labor, and distal factors, such as interactions with the formal health care system and other aspects of being a caregiver, there has been little progress in the actual adjusting of measurements of caregiver burden to include relational aspects of providing care to others (Levine, et al, 2003). “Caregivers do not think of what they do in terms of performing tasks related to ADLs and IADLs; they do whatever needs to be done. Then they watch and wait until the next thing needs to be done, and the next, and the next” (ibid., p. 2).

The emotional support and interactions with and management of care involved in caregiving is left out of the overall picture. Specifically, according to Levine, et al the areas of caregiving pointed to as being left out of definitions of caregiving include behavior supervision, high-tech homecare, pain management, managing paid homecare workers, and advocacy in negotiating the healthcare system (2003). This research further expands on this and points to the difficulties caregivers experience in managing myriad aspects of the Relational Activities of Daily Living (RADLs) they must navigate as part of a caregiver/care receiver dyad.

The Distal: Stress From Social Structures

As discussed above, the proximal factors of providing care remain the privileged explanations for the burden of caregivers even as the suggestion that individual stress may result from distal social structures that are beyond peoples’ individual control. As Abel pointed out twenty-five years ago “[a]lthough stress often results from social
structures, it is a property of individuals” (1990, p. 147). Despite suggestions to look beyond task-based sources of stress, this perspective has yet to adequately emerge in the literature or in measures of caregiver burden (ibid., Levine, et al., 2003).

It is easier to ask questions focusing on the relationship between caregivers and care receivers than it is to wade into the complicated and messy relationships making up today’s health care system, of which caregivers inevitably find themselves a part. Unless they actively opt out of utilizing available services, which we can assume many do if we look at the numbers of caregivers who provide care alone, they are beholden to the rules, regulations and professional assumptions of service providers.

There exists a juxtaposition of identifying the problem in the home and between caregivers and care receivers, as opposed to analyzing the system, which is built on the relationships between informal and formal caregivers and myriad service providers. While this complexity makes looking at caregiving extremely difficult, it should not be an excuse for ignoring the impacts of larger systems and social processes on caregivers who are involuntarily embedded within the long-term care system while providing care at home.

Additionally, it is easy to put the onus of difficult situations related to caregiving on the fact that there is a person in need of care. It is more difficult to recognize structural distortions and identify their role in the stress process involved in being a caregiver. The underlying assumption is that services equal assistance, and therefore reduced ‘burden’ for caregivers. This assumption must be challenged, as much of the research on caregiver services and interventions remain equivocal in terms of reducing

**Unquestioned Assumption of the Usefulness of Services**

As recently as 2015, there remains an unquestioned assumption that when services are in place, caregiver burden is reduced (Rose, et al, 2015). This is the case with in-home formal care for care recipients, as well as “respite care” for family caregivers, as these services are essentially the same, only called something different when they are provided to provide a break from caregiving for the family. In-home respite care involves a paid caregiver being sent into the home for the direct purpose of allowing family members to be temporarily relieved of their caregiving duties. “As a core component of caregiver support, respite services function as a bridge for building relationships with family caregivers, leading to their engagement with a broad continuum of services enabling them to continue in the caregiving role” (ibid., p. 306). Here, there is an unquestioned assumption of the benefit of services in the lives of caregivers, even though research suggests that people may forgo the use of services due to service design and delivery rather than need (Kosloski, et al, 2001). Although, it is often these very services that require considerable management and emotional labor on the part of caregivers to nurture the resulting relationships that may account for a significant portion of the burden they face, there remains no critical assessment of whether these services are actually helpful to caregivers. Moreover, the fact that the services may make things more stressful for caregivers remains almost completely ignored, with services simply seen as beneficial.
Trauma

Trauma is an emotional response to a terrible event, such as an accident. (American Psychological Association, n.d.). It is important to acknowledge the presence of trauma in relation to the catastrophic nature of the accidents or injuries that result in brain injuries. It is acknowledged that brain injuries happen to families, but the response is to provide services to the individual, omitting their place in the family unit. Going further, family members are blindsided by the traumatic experiences of the injury, but don’t receive emotional support to help them deal with the initial medical trauma in their family. With the initial focus being on survival, important emotions are not tended to, creating the conditions for the development of post-traumatic stress disorder.

Post-traumatic Stress Disorder

Post-traumatic Stress Disorder (PTSD) is a psychiatric disorder that can occur in people who have experienced or witnessed a traumatic event such as a natural disaster, a serious accident, a terrorist attack, war/combat, rape or other violent personal assault (American Psychiatric Association, 2013). “People with PTSD continue to have intense, disturbing thoughts and feelings related to their experience that last long after the traumatic event has ended. They may relive the event through flashbacks or nightmares; they may feel sadness, fear or anger; and they may feel detached or estranged from other people. People with PTSD may avoid situations or people that remind them of the traumatic event, and they may have strong negative reactions to something as ordinary as a loud noise or an accidental touch” (ibid.)

A diagnosis of PTSD requires exposure to an upsetting traumatic event. The exposure could be indirect rather than first hand. For example, PTSD could occur in an
individual who learns that a close family member or friend has been involved in an accident, as is the case in most life-threatening brain injuries.

Symptoms of PTSD involve four categories- intrusive thoughts about the traumatic event, avoiding reminders of the traumatic event, negative thoughts and feelings (fear, anger, guilt, shame, loss of interest in activities), and arousal and reactive symptoms (being irritable or angry). Not everyone who experiences a traumatic event will have symptoms of or develop PTSD. For those who do, the dissemination of effective early interventions (within 3 months post exposure) following trauma is necessary in order to ensure the best care. (Bisson & Cohen, 2006).

From the above description of PTSD we can see how the initial sudden and catastrophic medical events that lead to brain injuries, the accidents or sudden illness that cause them, could be traumatic events for family members. Treatment of PTSD includes psychotherapy, other therapies and medication are common ways of treating PTSD.

Post-traumatic Growth

In addition to the negative outcomes associated with traumatic experiences, there is growing acceptance that people may also experience psychological benefits after traumatic events. Post-traumatic growth has been applied to these positive changes and is discussed in terms of three main domains: improved inter-personal relationships, positive change in the perception of the self, and an emerging or developing philosophy of life. (Snape, 1997; Tedeschi & Calhoun, 1996 & 2004; Linley & Joseph, 2004).

Although Post-traumatic growth has been increasingly accepted, it has been studied more in relation to people who have experienced serious medical events themselves (Moore, et al, 2001; Elliott, et al, 2002; McGrath & Linley, 2006; Steel, et al,
2008; Weiss, 2002), and only minimally so with family caregivers, specifically in relation to HIV/AIDS and cancer caregiving, as well as in families with traumatic brain injury (Cadell, 2003; Cadell, 2007; Kim, et al, 2007; Thombre, et al, 2010). Post-traumatic growth occurs when people move beyond the initial trauma and develop coping skills that help them move through the initial traumatic experience. Supportive services can make the difference between positive emotional responses and negative ones.

Family Caregiver Needs Assessments

A major outcome of the measurement of caregiver burden has been to develop family caregiver needs assessments which focus specifically on the needs of family caregivers (Feinberg & Houser, 2012). These assessments are endorsed and recommended by the major caregiving organizations in the United States and are tools dedicated to directly assessing the needs of family caregivers (National Alliance for Caregiving, n.d.; Family Caregiver Alliance, n.d.). Positive aspects of these assessments are that they are family-centered and focus specifically on family caregivers, while acknowledging their connectedness to the person they care for. In addition, it has been suggested that these tools, when focusing on practitioner-caregiver relationships, have the possibility to encourage and nurture these relationships, which has the possibility of creating genuine and trusting alliances between caregivers and service providers (Lévesque, et al, 2010). These caregiver assessments, although recommended by experts, remain minimally utilized with informal family caregivers. As of 2012, only about 30 states had some form of caregiver assessment included in their Medicaid HCBS Waivers (Kelly, et al, 2013). Similar to existing measures of caregiver burden, caregiver needs assessment instruments focus mainly on the relationships between caregivers and care
receivers and ADLs and IADLs. Specifically, they ask how caregivers feel about their caregiving activities, but they don’t ask why they feel the way they do. The omission of interactions with providers creates a situation where the assumption is that people are depressed and overwhelmed because of the care they provide, at the exclusion of other possible issues within the caregiving situation (National Caregivers Library, n.d.).

While these assessment tools recognize the value of the work that family members do to keep people at home, the ultimate recommendation of these assessments is to recommend more services (i.e. respite care, support groups) in order to support the family caregiver in providing care (Montgomery & Kwak, 2008). In this case, the political and social construction of informal caregivers identifies and frames both care receivers and family caregivers as co-clients of formal services (Milligan, 2003), thus subsuming caregivers into the inescapable medical-industrial complex (Relman, 1980).

In the end, families are referred to community-based service providers, which are the very same providers who, as we will see, are often a considerable source of the difficulties they face in providing care for their loved ones at home. The result is that families are thrown to the wolves, so to speak. They are sent off once again to inquire about and attempt to access services. This time, they will be considered the ‘consumer’ or service user and, will have a repeat of the same difficulties which impact the ‘caregiver burden’ they face in helping get support for their loves ones, but without the kind of assistance they themselves provide to the care recipient. Family members face interacting with more providers, with the hope of being supported and getting the help they need to sustain the care that they provide. Here, we see the possibility of an endless cycle of people trying to access services, only to get frustrated, be neglected, and ultimately opt out.
of accessing these services either because no one will provide them with services or because the initial access procedures are too cumbersome to bother with.

**Caregiver Self-identification & Service Utilization**

Existing caregiver support services remain underutilized (Eifert, et al, 2015; Strain & Blandford, 2002; Winslow, 2003), with one of the main reasons believed to be that many caregivers do not self-identify as ‘caregivers’, but as wives, daughters, sons, husbands and friends (Eifert, et al, 2015; Kosloski, et al, 2001). Despite this underutilization of services, the response from professionals is to develop more services. This research indicates that caregivers do in fact seek out services, but often have so much trouble accessing and/or interfacing with them that they give up or find other, informal or grey market paid home-care to fill the gaps in care.

**Brain Injury**

Caregivers of people with brain injuries (BI) will be the focus of this study. They provide an example of caregivers with a documented desire to remain actively involved in the lives of the people they care for, despite the extreme difficulties they face in their roles as caregivers (Degeneffe et al, 2011). It has been suggested that caregivers of people with BI are under greater stress for longer periods of time than caregivers for people with other disabilities (Greenberg, et al, 1993). This is likely due to the severe cognitive impacts that result from brain injuries that are chronic, often leaving people with the need for life long assistance with daily life.

Acquired brain injury (ABI) includes all types of traumatic brain injuries (TBI) as well as brain injuries caused after birth by cerebral vascular accidents (i.e.- stroke), and loss of oxygen to the brain. TBI is “an alteration of brain function, or other evidence of
Brain pathology, caused by an external force” (Brain Injury Association of America, 2011). Brain injury is considered an invisible injury because often a person with BI might look fine, but have significant cognitive impairments that impact their ability to function as they did prior to their injuries. It has been recognized that when a person suffers from a brain injury, the entire family is impacted and can be involved in their care (Kay, et al, 1995; Degenneffe, 2001; Kreutzer, 2009; Brandon, 2013). ABI does not happen in a vacuum and therefore must be looked at through a relational approach in order to understand the complex and interlaced relationships the people with brain injuries and their families become a part of as a result of the sudden, unexpected and catastrophic injury.

In terms of caregiver burden, there is evidence that caregivers of people with TBI demonstrate greater levels of distress than caregivers for people with other types of disabilities (i.e- intellectual disabilities) over longer periods of time (Greenberg, et al, 1993). Through questionnaires, caregivers of people with TBI have expressed a desire to remain actively involved in their family member’s care and receive better information from professionals (Bishop, et al 2006). Additionally, it has been suggested that caregivers’ abilities to successfully cope with their caregiving role is directly related to their belief in their ability to provide care (Man, 1998). While this is an important finding that has been echoed in research with other types of caregivers, it is surprising that this feeling of empowerment has been virtually ignored by caregiver research to date, with, as noted above, a near complete focus remaining on the negative aspects of caregiving.
The Caregiver Empowerment Scale (CES) is an exception to typical measurement tools, in that it focuses extensively on empowerment and positive aspects within the caregivers themselves (Degeneffe, et al, 2011). More in-depth and nuanced information via qualitative interviewing is needed to more fully understand the positive aspects of providing long-term care to people with BI at home. The research that led to the development of the CES captured caregivers’ desires to remain actively involved with the person needing care. This is interesting, as most caregiver support services revolve around giving caregivers breaks and taking them out of the caregiving situation, if even temporarily. This may be counterintuitive to what caregivers want and need- to feel they are capable and supported in providing care to loved ones whom they are deeply embedded in relationship with.

Ethic of Care

Fisher and Tronto define Care as “a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web” (1990, p. 40). Within this notion of care as a continual social process, it is suggested that care has four phases: caring about, attentiveness; taking care of, responsibility; care-giving, competence; and care-receiving, responsiveness (Tronto, 1995). Importantly for this work, care theory takes as starting point notions of relationality and interdependence (Sevenhuijsen, 2003).

By utilizing an ethic of care in policy development, there is an opportunity to re-think the broader social goals of our communities and larger social systems (Gilligan, 1982; Glenn, 2010; McKnight, 1995; Noddings, 2002); Poo, 2015; Tronto, 1995).
Instead of focusing only on needs at an individual level, there is a necessity to facilitate reciprocal caregiving extensively within the communities within which care takes place. In policy development, service provision and other aspects of life that impact the caregiving experience, utilizing an *ethic of care* as a basis could have wide reaching implications for how people are responded to and how needs are addressed. Family caregivers are ignored, exploited, and maybe even abused by the formal system as they provide free labor, often at their own expense (Glenn, 2010). Their needs are not attended or responded to, the long-term care system is not responsible to them in any way, nor are competent services provided so they can alter their situation if they choose or need to. An overall facilitation of reciprocity in caregiving would benefit all caregivers and the people they care for.

Incorporating an *ethic of care* into policy development and service provision for caregivers would be attentive to individuals’ needs within the context of their being enmeshed in relationships of care, as opposed to developing services to individuals devoid of their place in these relationships. An *ethic of care* provides a framework for re-imagining what it means to be a caregiver enmeshed in the myriad complex relationships that inevitably surround the caregiver/care receiver dyad, which is part of the larger caregiver/care receiver/service provider triad (Talley & Crews, 2007).

**The Geography of Care**

Health geography is a sub-discipline of human geography and views health holistically, while conceptualizing the role of space and place in health, well-being and disease. Health geography explores social, cultural and political contexts for health within a framework of spatial organization (Meade & Earickson, 2000). With an
emphasis on context and setting, health geography provides a framework to situate the public health needs of family caregivers within the larger long-term care system, particularly as the boundaries of home care collide with combinations of care by families and professionals within the private space of the home.

Health geography as a sub-discipline has been broader in its discussion of care than medical geography and calls for a different kind of research that more generally examines the “multiple material and symbolic dimensions to the giving and receiving of care” as well as explicating care as a concept, while critically assessing caring practices, roles, and relations (Parr, 2003, p. 213). Popke takes this further by calling for a reclaiming of care as social and political and reframing care as an orientation rather than an activity (2006). Here, caregiving has the potential to emerge from under the oppressive burden filled discourse to a place of dynamic life-course relationships which are not temporal, but ever shifting and evolving (Grant & Nolan, 2003).

Moreover, looking at caregiving in the context of familial relations, which have been noted to be “an absent presence” within the field of geography, provides additional insight into the spatial relations involved in the ‘doing’ of intimacy within families (Valentine, 2008). As an orientation, providing care would be looked at in the context of the whole of caregivers’ lives, and as enmeshed in various relationships of care, not solely in relation to the caregiver/care receiver relationship at the exclusion of all other relationships (Tronto, 1995).

While cooking for the person they care for, is the caregiver also cooking for other family members? When laundry or shopping is done, is it only for the person for whom they provide care? Does the care receiver also care for the caregiver? Does the home
care worker cook for everyone or do the laundry of everyone in the household or only the care receiver? How has providing care influenced the location of where the caregiver lives or where or how much they work outside of the home? These questions seek to frame care as a reciprocal life course activity that acknowledge complex relationships of care existing within familial relationships, especially when there are extreme care needs due to the presence of a disability. It is recognized that everyone needs care throughout their lives, not only those unable to care for themselves due to age, injury or illness (Glenn, 2010). The assumption that “care” is provided by “caregivers” only when a family member becomes old, ill or disabled\(^2\), as opposed to being a continuous aspect of intimate relationships, is shortsighted and requires further exploration, but remains outside of the scope of the current project.

This study provides an in-depth exploration of the experiences of caregivers’ interactions and relationships with the formal health care system, rather than on the activities they carry out for the care receiver. In order to broaden the scope of possible solutions to the challenges facing caregivers today, we must move toward orientations to care, as opposed to activities of care. The ways in which caregivers organize and orient their lives due to their caregiving or aspects of the social welfare system they have to consistently interact with may be missed with the kinds of questions currently asked in burden assessment surveys. This point of view contrasts to the way care is currently conceptualized and responded to in the caregiving literature and within long-term home care systems.

Microgeographies of Care

“Micro-geographies” are the resulting spatial productions of various intersecting social relations (Elwood & Martin, 2000). Careful observation of the people, activities, and interactions that constitute specific spaces and places can lead to a better understanding of the social geography of spaces. For example, Gesler (1999) suggested that we need a better understanding of the micro-geographies of care in hospitals in order to better understand these spaces where care is provided. Milligan initiated the study of the micro-geographies of caring practices in the home to better understand informal home care practices as carried out by family caregivers (2000). This study will follow Gesler’s model and take an in-depth look at the micro-geographies of long-term home-based care for caregivers of people with brain injuries with a particular emphasis on the interactions between the various people involved in the provision of care.

Contributions and Significance

This is an important time in policy development surrounding the growth of caregiver support and services. Currently, caregiver services are becoming increasingly available and are being acknowledged nationally and at the state level as essential to the well-being of caregivers and those for whom they provide care. It is imperative to explore how caregivers experience the services they inevitably interact with as part of their involvement with the person they care for. A recent New York State Office for the Aging survey found that 88% of caregivers utilizing services indicated ‘help in dealing with agencies’ as something that would be valuable to them. However, this important information has not translated into tangible assistance, with a majority of caregivers

3 See the New York State Office for the Aging and National Alliance for Caregiving for more information: http://www.aging.ny.gov/NYSOFA/Programs/CaregiverSvcs/FamilyCaregiverCouncil.cfm and http://www.caregiving.org/.
continuing to care alone, as they provide assistance to family members (Caprio, et al, 2009). Without understanding the intricacies of the assistance caregivers want and the translation of this information into practice, services will continue to be developed and provided whether or not they are useful to or utilized by the caregivers they intend to serve.

Detailed information about interactions between informal caregivers and formal service providers has the potential to impact the way long-term community-based services are developed and delivered. There are policy implications for the improvement of the support of informal family caregivers as well as for increased knowledge about how family caregivers experience their interactions with the long-term care system in general and in-home service providers, in particular.

It is important to know what caregivers think of what they do, as well as if, and how the current negative mainstream discourse influences caregivers’ and care recipients feelings about providing care. If in fact people internalize popular social messages related to dependence and burden then the current negative messages about caregiving will prove detrimental to caregiver/care receiver dyads (Brown, 2007; Marks, 1998). Reframing caregiver burden to focus on the positive aspects of providing care as well as highlighting the negative interactions caregivers have with the long-term care system are potential contributions of this study. Identifying and situating caregiver stress as a result of interactions with the system, and not simply as a result of the ADLs and IADLs they assist care receivers with, has the potential to transform the provision of community-based services.
Chapter 2: Research Methods

The Sociological Imagination enables us to grasp history and biography and the relations between the two in society. The challenge is to develop a methodology that allows us to examine how the private troubles of individuals are connected to public issues and to public responses to these troubles. That is its task and its promise. Individuals can understand their own experience and gauge their own fate only by locating themselves within their historical moment period (C. Wright Mills in Denzin, 2014, p. vii).

Mixed Qualitative Methodology

Qualitative inquiry is a situated activity that is distinct from quantitative research, which involves a naturalistic approach and locates the observer in the world and examines social situations in their natural settings. Qualitative research “consists of a set of interpretive, material practices that make the world visible. These practices transform the world” (Denzin & Lincoln, 2011 in Creswell, 2013, p.43-4). By delving deeply into the lived realities of research participants, qualitative research answers ‘how?’ questions rather than ‘how many?’ and examines and articulates processes in order to discover and describe, rather than test hypotheses, as in quantitative research (Denzin & Lincoln, 2003; Denzin & Lincoln, 2008; Pratt, 2009).

While quantitative research has specific language and tools for looking at representativeness, generalizability, validity and reliability, qualitative research focuses on how well the researcher has provided evidence that the descriptions and analysis of the data represent the situations of the people included in the study. There are systematic methodological and analytical processes for doing this, although utilizing the language of quantitative research and analysis does an injustice to qualitative research, as it is left to ‘live up to’ the standards of quantitative research. The danger of this is important to recognize, as there are pitfalls associated with confusing qualitative and quantitative
research that must be avoided. Specifically, Pratt warns against attempting to make qualitative research appear quantitative by utilizing language and tools for the analysis or presentation of qualitative data (2009). Doing this could propel the reader into a quantitative mindset and set the research up for criticism by not living up to the ideals of quantitative research because of the different modes of assessing the different methods. Further, as stated by Creswell, qualitative research “represents a legitimate mode of social and human science exploration, without apology or comparisons to quantitative research” (2013, p. 6).

Mixed qualitative methods were utilized in this descriptive and naturalistic grounded theory study in order to gain a depth of knowledge and understanding from various viewpoints (Strauss & Corbin, 1998). In a grounded theory study, a general explanation (theory) of processes, actions or interactions is generated or “grounded” in the data from participants. Critical ethnographic methods specifically, analytic autoethnography (AA), in-depth semi-structured interviews with caregivers of people with ABI who live with the person they care for and participant observation were the basis of this study. Previous qualitative analysis of caregiver burden, including grounded theory (Carson, 1993), typological content analysis (Chawalisz & Stark-Wroblewski, 1996), and phenomenology (Johnson, 1995) have revealed new themes related to positive aspects of being a caregiver.

Critical ethnography encourages the engagement of work within the public sphere for it to become a starting point for social critique and transformation, which supports the overall goals of this research (Simon & Dippo, 1986; Ellis, et al, 2011). It is described as being “organized by a standpoint which implicates us in moral questions about desirable
forms of social relations and ways of living” and formed the basis for my approach to understanding the relational spaces between caregivers and service providers within the long-term care system (Simon & Dippo, 1986, p.196).

This research is highly reflexive, as I position myself within the study itself by utilizing autoethnography as a method that conveys my background and how it informs my interpretation of the data, as well as what I have to gain from the study (Creswell, 2013). Reflexivity within qualitative research is often misunderstood as “a confession to salacious indiscretions”, “mere naval gazing” and even “narcissistic and egoistic”, implying that the researcher failed in their objective neutrality (Oakely, 1992; England, 1994). However, reflexivity is about self-critical introspection and analytical scrutiny of the self as researcher (England, 1994). Reflexivity is a key component of this research, as is required in the interrogation of myself and my lived experience in relation to the data that emerged through the interview process. Furthermore, Fieldwork, according to England is “intensely personal”, with the positionality and biography of the researcher playing a central role in the research process, from field to final textual analysis (1994).

Critical ethnography helped situate the research questions in the macro level social process that impact the daily lives of caregivers, specifically as they are enmeshed in interactions with others in the long-term care system. This allowed for the description of caregivers’ narratives of their caregiving experiences in relation to professional service providers, giving them voice around these social components of their experiences that are often excluded from research about caregiver burden (Polkinghorne, 1988).
Analytical Autoethnography

Autoethnography is a form of ethnographic research that uses the ethnographer’s personal narrative in order to illuminate aspects of culture, social phenomena and problems which the author is living through as a part of their naturally occurring life (Chang, 2008; Vryan, 2006). It is a method and a text that places the self within a larger social context (Reed-Danahay, 1997). I utilize analytic autoethnography in this study as a method for rendering visible social phenomena that I lived through personally in order to, as Mills states, “… examine how the private troubles of individuals are connected to public issues and to public responses to these troubles” (C. Wright Mills in Denzin, 2014, pp. vii). To that end, my life experiences as an informal family caregiver were included in this study as data points (journal entries, personal writings) that were analyzed simultaneously along with the interview data. For the purposes of this study, I am included as an interview participant throughout, with responses made anonymous and included in the findings.

There are well-documented debates surrounding the value and merits of a range of different types of autoethnography, from evocative and performative to interpretive and analytic (Anderson, 2006; Review Symposium, 2002; Denzin, 2014; Vryan, 2006). While they all have value and use in a variety of research approaches, my approach to autoethnography is rooted in an analytic autoethnography, where I use my personal narrative in an attempt to shed light on broad social phenomena.

Analytic Autoethnography (AA) has been acknowledged as being able to reveal a level of intimate knowledge which would be next to impossible to obtain in researching others by using the self as an instrument of data collection and analysis (Gannon, 2006;
Chang, 2008). The five key features of AA, as explained by Anderson, which make it an especially suitable method, given my extensive experience are: complete member researcher (CMR) status, analytic reflexivity, narrative visibility of the researcher’s self, dialogue with informants beyond the self, and commitment to theoretical analysis (Anderson, 2006).

I meet each of these features in their entirety, as a CMR by nature of being an informal family caregiver for so long and a member of this group prior to my decision to engage in this research. I engage in analytic reflexivity in my awareness of and disclosure to participants of my personal connection to the research and, thus, my effects upon it. My inclusion of my own personal narrative renders me highly visible as a ‘social actor’ within and related to all aspects of the research from development of the research questions, to the ultimate analysis of data. My inclusion of dialogue with informants beyond the self was imperative in order to step outside of my own limited experience in order to better understand the social group I was studying. In my mind this is directly connected to the next feature of a commitment to an analytic agenda. However, while Anderson makes the point that engaging with others is an important element of AA, with which I agree and have done here, his statement that no ethnographic work “is warrant to generalize from an N of one” is misleading, because, as mentioned above, generalization is not necessarily the point of this kind research (2006, p. 386). Finally, my use of analytic autoethnography includes a dedication to an analytic approach which points to a broad set of “data-transcending practices that are directed toward theoretical development, refinement and extension” (ibid., p. 387). While I don’t necessarily agree that the inclusion of empirical evidence in its traditional form must be a requirement for
all AA, it is a part of this study nonetheless, as I feel it strengthens and supports my use of autoethnography as a method in this particular study. I agree with Vryan, who supports Anderson’s view of AA, but also allows for an analytic autoethnography that is “less restricted, more flexible and inclusive, and more able to enhance our abilities to learn and teach about human life in new ways” (Vryan, 2006, p.405).

Due to my nearly two decades of personal experience providing care to multiple family members and my fifteen years of professional and academic experience in the areas of brain injury rehabilitation, long-term care and family caregiving, it is insufficient to simply situate myself in my research process. The depth of my involvement in the various systems of long-term care, both professionally and personally have provided me with insights and proximity to other peoples’ experiences which go beyond simply being an active and ‘situated’ part of my research. My life is made up of the very fabric of the lives of those I have done research with. It is in the living of my life as a family caregiver that I first realized how different caregivers’ struggles were from what was represented in the mainstream discourse and academic literature about people like me. If I didn’t have this personal experience of living life along with other caregivers, I would not have seen what I did, nor what to look for in the lives of other caregivers who I interviewed. Simply situating myself in order to explain how I came to do this research would be insufficient.

There is awareness on my part of the need to simultaneously delve into my lived experiences, the literature and my current research in order to clarify, dissect and re-frame family caregiving, while at the same time re-imagining what might be useful to caregivers in supporting their work. There would be no other way to fully grasp and
explore the depth of my experiences without rooting them in the larger cultural picture of caregiving in today’s world. My use of autoethnography helps illuminate aspects of the caregiving experience that I have learned through my close experience caring for others in multiple settings and observing and interacting with caregivers, care recipients, and formal service providers in close contact over two decades.

Autoethnography is a new and still emerging method thus, there are few specific guidelines for this type of research. Tolich addresses ethical issues involved in doing autoethnography and lays out guidelines for autoethnographers to consider in their research (2010). In particular, autoethnography brings to light issues with consent. It is not possible to receive consent from all of the people whose lives shaped my life and upon which my autoethnography is based. In dealing with this ethical implication, I have been as non-descript as possible, omitting or changing names of hospitals and people, in an attempt to minimize their recognizability to readers. The point here is to highlight the nature of relationships; the actual people do not need to be identified in order to get to the point of the research. I have attempted to be as careful as possible of other peoples’ privacy and have consistently tried to balance my side of the story with a regard for the experiences and feelings of others who I have included. In following Medford’s advice, I will not publish anything that I would not want to show to the people mentioned (2006). I have received permission from people whom I discuss who are currently available to me and they have had the opportunity to read anything I wrote that includes them, prior to publication.

I have been diligent and thoughtful as to what details I chose to share, but also realize that my perspective is only one side of the story. I do not, in any way, attempt to
explain aspects of others’ experiences about which I have only minimal knowledge. Readers should keep in mind that the experiences that I reflect upon are my own. I have limited my inclusion of and discussion about others in my autoethnography only to essentials, without which the story would be incomplete or incomprehensible to readers. I have attempted to extract meaning from experiences, not necessarily to depict the experiences as they were actually lived, as we must be aware of the one-sided nature of our experiences, as well as the limits of our self-reflexivity as we are having these experiences (Bochner, 1999; Ettorre, 2005). The analysis comes after the experience has been lived and reflected upon in relation to the larger culture in which it was lived. It is in full awareness that past events are interpreted from my current position (Ettorre, 2005).

The writing of an autoethnography is not without conflict, as there are many choices that must be continuously made, as well as new insights formed as I reflected on my history and heard the stories of the people I interviewed. Sometimes my experiences informed probing questions I asked about what I was hearing during interviews. At other times, I would hear a caregiver’s story and realize that I’d had similar experiences, but had not previously considered it important or realized the broader, political implications of my individual experience. This led to an iterative process in which I was constantly listening, analyzing and revising the autoethnography while simultaneously producing research findings from the insights I gleaned from the interviews. (Bloomberg & Volpe, 2008). The materials I drew from for my autoethnographic material included journal entries, memos and notes kept over the course of the last twenty years, as well as film, voice and print interviews I’ve conducted with various media outlets.
Semi-structured interviews

Elwood & Martin (2000) suggest that conducting interviews in specific places allows for simultaneous participant observation and has the potential to generate useful research material. With this in mind, seven of the caregivers were interviewed in their homes, which are the places where they provide care. The other two were interviewed in their offices. The interviews that took place in family homes provided an opportunity to observe firsthand their environments and the activities they engaged in, the dynamics that occurred among and between family members and provided for in-depth examination of the micro-geographies of long-term caregiving within the homespace. The goal of the interviews was to gain insight into the nature of relationships between caregivers and anyone they interact with because there is a person with a brain injury in their lives.

Interviews began with this initial grand tour prompt:

Tell me about interactions you have with anyone you are involved with because you have a person with a brain injury in your life.

In addition, I asked clarifying questions throughout the interviews to better understand the interactions they were describing. I have learned from caregivers why they provide the care they do, what might make life easier for them and the nature of their experiences interacting with the medical system and service providers, including home care agencies, insurance companies, and public benefits services, as well as others outside of the formal medical system.

Detailed field notes were written during and immediately after the completion of interviews and fieldwork. Fieldwork consisted of time spent in hospitals, nursing homes and community settings with family caregivers. Due to my intense personal involvement in this work for so many years, it inevitably came up with strangers in random places.
There were many times people would volunteer information and share a care story of their own, without any prompting. These stories contained rich material that helped inform my overall thinking and development of research questions. The fieldwork provided initial material and a first level of analysis. The time spent with the participants doing interviews served as the secondary level of analysis, with themes recorded during the interview process, re-visited while writing field notes, during transcription, and finally during analysis. All interviews were digitally recorded and transcribed for thematic analysis with a consent form signed by each participant.

**Participant Observation**

Participant observation (PO) is a widely used ethnographic qualitative research method in which the researcher actively participates in the communities they are researching (Creswell, 2013; Spradley, 1980). In PO, the researcher isn’t a distant and objective observer, but through fieldwork, is an active participant in the lives of the culture-sharing group being studied (Creswell, 2013). In addition, the research setting is the study informant’s daily lives, not an objective setting separate from the lives of the participants. Due to my personal involvement in this study through the utilization of autoethnography, I was truly an ‘insider’ and complete member of the culture of caregiving I was studying due to my extensive personal caregiving experience (Spradley, 1980).

Participant observation provides a different perspective and thus, different data than obtained from participant self-reports during interviews. Over the course of many years, observing caregivers and care recipients in their natural environments allowed me
to experience the contexts in which caregiving was taking place. In doing so, I was able to frame research questions accordingly.

Through participant observation, I witnessed caregivers’ interactions with providers, as well as their responses to these interactions. It was during this process that I became aware that the interactions and relationships in need of managing were more of a problem in the lives of caregivers than the ADLs and IADLs caregivers assist the care recipients with. In addition, in speaking to caregivers during the course of several years, I took note of the positive aspects of providing care they discussed; even in the face of the difficulties they were experiencing. These observations ultimately led me to my research questions and helped frame the way I approached the study.

Combining interviews with critical ethnographic observation has lead to thick descriptions of the caregiving experiences, relationships, and overall home environments where care is provided (Geertz, 1973). This allowed me to witness activities and interactions which might otherwise be left out or missed in a traditional interview situation, and provided important insights into the caregiving situations.

**Ethic of Care: Method as Caring Practice**

In an attempt to use care ethics within my research and be consistent with an *ethic of care*, I acknowledged the extent of the relationships between the interview participants and myself and was attentive and responsive throughout the interviews (Herron & Skinner, 2013). Many people, knowing my personal involvement with caring for my mother asked me questions in attempts to validate what they were saying or to learn about my experiences. In building personal rapport, I responded honestly to questions they asked me about my own experiences, as well as similar experiences other caregivers
had shared during the interview process in order to show people that though they may feel isolated, they are not alone in what they are doing. I waited until the end of interviews to share my personal experiences so my interactions and responses wouldn’t influence what they had to say. In some cases I have continued to see and interact with the people I interviewed. From a relational ethics and ethic of care standpoint, this furthers highlights the interconnectedness between my research participants and myself and provides for possibilities that any outcomes of this research will be shared with those most intimately involved with it (Ellis, et al, 2011).

Through the interview process a few caregivers had realizations and perspective changes about their lives that they didn’t have prior to the interviews. They shared this with me as a positive outcome of being interviewed and being given the opportunity to be listened to and share their stories, as they don’t often talk about their situations in the way we did during the interview. They expressed that these new insights gave them valuable new ways to think about their family situations, which they thought would be useful to them in the future.

In addition, I provided something tangible in return for participants’ time and involvement in this study. I offered and provided participants with caregiver support resources as well as local resources for the person with the brain injury, if desired and appropriate. All participants were given my personal contact information so they could follow up with additional questions after the interview.
Study Design

Selection criteria

The only requirement in order to be included in this study was that the person be a caregiver who lives with the person they provide care to. I immediately ran into decisions that had to be made regarding this eligibility criteria, as several of the interviews I conducted were with people who didn’t technically live with the person whose lives they manage and who they provide care to.

This study focuses on family members who live with the people they provide care to because I wanted to focus on the nuances of the interactions that caregivers have with people they live with and care for as well as with any community-based service providers who caregivers ultimately interact with because they live with the person they provide care to. There is something about living in and with a family situation in which care is required that allows for the caregiver to interact with professionals in a way that is more intimate and involved than if the caregiver does not live with the care recipient. In addition, the shared household provides a place-based micro-geography of the social spaces of care to emerge. It is in these close and intimate encounters that many of the complexities of care relationships become visible and seen as an important component to the overall care situation.

In line with the goals of understanding why people choose to care for people at home when alternatives exist, caregivers who care for people with ABI who they live with were the focus of this study. I focused on caregivers of people with ABI due to the nature and onset of brain injury. ABI results from a sudden medical event that thrusts the

---

4 See chapter 6 for a detailed discussion of what “living together” means for caregivers and the various living arrangements of the participants in this study.

5 The management of services will be discussed at length in chapter 5.
person and caregiver into a medical emergency. This is in contrast to caregivers who care for spouses or parents as they age or children with developmental disabilities. These types of illnesses might carry more social expectations in terms of what is expected of children caring for aging parents or a parent caring for a child with a disability. Caring for an adult child or a young spouse after an ABI comes with a different set of issues than more traditional caregiving roles of adult children or spouses. Why they choose to provide care will be an interesting exploration of caregiving outside of the typical life course path.

There are potential implications here, specifically in relation to interactions with service providers due to the nature of brain injury and the age of onset. Brain injuries occur due to traumatic medical emergencies at all ages and, as a result, are very different from the gradual development of Alzheimer’s Disease or dementia, which are more expected outcomes of a long life. And, as stated previously, remain the population that caregiver burden measures are based upon. Additionally, as discussed above, the treatments and rehabilitation goals for brain injury are different from those of people with dementia. Caregivers of people with dementia are likely to be expected to participate in activities that increase quality of life of the care recipient due to the continuous decline in functioning of people with dementia, whereas caregivers of people with brain injuries are likely to be expected to support and facilitate independence, whether or not this is reasonable for the care recipient.

This non-representative convenience sample includes young adult and adult children, spouses and partners, and parents where the onset of illness was sudden and traumatic. While the experiences of older spouses who care for people with dementia
provide insight into what it looks like to be a caregiver, it does not take into account how people come to be caregivers outside of the typical progression of age within the typical life course trajectory, nor is there a traumatic medical event, as there is with brain injuries. Importantly, the original research does not look at the various combinations of formal and informal ‘service mixes’ of caregiving and how they work together or in opposition to each other in order to provide care.

Caregivers were selected through purposive sampling that included criterion and disconfirming or negative case sampling (Hay, 2010; Palys, 2008). The only eligibility criteria I had were that the caregivers were people providing care to someone with acquired brain injury at home. Some participants were recruited directly as they were known to the principle investigator through personal and professional contacts. Professionals who work with caregivers through the Brain Injury Association of New York State (BIANYS), the Department of Health Traumatic Brain Injury Waiver Program and various service providers were contacted as the second level of recruitment. Snowball sampling was utilized by asking participants to refer caregivers they knew who might be interested in participating in this study. Disconfirming or negative case sampling was utilized by including families who did not utilize paid in-home services (Palys, 2008). This provided additional insight in relation to interactions with in-home service providers and allowed me to compare the difficulties of families utilizing in-home services and to those who did not.

**Recruitment**

The number of people recruited for this study was the result of an iterative process, which attained theoretical saturation, and material that was grounded in the data
that emerged in the field from caregivers who were actively providing care at the time of
the interviews (Glaser & Strauss, 1967). Theoretical saturation is a standard in
qualitative research and is reached when there is little or no new information or themes
that emerge through the research process (ibid.). Specifically, the development or
generation of new theory is grounded in data from the research participants. Theoretical
sampling was employed to fill in gaps as themes emerged from the interviewing process
(Ccharmaz & Mitchell, 2001).

The difficulties I experienced in finding people to be interviewed was surprising
to me, especially given the fact that I am deeply embedded in the brain injury
community, both personally and professionally. It was telling that service provider
agencies who serve people with brain injuries often told me during the recruitment phase
of this study that they didn’t have people with family members involved. One agency
supervisor from a large urban area indicated that the individuals they work with “don't
have families involved.” She suggested that they “burned bridges” with family members
who “didn't understand TBI and the behaviors and cognitive issues or substance abuse
issues.” She also questioned if this might have something to do with the location, stating
that, “outside of the city there are more families involved”. Other providers in the same
city indicated that they did not have people with family members involved in their care.
This suggests that agencies are not serving families, but individuals, where there are no
family members present. This was reinforced by one research participant who stated,
“the TBI staffing program does not work well for people with families. Individuals, you
might get a whole different story.”
The fact that it was so difficult to find family caregivers through agencies that provide services to people with brain injuries seems important to mention for several reasons: first, it supports the research that indicates that 80% of caregivers receive no outside assistance and, second, it leaves questions about who is actually served by these provider agencies and speaks to an inequity about who services are provided to, or accessed by. Are people with family members present utilizing services or opting out, as will be discussed below? In addition, the recruitment process made it clear that people who were known to me personally, either through personal or professional connections were more willing to participate in an interview and share their caregiving stories.

Participants

Interview participants included five spouse/partner dyads and five parent/child dyads, which is representative of caregivers in the US, who are most often either aiding a parent or spouse with a chronic disease (NAC, 2009). Ages ranged from the mid-thirties to the early eighties, with 6 caregivers being middle-aged (40-60). The caregiving experience of the 10 participants varied greatly, with 30% of caregivers providing care for less than two years, 30% caregiving for five to ten years, and 40% of the participants providing care for between 17 and 25 years, representing a total of more than 114 years of caregiving combined. The number of caregivers providing care for more than ten years is greater in this study than what has been shown as representative of the US population, with just over 10% of caregivers providing care for ten years or more (NAC, 2015). 50% of families were receiving in-home services at the time of the interviews. Six families were in a major northeast city, with two in the surrounding metropolitan area.
<table>
<thead>
<tr>
<th>Participant (by interview order)</th>
<th>Type of caregiver/care receiver dyad *** Receiving in-home services?</th>
<th>Ethnicity</th>
<th>Length of time caregiving (years)</th>
<th>Cause of injury</th>
<th>How they came to be included in the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>#2</td>
<td>spouse/partner *** No</td>
<td>Mixed race</td>
<td>1.5</td>
<td>fall</td>
<td>From local support group</td>
</tr>
<tr>
<td>#1</td>
<td>parent/child *** Yes</td>
<td>Caucasian</td>
<td>20</td>
<td>ABI- stroke</td>
<td>Personal contact</td>
</tr>
<tr>
<td>#7</td>
<td>parent/child *** Yes</td>
<td>Caucasian</td>
<td>25</td>
<td>unknown</td>
<td>Personal contact</td>
</tr>
<tr>
<td>#6</td>
<td>parent/child *** Yes</td>
<td>Caucasian</td>
<td>25</td>
<td>Complications at birth</td>
<td>Professional contact</td>
</tr>
<tr>
<td>#9</td>
<td>spouse/partner *** Yes</td>
<td>Caucasian</td>
<td>8</td>
<td>Suicide attempt</td>
<td>Professional contact</td>
</tr>
<tr>
<td>#5</td>
<td>spouse/partner *** No</td>
<td>Caucasian</td>
<td>&lt; 2</td>
<td>ABI-stroke</td>
<td>From local support group</td>
</tr>
<tr>
<td>#3</td>
<td>spouse/partner *** No</td>
<td>Caucasian</td>
<td>1.5</td>
<td>fall</td>
<td>From local support group</td>
</tr>
<tr>
<td>#8</td>
<td>spouse/partner *** Yes</td>
<td>Caucasian</td>
<td>9</td>
<td>fall</td>
<td>Personal contact</td>
</tr>
<tr>
<td>#4</td>
<td>parent/child *** No</td>
<td>Hispanic</td>
<td>17</td>
<td>Hit and run (MVA)</td>
<td>From local support group</td>
</tr>
<tr>
<td>#10</td>
<td>parent/child *** No</td>
<td>Caucasian</td>
<td>6</td>
<td>Suicide attempt</td>
<td>Professional contact</td>
</tr>
</tbody>
</table>

Table 1: Participant Demographics

One was from the Pacific Northwest and one from rural New England. All of the participants were female and, the majority of the care recipients were male (all but two). Respondents were mostly white, and highly educated, with half of them having advanced
graduate degrees (including three PhDs). Of the nine caregivers interviewed, seven of them were interviewed in their homes, the places where they provide care and live with the care recipient. Of the ten caregiver dyads, I met six of the care receivers, as they were home at the time of the interview. The other two interviews took place away from home, in the caregivers’ offices.

Analysis

The interviews were audiotaped, transcribed, sorted and analyzed. Data analysis utilized the constant comparative method developed by Glaser and Strauss, with the first level of analysis taking place through field observations and field notes (1967). Interviews were sorted through a process of open coding, with raw data being coded into categories, which then became clusters of categories, or items sharing similar content (ibid; Miles & Huberman, 1994). Clusters were then sorted into themes, with the emergence and development of themes and findings coming directly from the data through grounded theory. Categories with similar meanings were clustered, compared and contrasted and examined for themes. Data was constantly compared within and between other interviews as well as with the autoethnographic component of this research in order to find meanings and develop theory out of the words, meanings and lived experiences, as articulated by the participants.

Autoethnographic Analysis

Autoethnography remains a largely uncharted method, with few hard and fast rules. Autoethnographers find the usefulness of their method in terms of what it is capable of doing, explaining, or evoking in others (Chang, 2008; Ellis, 1999; Ellis, et al, 2011; Bochner 2000). Therefore, measures of validity within autoethnography are
evolving. One important measure is verisimilitude, whether the ethnography allows readers to enter the subjective world of others in a way that is lifelike, believable and possible (Ellis, 1999; Ellis et al, 2011). Much of the validity of autoethnography surrounds usefulness. Does the narrative allow readers to see, even feel the perspectives and experiences of others and to connect readers and writers to each other? During this research process I was aware of the validating process of comparing and contrasting my autoethnographic narrative with the content of the interviews. This went both ways, between myself as researcher, and those being researched and contributed to my overall approach involving an ethic of care, as discussed above. During interviews caregivers sometimes asked, “did that ever happen to you?” By acknowledging what they were saying and sharing a similar personal caregiving experience, I was able to connect with the participant and validate the experiences they had. This is important here, as a well-documented characteristic of caregiving is isolation (NAC, 2009). Even though so many people provide care, many of them, in their need to be close to home to provide that care, rarely interact with other caregivers who understand what they are going through.

**Limitations**

A major limitation of this study is that there were no male caregivers or caregivers who are people of color. This is of particular interest given the fact that I worked in social services and theoretically, had access to myriad service users. This may be in part due to the ways in which services require advanced knowledge or skill to access or interact with, that effectively exclude marginalized populations. There remain questions as to why men were not accessible to be interviewed, given that they represent 40% of caregivers among the general population (NAC & AARP, 2015)
Interviewing and observing people in their homes while they engage in their normal daily activities may alter their behavior. It is possible that people will change their usual behavior with a researcher present. People may think that certain taken-for-granted elements of their daily lives are of little relevance and leave them out of the interviews, but these observed details might actually provide fresh insights into the home caregiving experience.

Due to my extensive “matching characteristics” (Lewis, 2003, p. 65) (i.e.-life experience as a caregiver) with the people interviewed, I was able to establish rapport easily due to my "insider" status (Hay, 2010). Participants were familiar with my caregiving experience from interacting with me prior to being a part of the study or as a part of the outreach process. This was particularly true of caregivers who were recruited from support groups I previously attended. The danger here was that participants might not provide as much detailed information because of the assumption that I fully understand what they have been going through and the nature of their experiences in caring for a person with brain injury. At times, while explaining difficult situations, caregivers would say “well, you know” or “you understand.” I was fastidiously aware of this potential for incomplete information and always encouraged them to pretend that “I know nothing” so that they would share aspects of their stories that they may have otherwise left out. The benefits of sharing personal experiences and information about myself prior to the interview provided for deep rapport with the people interviewed. The benefits of this connection outweighed the drawbacks.
Chapter 3: Autoethnography: Process and Product

Autoethnography is process and product, a challenge of telling and showing (Ellis, 2000; Ellis, Adams & Bochner, 2011). It is at once personal and political and inclusive of the self and the social, as co-creators of our lived realities (Jones, 2008). To complicate the autoethnographic process further, it is also a past as well as present process. In my autoethnography, I have engaged first in the process of living through and with the experiences that I am now, in the present, attempting to explain, interpret and analyze.

In order to do this systematically, I have made the decision to treat my lived experiences as data points, using the same theoretical lens I have utilized with the interview data. I have approached this utilizing an archival method to autoethnography, with the archives being my own journal entries from the time certain events were actually taking place over the course of the past two decades. I refer to this as archival autoethnography, if you will, as these early documents were produced and archived as they were occurring well before I knew I was going to be conducting research utilizing this method. To keep them true to my original thoughts and feelings, I have not edited these early writings but analyzed them theoretically in the same way I have the data from interview participants. In addition, there are more recent journal entries and ‘field note’ type writings that I have produced since my decision to use autoethnography as a method.

These two different types of data are being acknowledged as different from one another (far past and recent past) because some of the data points were produced prior to my knowing that they would be looked at through an analytical lens and some after. The data points that were written after I decided to utilize the method of autoethnography...
have a more obvious analytical approach to them, as I was writing them with the knowledge that I would ultimately be looking at my experiences analytically, in relation to the literature, as well as the interview data in a way I wasn’t earlier on in my life as a caregiver. Here my caregiver self and my researcher self collide as I grapple with aspects of my life that have been troubling, rewarding and sometimes confusing and anger provoking.

My personal engagement with and identity as a family caregiver, in combination with my academic and professional identity as a teacher, researcher and service provider in the field of brain injury is of utmost importance to the process as well as the product of this particular autoethnography. I hope it provides a solid foundation and theoretically rich interpretation to the ever-growing knowledge base upon which we can build adequate support of family caregivers into the future.

It was only after I had decided on autoethnography as a method that I conducted formal interviews with other caregivers. Because of the decision to use this method, my awareness was heightened as I began to analyze my own experiences in relation to other peoples’ experiences. I soon recognized my experiences to be both similar and different from those of the people I was interviewing. Pieces of the puzzle came together as I saw my own experiences through a different lens. The resentment I had always felt in relation to the picture painted of caregivers by the literature began to morph as I heard stories and sentiments that were similar to mine, but underrepresented in the academic literature and thus, in the public discourse around caregiving. Specifically, I resented people talking about my mother as the main problem in my life, with no discussion of how the ‘system’ made life consistently more difficult for people like me. I regularly found myself thinking
‘things don’t need to be this difficult’, but I also knew that I needed help in managing my mother’s life and her new altered abilities, that doing it alone while trying to maintain normalcy in my own life would be very difficult.

I realized at some point that taking care of my mom wasn't my only problem, the larger and more troubling problems were the uphill battles that were required with each new and difficult interaction with a formal service provider, whether public benefit system or in-home service providers, who I needed to diligently manage in order for things to go smoothly. Additionally, even with my constant supervision, there were often times when things didn’t go so well. I wondered what would happen if I wasn’t putting so much time and energy into managing these services and providers? It seemed likely that the entire structure of our lives would fall apart, or we’d be a lot less well off than we were with all of my daily effort to hold life together.

It was striking to me that this aspect of caregiving, family members’ holding things together and picking up the pieces when things don’t go so well with providers, was practically non-existent in the current literature and public discourse around family caregiving, especially since it was one of the most difficult and unpredictable aspects of providing care for me over the years. Second, the predominant public message to family caregivers is “you must care for yourself in order to care for others”, as is evident in the “Caregiver Health” section of the website, a national organization that focuses on improving quality of life for caregivers (NAC, n.d. b). This message is very popular, yet there remains very little in place to assist family caregivers in actually taking care of themselves while they provide care to others and provide extensive management of services. Further, it ignores the possibility that through the process of caregiving, people
are actually caring for themselves. By nurturing our families, we also nurture ourselves, although this is inconsistent with the messages around independence. The “take care of yourself” message becomes yet another source of stress for caregivers who are left feeling that they are neglecting themselves in the process of providing care. From a public health perspective, the “take care of yourself” message focuses on the proximal causes of caregiver burden, but exclude distal factors that cause caregiver stress, the structural issues that often remain hidden and thus untouched by interventions (Link & Phelan, 1995). This is problematic because current interventions focus on the individual, as opposed to structural issues that negatively impact the lives of caregivers, such as the delivery of services.

Finally, another significant omission I have felt in my life over the years has to do with the positive aspects of providing care to others. Listening to the public messages around caregiving being rooted in all of the negative aspects of care made me feel like I was living a different life from other caregivers. Sure, it was extraordinarily difficult to provide all of this care alone, but it was also some of the most rewarding work I can imagine doing in life. I realized over the years that other family members also felt great pride and love when their caregiving yielded good results, often measured by quality of life, not necessarily by the ultimate independence of the person they cared for. In fact, some of the positive discussions around care have to do with increased feelings of closeness and being there for others, which in turn, makes people feel good about themselves. I wondered again and again why these more positive aspects of care weren’t recognized, with support stemming from this, as opposed to coming from a place of negativity? Looking at caregiving positively, and with care, shifts the way we respond to
it as a society and alters the kinds of support that gets developed or is recognized to facilitate caregiving and make the experience easier on family members.

There is awareness that in order for caregiving to be valued in society, the discourse around it needs to change. Yet, there remains a disconnect between how caregivers see themselves and their care work and how we are viewed, labeled and described by others. The main themes that emerged during the interview process were-1) interactions with and management of the long-term care system, 2) ideology of the individual, 3) positive aspects of providing care, and 4) living together and household negotiations. All of these were immediately recognizable to me in my own experiences, but became clear only through the process of hearing again and again similar sentiments from a variety of caregivers. Moreover, family members were saying things that were in direct opposition to the public representations of family caregivers. For example, most people discussed very positive experiences and fulfillment in life due to the caregiving they were providing. This was something I’d felt over the years, but didn’t see this depiction of caregiving in mainstream discussions of caregiving and so didn’t have a context within which to situate or openly express the positive feelings associated with my own caregiving. While the positive aspects of caregiving are mentioned in popular representations of caregiving, this perspective remains overshadowed by the privileged meaning surrounding caregiving, namely, that caregiving is a burden and that respite from it, in the form of social services will reduce caregivers’ problems (Todd & Weatherhead, 2014). I had been struggling against strong currents, but couldn’t identify or understand them coherently while I was living them. It was a great coming together of my own decades-long experiences as a caregiver and my research that allowed me to see
deep connections between caregivers that spoke volumes about the lived realities of taking care of people in our current socio-political climate. Indeed, it is more complex than any of the reductionist popular messages would lead us to believe.

It is my hope to render visible some of the complexity, contradictions, and implicit meanings that are portrayed in the dominant messages surrounding family caregiving that exist today. Specifically, exploring the often-absent narratives of family members regarding positive experiences they have while providing care, as well as the difficulties they experience when interacting with service providers, these relational aspects of care will shed light on these implicit and unquestioned messages surrounding the provision of care by friends and family. If I hadn’t lived through decades of providing “informal care” to multiple family members over the last twenty years, I would not be able to provide as nuanced an understanding of the complexities involved in providing and managing the long-term care of a loved one at home. This chapter will provide the reader with a detailed and historical personal narrative in order to provide the context for understanding the depth and extent of my own personal caregiving situation that I have been living with from 1996 through the present, and that continues to be a part of my life indefinitely into the future.

The following section was written well before I initiated the utilization of autoethnography as a research method. As such, I wanted to preserve the original voice and material I presented about my experience of being a “young caregiver” and so have not changed any of the original narrative text (NAC & UHF, 2005). Instead, I include analysis layered into the text in analytic boxes so the reader can follow along with my story, while experiencing an initial level of analysis and introduction of themes. As
mentioned above, the analysis and emergence of themes, was an iterative process that emerged as the research progressed and was grounded in the data. My original write up and analysis of the autoethnography informed the interview process. The interviews helped me recognize things from my own life that I had previously been unaware of or that I felt at an emotional level, but did not have a place in which to contextualize because of the power of the dominant discourses around caregiving, which influenced how I thought I felt about my experiences more than I initially recognized.

The narrative is followed by an examination of major themes that I theorize utilizing an ethic of care, and includes excerpts from my personal journal from 2009 through the present.

**Personal Narrative: Autoethnography**

**Taking Charge: A Young Caregiver’s Story**

“Maggie, it’s Grandma…” My first reaction was, “Why is she calling me? We’re not on speaking terms right now?” In an instant, the reason: “Your mother had a stroke.”

February 23, 1996. I was 17, a high school senior on a ski trip with friends, my first trip away from my mother. The most important things on my mind were who I was going to the prom with and going away to college in the fall. Being thrust into an incomprehensible, long-term medical nightmare was not part of my life plan. My first thought was that mom would be in the hospital for a bit before coming home, good as new. I had no idea whatsoever, what lay ahead for us.

**From Orchards to City Streets: An Earlier Caregiving Transition**

My parents separated before I was born, and Mom and I lived happily on our own in rural Northern California. When my grandfather died in 1987, we moved to New York
City to live in my grandmother’s house in Queens, New York. I do not know if my grandmother, who was then 78, was concerned about living alone. I suspect that my mother’s sense of obligation was the reason we moved. This theme of responsibility for family underlies our three-generational relationships. I was as bitter and angry as a 9-year old could be that I had to leave the only home I’d ever known, in the majestic redwoods, and live in gritty New York City.

That one phone call propelled me into a world where I became a full-time health care advocate, financial manager, and hands-on caregiver; and I did not even know it.

My Caregiving Begins

After a hurried trip back to the City, facilitated by friends and their parents, I walked into the ICU. Mom was in a bed near the window. I didn’t know then how handy the windowsill would be for homework over the next few months. She was hooked up to blue, white, and clear tubes. Monitors buzzed and beeped. She had a large purple mark over her eyelid- blood from where the hemorrhage had occurred. Except for all the machines, she looked like she was sleeping, not in a coma. I learned that Mom had suffered a ruptured cerebral aneurysm in her frontal lobe. An aneurysm is the ballooning of a weak blood vessel wall, which can break due to prolonged and excessive pressure. I remember on the first or second night sitting at the nurses’ desk in the ICU reading a book someone had handed me. It was full of medical situations with statistics about outcomes. What I vividly remember reading was that 75% of people with what Mom had die immediately and of the 25% who survive, 75% of them die within the first two weeks. Grim statistics, to say the least, and I must have made a subconscious decision to disregard them. If I hadn’t, I’m not sure I would have been able to go on.
The weight of that information would have crushed me. My mother was the most important person in my life. She was my everything, and I hers. It was unfathomable to imagine life without her. I couldn’t even entertain the possibility, so instead I began to fight.

The above passage depicts the initial medical trauma I faced after my mother’s initial injury and, that is universal in the lives of families when someone suffers from a brain injury. The scene in the hospital is one of a teenager who has just experienced the trauma and loss of her mother, as she previously knew her. I was alone, with no emotional support, or even acknowledgement of the fact that my mother was dying. I didn’t realize then how initially being ignored by the health care system and professionals within it would impact the way that I interacted with other health care professionals in the future. This can be seen as an initial stage of trauma inducing services, which will be discussed further in chapter 4. The last sentence provides an indication of a trauma response in the form of hypervigilance around clinging to and, literally, fighting for life.

I took the first week off from school to deal with paperwork at the hospital. Mom had been working full time, but had no health insurance from her employer. Her income was low and her assets negligible and so she was eligible for Medicaid, New York’s needs-based medical insurance. To enroll her, the hospital staff needed me to supply proof of her income and assets and much more information. What very little family we have remained uninvolved in my mother’s care and so I took on the task of a lifetime in caring for my mother. Initially, friends and family visited mom and I, but my grandmother never visited my mother in the hospital. Even though I was technically still a minor, I became the caregiver by default. I felt extremely lucky that she got sick only two weeks before my 18th birthday. As soon as I turned eighteen I was legally able to make medical decisions for her. If I’d have been younger that would have fallen to others and my wishes may not have been considered. I was able to say ‘no’ when they wanted me to sign a DNR (Do Not Resuscitate Order) only two weeks into her coma and
later make the decision (with the help of a friend’s parents) about the kind of brain surgery she would have. Most of the estimated 1.5 million American children and teens who are involved in caregiving for an ill or disabled relative have assistance from other family members (NAC & UHF, 2005). My situation was extreme but not unique.

I had to learn how to navigate the health care system, a daunting challenge for an adult, much less a 17-year-old. Most of the hospital staff was helpful. The social worker, however, was not. She came around when she needed me to sign something or to let me know I hadn’t given her some piece of paper she needed. She offered no support or guidance whatsoever and never checked to see how I was doing. I was a teenager with a dying mother, and she expressed less interest in our situation than did the food service people, who eventually got to know Mom and me quite well and gave me food in an attempt to take care of me- a touch of humanity during difficult times.

This passage speaks to the problem of health care professionals and service providers who were not being supportive, but also the support that can be found in the kindness and connection from others, who are not formal service providers. As we will see from the interview material below there is a phenomenon of services, not support as well as support, not services. Here, places where family caregivers might expect to find support, in the presence of formal long-term care services and professionals, we may actually find difficulty and strain as we care for our loved ones. At the same time, family members often find support in unlikely places, such as in the human connection with the food service workers who were kind and caring in the face of an otherwise cold and detached response from many health care workers.

When I went back to high school, teachers and classmates tried to understand what I was going through but it was hard for me to explain the realities. How could I? I had little time to understand what was happening and even less time to consider how I felt about it. I was spending every possible moment I could at the hospital, which was usually several hours a day and more on the weekends. I was able to get extensions on
assignments and come to school later than everyone else because I had no class the first period. Every day right after school I drove from Queens to Manhattan and double-parked on a block with no parking meters so once I was inside with mom I had no time constraints. I started my homework in the car while waiting for a parking spot to open up.

**Leaving One Hospital for Another**

Mom had been in the intensive care unit (ICU) and in a coma for about two months with no change when a social worker called to tell me, “You need to find a place for your mother. If you don’t do it we will find one for her.” I asked where it could be and she responded coldly, “There is no way to know. It could be as far away as Albany.” That was the only advice I got, even though Medicare, Medicaid, and The Joint Commission require hospitals to provide information about possible placements in a timely manner before a discharge (Li, et al, 2014; Moreño, 2014). I had no idea that the discharge could be appealed.

Here, again, we see the theme of *services, not support*, as I am thrown into another crisis situation when I am told, with no notice or ability to prepare, that my mother could be sent very far away from me to be placed in an institution that had a bed for her. This lack of support led to further traumatization as I had to solve the problem on my own, without the assistance of the people I thought should be there to provide assistance. My mother was dying, I didn’t understand why I had to handle these aspects of her care without help or even minimal guidance. Wasn’t this someone’s job to be doing this with us?

Below, we see another example of *support, not services* when I am assisted by someone I called upon myself, not a member of my mother’s ‘care team’.

In a panic, I called a friend’s grandmother who was the director of rehabilitation at a local hospital. Within hours she had arranged for my mother to be admitted to her long-term care hospital. I made this choice without researching various programs or even
visiting any facilities. Certainly this was not a good way to make such an important
decision. I was not able to think clearly, however, after I was told that Mom could end
up hundreds of miles away if I didn’t find a place for her quickly.

My mother and I arrived at Hospital B on a very cold and snowy April day. The
ambulance driver and I wheeled my mother’s stretcher into the hospital through the
basement. I was somewhat unnerved by the gloomy atmosphere, but I thought it would
get better once we got upstairs.

Getting off the elevator to Mom’s floor was traumatic for me. We walked
onto an open ward containing many comatose patients on ventilators, some of them
moaning loudly. I had no idea places like this existed and the fact that this was to be my
mother’s new home was more than I could bear. No one greeted us. When we got to the
empty bed assigned to my mother, I gripped her stretcher and began to sob
uncontrollably. I looked at the driver and pleaded: “You can’t leave us here!” Of course,
he had no choice, even though I could tell he didn’t really want to go. All he could do
was repeat, “I’m sorry,” and stay a little longer until I was calm. When he left I was
totally alone. I was afraid. It was one of the worst days of my life. One of mom’s friends
met me there later and took me with her when she left so I wouldn’t stay too long. If not
for that, I likely would have tried to spend the night. I couldn’t fathom leaving mom
alone in this place, but really, what choice did I have? It was a dreadful day.

In the opening sentence of the paragraph above, I directly use the word “trauma” to
describe what we had been through on this life-altering day. Even now, I am able to go
back to that moment and re-live the sights, sounds and feelings that were pulsing through
me. I was alone and afraid and had no way of processing what I was going through.
Being left alone, with no supportive services reinforced the trauma, whereas responsive
and attentive hospital staff could have made the difference between a positive and
negative emotional experience during this difficult time. The ambulance driver tried to
calm me and provided a bit of support during this time, but overall, I was neglected by
This was a situation that could have been prevented. No one at Hospital A ever suggested I visit Hospital B before making a decision. I wasn’t asked why I chose it or if I needed a list of other hospitals to choose from. If I had visited this facility first, and still selected it, at least it would have been a partially informed decision. Instead it was one based on fear of the unknown about where Mom would be sent. Having seen it prior to her admission would have reduced the trauma for me. I would have known what to expect and have been more prepared. Instead, I was sent blindly to a dingy old hospital, which was a far cry from the first place she had been in.

I eventually got relatively comfortable at Hospital B. Mom was slowly weaned off the respirator and very slowly started to come out of her coma. No one ever discussed this process with me either, and I simply witnessed and improvised as it happened. I encouraged her as she started to open her eyes, then focus on me, and follow simple commands such as “squeeze my hand” and “point your finger”.

Here we get a glimpse into the life of a family member who is quite alone in the experience of caring for someone whose life is in danger. The initial medical trauma thrust my family into a situation that was completely foreign and then I was left to proceed alone and without support or guidance. No one was talking to me about what to expect, I had to learn as I went.

This hospital had nice grounds so I started to take her outside in good weather. Grandma also started to visit Mom once she was out of the coma. Though Grandma never saw the inside of the hospital. On the days she visited, I would get Mom ready and bring her out to where Grandma was waiting. When I was alone I spent at least five hours at a time with Mom, but visits with Grandma were shorter. I sheltered Grandma
from seeing Mom in Hospital B’s depressing environment. I’m not sure why this was the case, but it is the way we did it. Grandma was a very strong willed woman and if she had wanted to come inside she would have. My instinct was likely to shield her from the gloomy interior of the place, but I don’t fully recall how this ended up being our routine.

Making a Treatment Decision

After about two months, Mom was stable enough to go back to Hospital A for surgery to repair her aneurysm. There were two surgical options. The first, most common treatment for aneurysms is “clipping” them, which involves long, invasive brain surgery. The less common option, which had never been performed in this hospital, is an embolization. This involves only a small incision in the hip where a catheter with a camera on it guides a ball of platinum coils up to fill the aneurysm. Embolization cuts off the flow of blood from the aneurysm in order to prevent it from rupturing again, which is common in this type of injury. This option takes considerably less time and is much less traumatic to the body.

I, with the help of a close friend’s parents chose the embolization procedure, knowing that the doctors might have to do more invasive surgery if anything went wrong. The doctor who was doing the procedure on my mother was doing it for the first time in this hospital. The operating room had to be built and due to all the hold ups with getting it done, Mom was able to stay on the rehabilitation floor for intense physical, speech, and occupational therapies. We became a permanent fixture at this hospital and the staff was generally wonderful to me. I have many fond memories of wonderful people there. The procedure took place November 7, 1996. I spent the night at the hospital with Mom the night before. It was one of the scariest times for me anticipating all that could go wrong.
in surgery. I kept thinking that it could be the last time I saw her alive. I was pacing and
crying outside the operating room after they had wheeled her away from me when I saw
the doctor who was going to do the surgery. He approached me and through my tears I
said, “please do a good job.” Talk about putting him under additional stress! I just felt so
helpless and desperate for her to come out and be ok. I was so thankful for a friend who
came to be with me during the surgery. She stayed with me and distracted me while
Mom was in. Fortunately, the procedure was completed in about two and a half hours
with no complications. When I saw Mom in the recovery room it was as if nothing had
happened. She had a bandage on her hip and was as alert as she had been that morning.
We made it through a major milestone, but we were still only in the first year of her
rehabilitation. It was difficult to grasp the reality of all that was still ahead of us.

More Discharges, More Placements

By the fall of 1996 I was attending a local college on a scholarship and living at
home. My plan to go away to school had long since been abandoned. I was starting
college and planning for my mother’s surgery all at the same time.

By December Mom was ready to be discharged again. This time a different social
worker told me, for the first time, that what my mother had suffered was a “traumatic
brain injury” or TBI. The staff all suggested Hospital C because it had a special TBI
program. My mother was evaluated and accepted and I visited the unit. I did not research
other hospitals, but I felt much better about this transfer decision because I had
appropriate advice from hospital staff and was familiar with the place before we arrived.

Hospital C’s program generally only kept patients for two months. Mom
continued with intense therapy sessions there, but the doctors felt that she had
“plateaued” and that there was nothing more they could do for her. I despise the word “plateau.” The doctors used it often. In fact, they used it so that I began to completely ignore them each time I heard it. In their eyes it meant Mom would never progress any further in her recovery. Fortunately, every time they used it they were wrong.

In February 1997, a year after her aneurysm rupture, I had to make another decision. My mother had to go into a long-term care facility. Luckily, while at Hospital C I had made several friends among the family caregivers—all much older than I—who were making the same decisions at about the same time. We compared information about the places we were visiting. We discussed things like quality of care, cleanliness, staff attitudes toward patients, and proximity to our homes while trying to come to some decision we were able to live with. We held informal support groups in the lounge. I suspect that, even with websites containing information about quality measures at nursing homes, this kind of informal sharing of impressions is what people depend on to make decisions. It was of tremendous value to me.

The passage above reiterates the importance of support, not services in the lives of family caregivers. Essentially, it was the sense of an informal community of people in the same situation that provided support and information that was more beneficial than what professionals were providing.

Ultimately I decided on an extended care facility close to home. I decided it was more important for Mom to be close to me than to be at some prestigious hospital far away. My daily presence seemed more critical to her recovery than even the best hospital program. Looking back, I am confident that I was correct. I was nineteen years old.
Five Years in a Nursing Home

February 1997 would be the last time my mother was transferred from one hospital to another. We went together from Hospital C to the nursing home that would be her home for the next five years. During that time she received excellent therapy. She very slowly started using a walker to go short distances and was able to stay out of bed all day without being exhausted.

Because Mom and I were there for so long we got to know everyone very well--patients, staff, and other family caregivers. The other caregivers helped me through the many ups and downs at the nursing home. Although I had many wonderful friends my own age, none understood my life as well as the other caregivers.

One day, several years into our stay at the nursing home, I realized, by mistake, that the therapies Mom was receiving had been drastically reduced. I was still there constantly, spending countless hours with her and even spending time with and advocating for other patients. I had the realization that if they weren’t doing anything to help her get better, we might as well be spending our time together in our own space at home. At least we’d be home together and I wouldn’t have to keep spending all of my time in the nursing home. It was scary, but seemed that the time had come.

The microgeographies of the homespace are important here, as I negotiated daily life within the confines of an institution. My mother needed care and I needed to be a part of her daily life. These things were difficult at the nursing home, where I had to bend to their rules and regulations and ultimately, spend a significant part of each day in a home, but not our home. We were able to be together at the nursing home, but we were away from home and in space that was artificial, not the home we wanted to be in.
Bringing Mom Home

By 2000 I had graduated from college with a degree in psychology and was bringing Mom home for short visits. At first it was just for a few hours but gradually the stays became longer and longer. Having her home was a lot for me to handle, but as time went on it got easier as her condition improved. In the beginning she needed complete hands-on care, but gradually that lessened too as she became more independent.

One of the most difficult battles was with my grandmother. I knew I needed help in order to have Mom home full-time, but Grandma would not admit that Mom had many cognitive and physical deficits and would be difficult to manage without paid help. I needed to regain some degree of normalcy in my life while at the same time letting my mother regain as much independence as possible. Despite her lack of real involvement in Mom’s care, Grandma said “she is my daughter and I will take care of her because I am her mother.”

The ideology of the individual seeped into the discourse I used here to describe my life. Here, before I was aware of how the mainstream discourse influenced how I thought about the care I was providing to mom, I used the language that was available to me. The language I used was about mom and I as being ‘independent’, even though we were a dyad, whose needs were interconnected and deeply embedded in each other’s lives. There was an artificial separation of mom and one, I that didn’t actually exist. As a result, the goal was for mom to be independent; there was nothing about us being an interdependent unit, in need of support. This language was not available to me and so I used the language that supported the dominant ideology of the individual discourse and, as we will see below, that still permeates much of the discourse around family caregiving.

The thought of letting strangers in our home to work with Mom was too much for Grandma to deal with. I eventually insisted that we were going to have to give it a try, and ultimately she gave in. By this time I had finished my Masters degree in clinical psychology and was working part time from home for the Brain Injury Association of
New York State. I took that job because it gave me great flexibility to be home. It also provided me with medical benefits. Although the Association paid only a percentage because it was a part-time position, it was a big help. It seemed like the best of both worlds. I was able to do some professional work and balance my household and caregiving responsibilities and be on-call, as needed.

Above, we see again how the microgeographies of the homespace where care will be provided becomes a source of contention between the differing needs of the family members and the family unit, in relation to in-home services. Home becomes a site that will be invaded by outsiders. As professionals enter the home, it becomes a site of employment and conflict, as residents, care recipients and employees all have to coexist together in unfamiliar territory with the competing goals of providing care and living life.

On March 12, 2002, three days after my 24th birthday, my mother came home for good. For the first time, I realized that my life would never return to “normal.” My biggest worry was whether I would be able to accommodate all my mother’s needs at home without the support of the nursing home staff. As much as I wanted Mom home I also knew it was going to mean a big change in my life. As terrible as the nursing home experience was I knew that if I couldn’t get there mom’s basic needs were covered. Someone would ultimately be there for her. At home, that someone would be me.

Here we see the desire to be at home combined with the fear of being alone in the provision of care. Before my family had any interactions with in-home service providers there was a hesitation to have them, mixed with an acknowledgment of the need for assistance in providing care for my mother.

Through the New York State Department of Health’s Traumatic Brain Injury Waiver Program my mother is entitled to home care and various other services. We had waited to be settled in initially before starting with home care aides. A wonderful woman, whom Grandma loved, was the first person to work for us after Mom came
home. Unfortunately, however, she moved; and since then many aides have come and
gone, sometimes with significant gaps with no one. Grandma has gotten more accepting
of them, but even so, having strangers around is uncomfortable for all of us. We
anxiously await every new person, rather than looking forward to a helpful service.

Here there is a clear indication of the need for assistance, but mixed with the reality of the
difficulties involved in having paid caregivers in the home. Here the caregiver/care
receiver/paid caregiver triad presents itself as a source of discomfort and strain, as
opposed to being purely helpful, as is the predominant and unquestioned assumption
about in-home service provision. The recognition of the invasiveness of in-home services
on the caregiver/care receiver dyad within the homespace is important in terms of what
constitutes support of families with significant care needs.

Learning from the United Kingdom

Was I treated better or worse in the health care system because I was so young?
Both. Many staff were especially kind and helpful, recognizing my inexperience. Some
respected me because I did not run away from my mother when things got rough. Others
were patronizing and failed to treat me with the consideration I deserved as a family
caregiver, regardless of my age.

Certainly there have been some benefits. Through my activities on the family
advisory council at the nursing home, I was identified as a “young caregiver.” I began to
be included in professional meetings about family caregiving, lending a young person’s
perspective to what is generally considered a middle-aged person’s problem. Through
many contacts with researchers here and in Britain, I learned that in the UK “young
carers,” as they are called, are counted in the Census, are the subject of special
legislation, and have services provided by local councils and agencies such as the
Princess Anne Royal Trust for Carers. There are carer centers where young people
gather, participate in group activities, and receive support and counseling. In the US young caregivers are largely invisible.

Here, again the language used to describe myself is that which was put forth in the mainstream discourse about ‘people like me’ who were doing this thing called “caregiving” and I became labeled as a “young caregiver.” Like many caregivers, I didn’t recognize myself as such and I simultaneously felt proud of this label and resisted it in favor of just being a good daughter (Eifert, 2015). Who did this label serve? Was I going to get special help because I was a caregiver? No, I got a lot of praise for what I did, but not much actual help so I could “go live my life”, the advice given freely by many over the course of two decades.

Additionally, I mention positive aspects of my caregiving experience and how it has provided me with opportunities and benefits, not only negative experiences.

While studying for my second Master’s degree, this time in public health, I visited the UK, met researchers and social workers, and attended several sessions with young carers. I’ve remained personally and professionally committed to assisting caregivers of all ages get the recognition and assistance they deserve while they continue the difficult and rewarding care they provide.

Fast-forward many years. Life continues on at home. Grandma broke her hip in 2009 at 99 years old, and began a slow decline. She died, an amazingly beautiful death at home, and without medical intervention in the summer of 2011. Mom and I are trying to figure out a new life, sans Grandma. Mom is doing well, but needs constant monitoring and support. We are very lucky to have a wonderful home aide who has now been with us for several years. She is trustworthy, a fantastic cook and has become a part of our family. I will be forever grateful to her as it is only because she exists in our lives that I am able to tend to my own life and get away periodically. Now as I continue to fashion a life that balances Mom and myself, she will make the difference between Mom being 100% my responsibility and only partially so.
My mention here of our “wonderful home aide…who has become a part of our family” is yet another way the dominant discourse seeped into my description of our situation. The assumption of a paid caregiver as ‘family’ reinforces strong beliefs about the informal and undervalued nature of care work. It eliminates any critical discussion about the exploitation of domestic workers, who are paid poorly and typically receive no benefits or labor protections under the law (Aronson & Neysmith, 1996). When people are “like family” it is expected that they will do whatever is required of them, in this case provide care, without demanding fair and reasonable compensation for the work they do. The dominant messages about care being a private problem, as opposed to a public and political issue obscures the structural problems in our health care system that allow relationships based on abuse, neglect and exploitation to continue. Here the paid caregiver is an exploited, low-wage worker, with the family caregivers being the ultimately exploited group, as they receive no remuneration of any kind for the massive amounts of care work they contribute. The estimated economic value of the unpaid, caregiving by informal family caregivers was $470 billion in 2013 (Reinhard, et al, 2015).

Foster Care

I got the twins out of foster care last night. It has been quite a day. I took the kids to visit Tanya at the agency [agency name] and realize that it is all the same BS, different set of needs. I generally work in the disabilities arena, but now I’ve been flung full speed into the world of foster care. All these people at the agency will ‘help’ you and provide services, but when push comes to shove, you better be good at getting what you need for yourself or you are screwed. In the end, they are a bunch of paper pushers who every once in a while get something right. And, we get blamed for their (and the systems) inadequacies!

There is no introduction to this section because I didn’t want to re-write it, but wanted to leave it as it had been initially written. I became a kinship foster parent when a family member’s children were put into foster care. I was in my early thirties.

Dealing with the foster care system was a major ‘a ha’ moment for me when it became blatantly obvious that it was not the requirement of me to provide care, in this case to foster children, that was causing me so much distress, but that my most difficult problems were in my interactions with the ‘system’ that were causing extreme amounts of extra work, stress and strain. Here, there was a conflation of the problem; it was easy to believe it was because I had foster children that I was so burdened, however it was clear
to me at this time that the problem was not the children and my caring for them, but all of the systems negotiations that were required of me and the arbitrary rules and restrictions placed on me by the foster care system. The kids and caring for them were not the problem; the system was the problem. It was in the interactions with the foster care system that I clarified my research focus for this project. I needed to focus on the difficult interactions people have with the system in order to re-frame caregiver burden to include these problematic interactions.

Recovering My Life

The above title further indicates the infiltration of the dominant discourse into how I viewed my life. This title seems to stem from repeatedly being told by others that I wasn’t living my own life and that I should put my mother in an institution and ‘go live my life’. Looking back on this with an analytical lens, it is very interesting to me that I chose this language, as I’m not sure that I ever actually believed that I wasn’t living my life. Rather, I was living my life as part of a family unit, one that was unsupported by the system and rather than helping me figure out how to address our combined needs, would rather have me abandon my mother to an institution than help me figure out how to care for us both together as a unit in need of support.

At the age I began caregiving young people have not yet established a career or a family of their own. Older people who become caregivers have an established sense of self that young caregivers may not have. Instead of recognizing these differences, policies and programs tend to treat caregivers as all having the same needs and problems. Sensitivity to differences and flexibility are essential to providing appropriate support, training, and assistance.

It is telling here that I don’t say that we want or need more services, but that we need support in order to continuing providing care. This distinction between services and support remains throughout and is a key point in this research.

We have come a long way in simply recognizing that young people are providing substantial levels of care to family members. The challenge remains of how to support all caregivers so they can continue to provide care for as long as they wish to do so in the most appropriate setting for both caregivers and care receivers simultaneously. It is a
challenge we must take seriously for as Roslyn Carter told us: “There are only four kinds
of people in the world: those who have been caregivers, those who are currently
caregivers, those who will be caregivers and those who will need caregivers.” We owe it
to all of us to make the situation of needing care and providing care one that leaves us
healthy and safe and not in great need of something more.

The need for methods of supporting the caregiver/care receiver dyad is emphasized here. As seen above, the ideology of the individual permeates the provision of services, often to the detriment of the family unit and specifically, the caregiver/care receiver dyad that is an essential component of the care relationship and can’t be ignored by the long-term care system, if it intends to provide adequate and appropriate care in the community without exploiting the massive economic and care work inputs of family caregivers.

Concluding Reflection

In 2001, the last year my mother was in a nursing home, the federal government made payments of $43 billion to nursing homes (GAO, 2003). The Medicaid reimbursement rates paid to nursing homes vary by state and are based on the homes’ costs, with specific rates set differently at different homes based on costs specific to those places. As noted above, this pales in comparison to the $470 billion estimated economic value of care informal family caregivers contributions to the long-term care system (Reinhard, et al, 2013). However, family members who provide this care receive little support (social or financial) in return for this work.

When Mom first came home from the nursing home, she was technically on the Department of Health HCBS TBI Waiver, although we didn’t receive any in home services. This meant that I, then 23, was responsible for all aspects of my mother’s life, 24 hours a day. I was making my own personal contribution into the $470 billion of unpaid care work provided by informal family caregivers in the United States (Reinhard, et al 2015). Based on the New York State Medicaid reimbursement rate of $19.24 for
Home and Community Support Services (HCSS), the government saved more than $460 per day for everyday my family didn’t receive the 24-hour formal in-home services my mother was eligible for (J. Vollaro, personal communication, December 16, 2015). That adds up to nearly $13,000 per month or over $150,000 per year. Despite these enormous savings provided directly by my family as well as numerous others, informal family caregivers receive nothing in return to help us mitigate the financial costs of providing this care.

At the point Mom came home she was still in a wheelchair and unable to transfer herself, walk independently or even move the wheelchair from one place to another. A few neighbors carried her up the stairs to our second floor living quarters and there we were: Mom, Grandma and I, free from the confines of the nursing home, but all alone to navigate the care and assistance my mother needed in her daily life. I remember having the thought then that everything was all on me. When she had been in the nursing home I was there almost daily, but if I couldn’t get there until late or couldn’t bring her a meal, as I usually did, I knew that she was being taken care of, even if that care wasn’t up to my standards of what it should be. Now, I had to be there, all of the time to make sure that her entire life was appropriately supported; that the “illness problems” (Kleinman, 1988: 4), the way my mother’s physiological injury associated with her TBI played out in our daily lives were navigated in such a way that we could all go on living meaningful and engaged lives. What follows is an introduction of themes that emerged during the research process. They will be discussed in more detail in the chapters that follow.
Introduction of Themes

Over time engaging in the research process as well as attempting to make analytical sense out of what I had been living through for so many years, several themes emerged: 1) interactions with and management of the long-term care system, 2) ideology of the individual, 3) positive aspects of providing care, and 4) microgeographies of the homespace, specifically, living together and household negotiations. I recognized myself in each of these themes in a way that I’d not before recognized myself in the literature on family caregiving, especially related to caregiver burden. It was a revelation that freed me to realize that my experience and perspective was not at all unique, simply underrepresented and unprivileged as meaningful in the literature and popular discourse related to caregiving. Here, I will provide a brief introduction to each of the above themes, with data to support these themes provided in the following chapters.

Interactions with and Management of the Long-term Care System

Despite the knowledge that family caregivers do more than help with ADLs and IADLs and while I have known my own interactions with the system to be more problematic in our lives than the actual care that I provide to my family, it wasn’t until I began hearing accounts of neglect, abuse and exploitation of caregivers by the system that was supposedly there to assist them and make life easier, that I was able to acknowledge that what I had been feeling all along was accurate and also being experienced by others on a regular basis.

It wasn’t that I could have been doing things differently for life to be easier for all of us. It was, more realistically, that the system was flawed to such an extent, but hidden from view and ignored as a source of caregiver burden. This directly related to
my first frustration that helped me develop my research agenda: that the literature and public discourse was rooted in the belief that my mother was the problem in my life, with no discussion of how the ‘system’ made life consistently more difficult for me and others like me. The result being that caring for people with disabilities becomes conflated with interactions with the system in such a way that the caregiving becomes identified as the problem, while the system is left to abuse and neglect without notice.

It is my intention here to relocate the origin of ‘caregiver burden’ in the disorder of the state (i.e.- social services) and the long-term care system bureaucracy itself, rather than in the caregiver/care receiver relationship, which is where the burden currently is located by research in this field. As we will see, time and again, caregivers experience consistent and repeated difficulties navigating ‘the system’. This becomes a constant source of the burden they face, although the blame gets placed on the fact that there is a person with care needs and not with the overall functioning of and way services are provided in this complex and complicated system.

An example of this is evident in a journal entry of mine written in 2013 after a very distressing and unfortunate, but typical, visit to a Department of Social Services (DSS) office to apply for benefits, for which my mother is eligible. It was a turning point for me, and the first time it became clear that I was conflating the difficulties I had with the system with my mother’s disability.

**Food Stamp Office Nightmare**

We had to apply in person for the Food Stamps Mom should have been receiving for many years, basically since she came home in 2001. She has not had them because it has taken me this long to make it a priority and make the time to visit the Food Stamp office. Isn’t this something the service coordinator should have done?
We arrived at the office together to find a line a few blocks long coming out of the front door. It was beginning to rain. I couldn’t put her on line and go to the front, but was afraid that she would not be able to stand as long as the line might require. We went to the security guard at the front door and I told them that my mother couldn’t stand in a line for that long. “Do you have a letter that says she can’t stand in line?” Me: “I have a letter from the doctor that says she has a brain injury.” Security: “Does it say she can’t stand in line?” Me: “No” Security: “It has to say she can’t stand on line. You’ll have to come back with a letter.”

So, we go and get in the line, which has grown even longer while I was trying to reason with the security guard. And, we wait. I had her lean against the wall. She managed.

We got in and waited, and waited, and waited after being herded through the building like cattle. The atmosphere is one of intimidation; there feels to be a general lack of concern for the people visiting the office. There are security guards monitoring everything and we all seem to have attitudes. How could we not being in a place like this?

At some point I realize that my parking meter would expire soon and I need to go out to the car, but leaving Mom alone is not a good idea. If she gets called she will go to whoever is calling her, but won’t be able to give any information beyond her name and address and she may forget that I was with her in the first place. She would not be able to simply say, ‘we have to wait for my daughter to come back with the paperwork.’ This scene is all very unsettling for me. I take a risk and leave her in the waiting area while I go downstairs. I figure I can run quickly and get back up fast.

As I am leaving the building I tell the security guard that I’ve been inside for a few hours and just need to put money in the meter. He tells me that I will have to wait on line again to gain re-entry. “But my mother is upstairs waiting and she can’t be left alone long, she has memory problems.” “You’ll have to wait on line.” What can I do? So, I go. I go to the car, get inside and cry. I cry as hard and as efficiently as I can so that I can get it all out and get back to her as soon as possible. While I am crying, it hits me: my mother and her disability and my caring for her, these things are not the problem here. In the everyday discourse around caregiving things get simplified down to the ‘person with the disability as the problem’, but really? The problem here is the (mis) treatment and disrespect people face in the necessary act of filing out paperwork.
and trying to get benefits to which they are entitled—things that will make life easier. *Mom is not the problem here; this merciless system is the problem.*

I pull myself together and get back on line. Luckily, a security guard who (apparently) witnessed my asking the other guy if I could come straight back in saw me on line. I was behaving and waiting as I had been told to do and he decided to take pity on me, show some compassion. He came to me on line and asked if I was the one with the mom upstairs? “Yes”, I shake my head, trying really hard not to cry. He called to his colleague to let me in and I was allowed to be next to go through the metal detector. Words cannot express how grateful I was to this man—an act of humanity in the midst of this inhumane setup.

When I got back upstairs mom was right where I left her, oblivious to the bit of *trauma* I had just suffered in the few minutes I had been away from her.

When all was said and done and the food stamp application process was over, the point that was solidified in me was that this system of ours, with its claims to provide assistance to those in need, is so fundamentally flawed. It becomes easier to conflate the problems within the system with the person with the disability. The problem seems as if it is my mom’s fault because she has a disability and we have to interact with this system because of that disability—this is a much easier conclusion to come to than ‘this system is fucked and needs to be changed’. The former is an easy conclusion to come to, the latter feels impossible to change and so out of reach for us to do anything about.

In the above example, we can begin to see the inescapable interactions we, as family members must endure as we struggle to get the benefits and services the people we care for need and are entitled to.

These interactions are an inevitable part of our lives because we care for and about people who are part of the long-term care system. In doing so, we embody an *ethic of care* while caring for and about (Glenn, 2000, p.86).
This example points to the difficult interactions people have with the system in general, not only when they are the recipient of in-home services. Below we will explore these interactions, both with the long-term care system in general, as well as when in-home service providers cross the personal boundaries into the homes of families in need of care.

**Ideology of the Individual**

The problem of the ideology of the individual\(^6\) presents itself as an extreme unexamined commitment to the individual that exists in the provision of long-term care services and is evident in caregivers’ difficult interactions with providers. In opposition to an *ethic of care*, individualism and thus long-term care services see people as “rational actors pursuing their own goals and maximizing their interests”, as opposed to treating them as people “enmeshed in relationships of care” (Tronto, 1995, p.142).

There was a clear point of departure for me while, in reading the scholarly literature about the life I was supposedly living as a family caregiver, it felt as though I didn’t recognize myself there. I wasn’t the middle-aged woman caring for aging parents, a partner or spouse. I was a twenty-something year old going to college and considering my future. I was also taking care of and overseeing the care of multiple family members—my mother who had been devastatingly injured during a brain hemorrhage, my grandmother who was in her late 80’s and my grandmother’s cousin and his wife. He needed dialysis; she had Alzheimer’s disease.

People would tell me that I was a good daughter, that I was smart and should pursue my education, but no one was engaging with me on a level consistent with an

---

\(^6\) Individualism has been heavily theorized by ethic of care proponents and theorists. See Glenn (2010), Kittay (1995), McKnight (1995), and Tronto (1993) for detailed discussions and critique of the notion of individualism.
ethic of care. That is, responding to our needs and actually helping me figure out what adequate care for my mother should look like or how I could go about both getting it and providing it so that I could actually do those things being suggested—go to school and have a “normal” life, while maintaining my relationship with my mother. Putting her ‘away’ in an institution was an option I was unwilling to choose. As will be shown below, caregivers would like to have care partners who would be as knowledgeable and caring about their loved ones as they are and be partners in providing care, making decisions and doing things in ways that have the best interest of the care recipient in mind, not relieving them from providing care to their loved ones, which is what caregiver services aim to do.

**Caregiver/Care Receiver Dyad**

There was a discrepancy between the way we were seen by others and the way I felt about life with my mother. I felt that we were a unit or dyad, “enmeshed in relationship” to use the language of an ethic of care; others seemed to think of us as separate individuals, whose needs were in opposition to one another. There was always a feeling that people wanted to, and at some times said, “put her away and go live your life, you will be better off.” That message was not one I was willing to listen to and it made me angry and resentful. I wanted to have my mother in my life and be in hers, even with the difficulties her injuries presented. The more time that went by without any help solidified in me the realization that to do this in a manner that was best for my family, I was going to have to do it on my own, with whatever help anyone offered to me along the
way, while allowing me the control\(^7\) necessary to provide care in a way that only I could, knowing intimately the wants and desires of those I cared for.

I remember wondering why no professional ever helped my mother parent me? If I had been 12 years old instead of 17, turning 18 when she got sick, would there have been some assistance provided to us as a family? As if parenting ceases when a ‘child’ turns 18. In reality, we know this isn’t the case, but in the world of service provision, with the focus exclusively on the individual care recipient, there is no acknowledgement of the individual’s place in their family, only an extreme commitment to ‘the individual’. I now see this as a major failure of the system to provide both my mother with help in being a parent, which is the thing that she loved most about her life, and to provide me with parenting from my mom, who sustained injuries that get in the way of her being able to parent me the way she would have had she not sustained her injury. The result is that I continue to do more to sustain our relationship and care for her than she does for me. I have come to realize that I long to have our relationship nurtured by someone other than myself and if she is unable, then there should be someone else to help her participate in our relationship, especially with all of the service provision she is currently receiving.

The example above provides insight into the artificial separation and lack of support at the family level because of services being solely focused on the individual. This is something that services could be better at- recognizing that individuals are embedded in families and helping to give people back their relationships (i.e.- parent/child, spouses, etc.) so their relationships aren’t ignored or become solely about being “caregivers” and “care receivers”, but also about engaging in other aspects of their personal relationships in reciprocal ways. We will see below the implications of this on household level interactions post-injury for family caregivers.

**A Triad: Paid Home Care Workers and the Caregiver/Care Receiver Dyad**

Another artificial separation occurs when there are paid in-home care providers in the homes of families where a person has significant care needs. Instead of being seen as a unit, each person is seen as an individual, not necessarily in relation to the others in the

\(^7\) Control will be discussed further as a caregiver response to services in chapter 5.
Talley and Crews identify a “triadic model of caregiving” which recognizes family caregivers, care recipients, and professionals as “caregiver teams” (2007, p.227).

According to this model, the strengths and needs of all three “care partners” are taken into account, each with associated needs as well as responsibilities. Here, the triad is shown to be influenced by social, political and scientific forces, the distal, that can either inhibit or facilitate the care situation (ibid.). It is unclear, but doesn’t seem to look at the
micro-relationships among people within the triad, but assumes that they are positive in nature.

Prior to discovering this triadic model, as presented by Talley & Crews, I had created a graphic to show the micro-relationships and specifically the flows of care between caregivers, care receivers and paid caregivers. Upon finding it, I was glad to see that my research, with slight differences in wording and meanings, basically confirmed the importance of framing caregiving in this triadic relationship. While the Talley and Crews figure shows arrows between all three individuals in the relationship, they do not provide a detailed discussion of the nature of these relationships. They stop short of a more detailed analysis and only say that these relationships can be impacted positively or negatively by structural forces (2007).

The simple figure I produced looks at the triad from the perspective of family caregivers and indicates, as per the findings of this study, that care often flows out of family caregivers to both the care receiver and paid caregivers, with little to no reciprocal care coming into the family caregiver from either of these other people with whom they are in close relation with due to the care situation.
While the nature of these relationships will vary with each triad, we currently have limited information about the importance and nature of these relational flows from the various perspectives of the different members of the triad.

Donelan, et. al., discuss the importance of the relationship between informal and paid caregivers and the difficulties involved in those relationships as important in caregiving situations (2002). Below we will see that more often than not, the “forces” surrounding the “care team” inhibit rather than facilitate care. The triads are of utmost importance because they are the people who enter the homes of the caregiver dyads and, as Kittay notes, “[i]n our dependency, we not only require care, but require a sustaining relationship with a care-giver who provides this care- for who does the caring is often as important as the care itself” (Kittay, 1995, p. 8). This signifies the importance of the various relationships that exist within care situations.

Figure 3: Triad Relationship with relational flows of care.
Relational Activities of Daily Living (RADLs)

With home care services in place, creating the above discussed triad, we can see how relational activities of daily living (RADLs)\textsuperscript{8,9} should be included along with ADLs and IADLs in order to have a more complete conceptualization of “caregiver burden.” We will see that these intensive relational activities are time and energy intensive, as caregivers are faced with having to manage new relationships with paid caregivers and service providers who enter their homes. These relationships can easily become an extra ‘burden’ on caregivers who, over time, become savvy in knowing that by nurturing these relationships the care recipient will be cared for and, in turn, they will be cared for if the care recipient is appropriately cared for. Here, the separation between caregiver and care receiver dissolves, as do many of the boundaries between the caregivers, care receivers and paid caregivers. This triad provides a possibility for all three individuals in the relationship to be mutually taken care of, providing that the management of this relationship doesn’t fall entirely on the caregiver to manage and nurture.

Currently, informal family caregivers and paid caregivers remain exploited providers of care whose needs are neglected within the long-term care system, but should be recognized and responded to accordingly (Glenn, 2010). While paid caregivers often receive very low wages for their work, family caregivers receive no remuneration for the care work they participate in. It has even been suggested that “informal care not only supplements professional care, but is a basic conditioning for the functioning of the organized health care system” (Milligan, 2003; ter Meulen & van der Made, 2000, p. 257).

\textsuperscript{8} See Graham (2010, p. 163) for an introduction of relational activities of daily living.
\textsuperscript{9} RADLs will be discussed in more detail below as a relational aspect of “caregiver burden” that is omitted from the current conceptualization.
If families and in-home providers were recognized and adequately supported within the triads they create, it would likely go a long way in creating a more caring environment for all involved. Here use of an ethic of care framework would recognize that all members of the relationship are interconnected and ensure that consideration be given to all involved in this complicated relationship. Relationality would be of utmost importance and each member of the relationship would have their needs acknowledged and responded to within the web of connectedness that makes up our human relationships.

Positive Aspects of Providing Care

Neglecting to acknowledge and include the positive aspects of providing care in the overall discussion of family caregiving is a subtle violence perpetrated against caregivers who experience both positive and negative aspects of providing care. Focusing primarily on the negative does an injustice to caregivers who give of themselves, but also reap benefits while providing care. Care is not a one-way interaction, but something we are all involved with through multiple relationships and throughout the course of our lives. To ignore the positive aspects of providing care within these relationships reduces our intimate relationships to “caregiver” and “care receiver” and does not acknowledge the totality and complexity of our human relationships, which vacillate between various levels of dependency and interdependence throughout our lives.

Living Together and Household Negotiations

While listening to and the stories of the lives of the caregivers I interviewed something slowly emerged that caused my thinking about their lives to shift. At first it
was elusive, but once I had identified the fact that ‘living together’ was a construct that the caregivers in this study negotiated in creative ways in order to get their needs met as best they could, it was then that the idea of space and place presented itself in various ways. As I simultaneously engaged in the analysis of my own life and the lives of the participants in my study, findings around notions of living together emerged and surprised me in ways I hadn’t anticipated.

There are household level tasks and relational negotiations that caregivers do within the home that serve the household- cooking, laundry, home maintenance, etc. With care recipients unable to contribute to the household in ways they could previously, these tasks disproportionately fall on caregivers. Currently, in-home services do not intervene at the level of the household to assist the person with the injury in being an active member of their household and relationships. This would contribute to the overall functioning of both the household and their relationships in ways that could benefit both members of the care dyad. This may in part, be due to services being developed under the ideology of the individual framework. Through an inclusion of an *ethic of care* in service development and provision care receivers could be assisted in contributing to their households, as well as actively engaging reciprocally in their personal relationships.

The following is a journal entry that was written in response to my being frustrated at being the main person in charge of household chores, even though I don’t live alone. There are tasks that fall to me, that if my mother was able to be aware of, would help with, but due to her injury, she is unable. It leaves me with questions of why I have to be the one to direct the household and take care of more than my fair share of the day-to-day tasks involved when my mother lives here too? If she lived alone, paid
caregivers would have the responsibility of helping her keep her home clean and cared for, but because this is my home too, much of the maintaining of it falls on me.

My space isn’t really my own and I don’t have control over it in the way most people take for granted about their homes. Not only do I have to arrange and order our home in a way that works best for my mother due to her memory challenges, but I’ve also realized that I do things such as always wash and put away the dishes before bed each night so that the in-home aide doesn’t come to a full sink of dishes in the mornings. This also allows us to follow the clues as to whether or not my mother has made her own breakfast in the morning. Because of the memory challenges, much of our lives are about solving mysteries. If mom’s cereal bowl and mug are in the dish drain when the aide arrives or I go upstairs in the morning, we know that she has had her breakfast. If these are absent, we know that we need to make sure she eats. All of this because within minutes of having breakfast, mom will ultimately forget and so asking her is futile. If dishes are left in the dish rack overnight, we may not know if she has had breakfast so each night I diligently clear the dishes whether I feel like it or not.

While the above example of clearing dishes is seemingly minor, it requires a complete dedication to a routine that interferes with simple activities like going to sleep early or leaving dishes in the sink if tired in the evening. As a housemate of someone with memory problems, this *simple task* can mean the difference between too much or too little food eaten. As food is a big part of taking care of someone, this seemingly simple routine can become a burden that interferes with the caregiver’s natural temporal rhythm of being within their home. It creates systems of organization that are ever present in the mind of caregivers. Here, home becomes a place where the caregiver must always be on, there is no longer a “backstage” for the caregiver to recharge before presenting themselves to the public world outside of the home (Goffman, 1959).

In addition, there is concern for the aide shown in the comment about clearing the dishes so the “aide doesn’t come to a full sink of dishes.” Here, I was acutely aware of not making more work for the paid caregiver, as I knew she was not there to do things for
me, such as washing *my* dishes, even if I did mom’s dishes, but she never did mine.

Through the presence of the home aide, the outside world entered the private space of the home and created new challenges as caregivers negotiate these relationships while losing privacy and personal space. This is important because of the extra work on my part of not making more work for mom’s aide. This was a residual effect of knowing that she was not there for me or us, but for my mother only. If we were, officially and according to the agency, more of a team, some of this extra burden might be minimized by all of us doing things for each other, as appropriate.

The recognition of dyad/triad negotiations begins to illuminate the complex household level interactions that must be negotiated by family caregivers. Living with a care recipient who receives in-home services means that the caregiver’s life is bound up with the home care provider in a way that otherwise would be reserved for intimate, chosen others (a live-in partner, roommate or spouse). The above example indicates an awareness that the paid caregiver is not around to assist other family members, as this isn’t her job. Sharing a household with someone who is unable to contribute to that household is something that takes a large toll on caregivers. This emerged directly through the interview process and is something that I was not fully aware of until engaging in this research.

The following chapters will elaborate on the above themes and discuss research findings in the context of the interview data. Chapters 4 and 5 will focus on the provision of services and responses to these services and chapter 6 will look more closely at the microgeographies of the homespace in relation to in-home paid caregivers interactions with caregiver/care receiver dyads.
Chapter 4: The Provision of Services

A day in the life…

Tuesday, April 28, 2009

3:30am- Tabitha\(^{10}\) calls me up to “fix her blankets”. Anastasia was confused and wanted her leg fixed even though it was as I left it a few hours earlier before I went to sleep. I shifted her around a bit and went back to bed.

10am- the troops begin to arrive:
Yolanda (aide)
Natalie (nurse to assess Tabitha for PT)
11:30- Irene (PT)- for Tabitha and Anastasia

Noon- Yolanda leaves for the day to return tomorrow from 10-1pm

1:41pm- message from Agnes [agency B] that home care hours will be reduced starting tomorrow from 3 to 2 hours and that a replacement for Yolanda will be sent.

I call back with a vengeance; I am not scheduled to be home tomorrow when the aid arrives and a new person in the house with no knowledge of the situation or Anastasia is unacceptable. Agnes tells me Yolanda can’t come tomorrow, I tell her Yolanda had said “see you tomorrow” when she left and had all intentions of being here. Agnes: “I’ll call you back”

I call [agency A] to complain, Nick will call me back.

I call the director of [agency B] (Rob: 123.456.7890). He will call me back.

Nick calls back and tells me that Elsa made the assessment that hours will be reduced beginning tomorrow, I say that it was my understanding that hours would be reduced starting Monday. He will call Elsa and call me back.

Rob calls back- he is in charge of the [agency B] TBI program. I tell him about the situation with Audrey (she works for [agency B], who is a provider under the DOH TBI Waiver that mom is on), he thinks it sounds like “a perfect solution.” He takes her name and I tell him he should be on the lookout for the NOD (notice of decision) from Albany. I also tell him about the situation with

\(^{10}\) All names are pseudonyms.
hour reduction starting sooner than expected. He is going to call the Branch Manager, Leon, and let him know what is happening. I should feel free to call him (Rob) back anytime. I tell him he will certainly hear back from me about Tabitha and beginning 12-hour a-day coverage with Audrey.

I call [agency C] to appeal (as per papers left by Elsa-nurse from agency A)- 000.123.4567. I say I want to appeal Medicare’s decision to reduce hours. Did we get a letter of non-coverage? “No.” We don’t deal with hour reductions, only non-coverage and termination of home care. “Call your doctor and get a letter of “significant risk” stating that more hours of home care are needed to ensure safety.

Call to Dr. Imani- tell his secretary I am fighting with Medicare and need a letter of “significant risk” to proceed. He will call me back.

3:40pm- Elsa [agency A nurse] calls (on her day off) to say that she heard there was a problem. All I said was that I spoke to a supervisor [Amy] and that hopefully it is fixed.

4:08pm- Agnes calls to say that she can’t get in touch with Yolanda about tomorrow. I ask if she heard from [agency A] about them keeping 3 hours a day for the rest of the week. No, “they are calling me now, I’ll call you back.”

4:09pm- “ok, they are keeping 3 hours for the rest of the week and 2 hours a day starting tomorrow. But I can’t reach Yolanda.” Apparently Yolanda had asked for tomorrow off, but told me she would be here. I have no idea who will show up at the house tomorrow and I am scheduled to leave for school in the morning before anyone shows up. Agnes leaves soon and will call me to let me know if she has heard from Yolanda yet about her availability for tomorrow.

This is all beyond ridiculous! Yolanda and I confirmed and negotiated about the schedule for tomorrow. I find it hard to believe that she wouldn’t tell me if she was off for the day.

4:21pm- Amy calls back to confirm that it will be 3 hours for the rest of the week and Yolanda will be the aide coming tomorrow and for the duration of home care. She apologized for the difficulty I’ve had today.
3 hours of my day was taken up and wasted with all this crap. I would like to keep track of all the hours I am putting into the coordination of these services and bill someone (but WHO?) for the time I’ve spent doing this.

5:18pm- Agnes called to tell me that Yolanda will not be coming back. Audrey? Maybe, she is trying to reach her.

5:20pm- Audrey will come tomorrow and be the regular for us from now on.

5:28pm- Call Dr. Imani- letter for Medicare? He said to have the nurse call him so he can try to influence Medicare’s decision about hours.

4/29/08: more phone calls

(the next day) 5/8/09

I got the NOD from DOH on Monday with a start date for HCSS of 5/4/09 (Monday). I called Agnes twice and she tells me today that Stella has not received the paperwork (from Nicole, I imagine). I call Nicole twice today to find out what needs to happen and what I might be able to do to move things along- she tells me she will be out of the office on vacation next week, but will call in on Monday to make sure the packet gets faxed to Stella (it was mailed, but she obviously has not yet received it).

Agnes calls again to tell me that [Anastasia’s] hours have been increased to 4 hours 5 days a week for next week. This will remain until PT is discharged (2 weeks?)

Elsa calls me to find out why Dr. Imani wanted to talk to her- I call Dr. Imani to tell him she will be calling again and to remind him he was going to try to influence the decision to have more rather than fewer hours of home care. I return Elsa’s call and tell her this.

How odd, Anastasia came home from the hospital with 3 hours a day home care (inadequate to say the least, but a help), it was reduced to 2 hours (hardly enough to make it worth it) and now she is given 4 hours a day because I told Natalie (nurse) and Irene (PT) that more help would be a big help. Go figure!! Be grateful, right? I think this goes to show how arbitrary the decisions are and how the initial assessment was incorrect- she should have been given 4 hours 5 days a week immediately after hospital discharge. At least all my work is paying off…
As is clearly shown in the opening journal entry of a family caregiver caring for two family members at home, caregivers contribute significant time and energy providing, coordinating, and managing care even when and sometimes because formal, agency-based home care services are in place. Not only is a lot of time and energy expended by the caregiver, but often more time and energy is required to obtain and manage these services than would be required to take care of the person themselves, without the disorganization, inconsideration and neglect families are subjected to through interactions with public benefits programs and service providers. This chapter explores the delivery of services and the nature of family caregivers’ interactions with formal service providers.

**The Procurement and Delivery of Services**

Home and community-based services (HCBS) are the focus of this project, as it is the predominant type of long-term care provided in the United States today. As such, it is important to understand the process by which people learn about, access and interface with the myriad services available to them. HCBS refers specifically to Medicaid services and while this project does not focus exclusively on Medicaid Services, HCBS-type services are also available to individuals through private insurance, as well as to those who have the ability to pay privately for these services. Thus, regardless of whether in-home services are in place and regardless of whether they are privately or publicly funded, caregivers are forced to interact with them, often in ways that are in opposition to what services under an ethic of care framework would look like.

Little is known about the “service mix”, the various ways that people meet their long-term care needs (Wysocki, et al, 2012). The combinations of care are often informal
(unpaid) caregiving (i.e. family caregivers), with some purchasing of services being paid for through a mixture of funding streams (i.e. public benefits programs (Medicaid), private insurance and private, out-of-pocket payments) and procured through either licensed home care agencies or through the “gray market”, which refers to the purchase of home care without using an agency. The gray market is often used because it is less expensive than hiring home care workers through agencies. As will be shown below, some families may prefer utilizing the “gray market” because they are able to retain greater control over the services and providers who work in their homes. This option is often discouraged by home care agencies, as there is no oversight of workers in the gray market as there is in the formal care sector. While the ‘service mix’ is not a focus of this project, it must be recognized, as it inevitably will come up in any work related to long-term home care. The various combinations of possible care providers, from informal family caregivers to agency-based home care workers must be recognized as part of this mix.

The following quote supports the suggestion which was made earlier, that social service institutions become conflated with people with disabilities who need care at home in ways that the system and people with disabilities become inextricably linked. As the family member discusses her difficulty in separating the work she does managing aspects of the long-term care system with caring for her partner, she has trouble separating the system negotiations from the direct care she provides. When asked how much time she spends with managing long-term care on his behalf, she responds: “I would say I have a minimum, [long pause] because it’s hard to separate caring for Cody and doing that [fighting with insurance and public benefits agencies to maintain insurance and benefits].
Both things are a 60-hour workweek, easy.” Here we see the impossibility of differentiating between care to the person and management of the system. It is this management of the system that remains in need of investigation and analysis to better understand how these tasks impact the overall notion of “caregiver burden”. This is explored in greater depth below.

**Ideology of the Individual**

Services are designed and provided to one person, the “patient” or “consumer” under the guise of individuality, assuming the goal of recovery, whether this is likely or not. This is problematic in the home when the individual doesn’t live alone, but is part of a family unit. Even as a part of HCBS, individuals aren’t seen as a part of a family (whether they are or not) and so services do not assist the individual in participating in the family or at the level of the household, as will be discussed in the next chapter. In terms of an ethic of care this is problematic because of the inherent nature of people as relational beings embedded in multiple and complex relationships. On the one hand, this makes sense because services are a continuation of the individualized notion of health and health care that exists in our society, on the other, this presents problems for caregivers, who are inextricably linked to the care receiver and are behaving in caring ways that are attentive, competent, responsive, and responsible toward the care receiver, but not getting this care back in a reciprocal way. We are falsely seen as individuals, existing on our own, but this is an artificial construct that becomes a problem particularly when the care recipient lives with a family caregiver. Problems arise out of the complicated interactions between the caregiver and care receiver dyad, as well as the caregiver/care receiver/ paid caregiver triad that is discussed below.
Caregiver/Care Receiver Dyad

Within the current discourse around relationships of care there exists an artificial separation between the caregiver and care receiver. This seems to follow from the ideology of the individual that exists in the provision of services to care recipients, as discussed in the previous chapter. When there is a caregiver present in the life of a care receiver, particularly when people live together, their lives are intertwined in relationships in ways that services do not account for. “…he’s my life…I want to make his life as good as possible and mine.” Here, this caregiver expresses wanting to take care of her husband in order to make both of their lives good. She doesn’t neglect either of them in her ideal notion of providing care, which is firmly rooted in and dedicated to a strong ethic of care. In another similar example, Rose discusses the lack of good options for her son’s care and the dedication she has to him, but also to her life being good.

It is very difficult, but when he was a child, I loved him and I wanted to raise my own child and it didn’t matter how hard it was, the options weren’t good, um, sending him away somewhere, that wouldn’t be good for him, he wouldn’t thrive, he wouldn’t have a good life and my whole goal has been to give him a life worth living and at the same time have a life worth living myself, but I come second.

Rose is dedicated to her child, but also to them both, in relation to each other, in terms of having good lives, even though she does put herself second to his life. This is an important point to keep in mind, the importance of mutuality in the caregiver/care receiver dyad and the importance of each individual to have a good life, as the provision of services and caregivers’ responses to them are explored below.

Instead of understanding the nature of the relationship shared by the care receiver and care recipient, services on the one hand ignore the interdependent nature of these close relationships, and on the other, assume that the caregiver will do a majority of the
myriad aspects of care, including household management and maintenance, even when services are in place, which will be discussed in-depth in the following chapter.

Often, service providers treat family members as if they are unwanted or that their presence is bad for the care recipient. “So the helping network wasn’t helping the family… but it made things lots harder. I mean, why did she push me out? … I’m a caregiver, I’ve got his back.” Here, a mother is clearly upset that a professional, who is supposed to have the best interest of the family in mind, alienates her as the caregiver, even as she is dedicated to the relationship with and providing care to her son. This lack of concern for the family unit can have devastating effects on family relationships, in particular the relationship between the caregiver and care receiver. We can see here how neglecting the relationships between caregiver and care receiver can be detrimental to this dyad.

Periodically, professionals understand the close relationships and interdependence between caregivers and care receivers and act accordingly. For example, in discussing a social worker “who gets it”, Alicia appreciates her understanding of her relationship with her partner. “…when I say ‘and about Cody’ she doesn’t say ‘don’t talk about Cody, this is about you’. What do you mean, it is inseparable.” In a similar positive interaction with a physical therapist who works with her husband, Rachel tells a positive story about the therapist taking her into consideration in relation to the care she provides for her husband:

The physical therapist that comes for him told me to get both of us a cane and worked with us on how to walk with a cane… so that I wouldn’t get hurt taking care of Lee and teaching Lee to use the cane.

11 Positive interactions with services will be discussed further in the next chapter.
In telling this story, she was clearly happy that the therapist had thought about her and was in a sense taking care of her as she cared for her husband. Instances like this were rare in the interviews, but when they were discussed, they were greatly appreciated by caregivers. Here, we see an ethic of care in action, as a provider attends to the caregiver and care receiver simultaneously.

With the caregiver/care receiver dyad being so important to the overall care of the care receiver, as well as a relationship in which the caregiver could also be nurtured, it is interesting to note how often this dyad goes unrecognized, undervalued and unsupported. If acted on utilizing an ethic of care framework, these dyadic relationships could be supported in ways that foster mutual interdependence, reciprocity and support of each individual within the relationship so no one is excluded or uncared for in the process.

**Interactions with and Management of Services**

As discussed in the introduction, the current conceptualization of caregiver burden omits caregivers’ interactions with formal service providers through the provision of community-based support services. The widespread assumption that caregivers lives are automatically made easier by the presence of services is problematized here, as we look at the nature of the interactions family members have with services as they provide care for their loved ones.

While the opening entry provides an insider’s view of what it takes to maintain and manage care once it is in place, there are various activities family members must do in order to learn about the available services, apply for and then manage them, if the person is lucky enough to be granted access to whatever service or entitlement program has been applied for. It is not uncommon for a lot of time to pass between applying for services
and either getting them or finding out, often by chance, that the care recipient did not get the needed service.

It’s taken longer than we thought it would. I mean he moved here in January and he didn’t start this program at [hospital name] until November, so almost a year. And that was like, I couldn't imagine how that much time had gone by.

Here the family member is making reference to a specialized program for people with brain injuries at a well-known hospital in a big city. They had not been told that the program they initially applied for didn’t take Medicaid and it was only after they had applied and waited for Medicaid to get sorted out that they discovered the program didn’t take it. This example indicates a lack of attentiveness on the part of the program and is in opposition to an embodiment of an ethic of care. The family needed to begin all over with the application process for another program, to which they would have applied sooner, had someone told them at the outset that the insurance would be an issue. In the end, they are waiting in limbo as to the direction life is going to take.

We had been applying, we had started the application process, oh god, I can’t remember if it was Medicaid or SSD or both, like even when he was still in rehab. One of the social workers was trying to get on that earlier, but yeah, so then that was still taking a while. And b/c he was rejected for Medicaid the first time around. The only way we found out was by going to the office. He hadn’t received a letter, he hadn’t received a phone call, but there was some record that a letter had been sent that said ‘we tried to call you’, you know, but there was never any call or any letter.

The above examples provide a glimpse into the complicated nature of home and long-term care services and the various points of complexity and confusion which can result from the myriad programs and providers making up the long-term care system, in addition to the extensive contributions to this system by unpaid, informal family caregivers. Below we will explore how the delivery of these services impacts the family unit and anyone who is involved in the life of the care recipient.
Trauma Inducing Services

For a variety of populations literature exists about social services re-traumatizing the people they serve (Edmund & Bland, 2011; Jennings, 1997; Poole, 2014; The Jean Tweed Centre, 2013). While there is no literature connecting re-traumatization of people with brain injuries or family caregivers specifically, there are examples provided overlapping with the findings from this research. Specifically, characteristics of services that result in re-traumatization which were discussed by interview participants in this study include aspects of services such as exerting power and control over the client, not accommodating the vulnerabilities of the trauma survivor, repression of emotions, being pathologized (i.e.-labeled), failure to listen, take seriously, or learn from survivors (conveys worthlessness), lack of mental health professionals who understand your experiences and can help you, protocols that make no sense and rules that are made and changed arbitrarily by providers (Jennings, 1997). The typical uninformed response to trauma by professionals, specifically ignoring and taking control, results from professionals being uneducated in how to respond to trauma. Due to a lack of training, the professionals, having an unconscious desire to protect themselves and not be effected by the trauma of others may unknowingly re-traumatize service users by leaving them alone, avoiding difficult discussions and problems or attempting to control the situation and/or family. It is this very behavior by professionals that further traumatizes people who need acknowledgement and support in dealing with the initial traumatic medical experience.

Trauma-informed services are offered as a corrective to the potential harm done to service users by providers (Edmund & Bland, 2011; Poole, 2014). It is of interest to note
here that characteristics of trauma-informed services, such as avoiding judgment, making appropriate referrals, acknowledging and discussing controversial issues, integrating various service provider philosophies, providing clear communication, and developing and maintaining flexible program guidelines all reflect aspects of an ethic of care (Edmund & Bland, 2011). In theory, these trauma-informed characteristics are attentive in that they appropriately attend to the needs of those they serve. They are responsive in that they react positively and are receptive to the needs of those they serve. They are competent in that they have the training, knowledge and skill to provide services successfully. And, they are responsible in that they have obligations to the people they serve.

**First Trauma: Initial Medical Event**

Brain injuries are the result of unexpected, sudden and catastrophic medical events outside of the typical life course or aging process. With the occurrence of brain injuries, there are losses of relationships resulting from the initial medical event in tandem with the near loss of life of the survivor. This loss is known to be devastating for families. However, it was not addressed with any of the families in this study during the initial hospitalization or recovery process (Degeneffe, 2001). If professionals’ avoid discussing the extent or reality of the traumatic nature of the injury with families, they will be unable to process the trauma they experience, leaving them open to emotional distress as a direct result of this initial trauma. With the initial injury comes the initial failure in terms of an ethic of care during a medical crisis involving brain injury.

Arthur Kleinman, a medical doctor and anthropologist, is known for his desire to bring the care back into medical care. In a personal story about being a young doctor who tried to “distract” a pediatric patient from “her daily confrontation with terrible pain”
he reflects on his learning from this mistake and the therapeutic value of his “connection” with her as a result of asking her to tell him what the pain was like (1988, p. xi-xii). The establishment of trust was essential for the patient as well as for the transformation of his avoidance of her pain and that “witnessing and helping to order that experience can be of therapeutic value” (ibid.). Here, Dr. Kleinman is speaking directly to the importance of an inclusion of an *ethic of care* in the interactions with people involved in extreme medical traumas in order to bring therapeutic value to them. The value of developing trust in interactions with providers is important to the inclusion of an *ethic of care* and will be discussed below.

In some cases it was interactions with the system and institutional failings and neglect, which family members believe created the conditions leading to self-inflicted brain injuries due to suicide attempts. In one case, the family believes that a doctor’s overuse of a variety of prescription medications led to her husband’s suicide attempt:

So the guy [doctor] put him on Welbutrin and other stuff, he had blood pressure medication and he gave him Risperdal and that was for his anxiety, it was supposed to help with his anxiety, only it made him worse, made him manic really. So then he doubled it b/c Lee would go and just say ‘yeah, I’m feeling better’ so they said, ‘well, if you are feeling better, we’ll give you more’. Within two weeks he…[details have been omitted to protect the identity of the participants]…And that medication, I really believe that medication did it [caused the suicide attempt] so did his doctors.

There was never any emotional support provided to assist with this initial family trauma, nor were medical professionals aware of how their behavior may have negatively impacted the family immediately after the injury. Instead of being acknowledged for experiencing a tragedy, hospital staff ignored this and even contributed to additional distress by being insensitive to her immediate situation. While at the hospital
immediately following the injury, a nurse insisted that she see the x-ray of her husband’s head, with an object puncturing his brain.

There was an ICU nurse who was gracious enough to show me the picture, ‘have you seen this? You should see this’. I thought, I don’t think I should see that, but why she thought I should see it, I don’t know …so he has a slice through his brain about that long…

This nurse, acting inappropriately and in a manner inconsistent with an ethic of care, adds insult to injury by showing her this x-ray of her husband’s brain. In another example of the mistreatment of families immediately following devastating injuries, a mother recalls an emergency room nurse yelling at her and blaming her for her baby’s medical problems:

The head nurse said to me that I caused a disruption in my baby ... she was yelling in a loud voice, yelling that I had done something to my baby and it wasn’t until other people saw and traced the heart rhythm and recognized that she was having seizures…the automatic default was that there was something defective in the parent. Defective child, equals defective mother.

In the above examples, this wife and mother were abused by the medical system during medical emergencies, which nearly killed their family members, as they were treated cruelly instead of with care and kindness.

In another case, a mother explains the moment she believes her son decided that he was going to commit suicide. She took him to a psychiatric hospital in an attempt to get help because he had told her he was suicidal. She recounts the negative experience,…we didn’t have very good insurance and he couldn’t stay very long. They had us sitting in a sterile, awful waiting room for 4 hours…had some social worker….ask some questions, had us sit out there some more and she came back and gave us a single piece of photocopied paper that had a men’s support group for depression in a town that was over an hour away that met once a month and said that should help. And so it was so discouraging… and I said ‘well, maybe you could be volunteering… you know I am desperate for him to try things to do and he says ’you know mom, I think that I know what I need to do and I’m going
to take charge of it’. And I thought that meant he was going to start getting invested and put himself out there. No, he had made the decision that day to kill himself because the service providers just blew him off. He had no option. He tried and tried to find help…

In this situation there were multiple instances of neglect. First leading up to the brain injury, as seen above. Next, when the family did not get immediate help to understand the scope of the injury, “we had no idea if he would come out of the coma, if he did whether he would be a vegetable, to what degree he would be able to do anything…” then finally again, long-term, when there were no home care services provided and the mother, when the decision that he was being sent home from the hospital was made, was told “…‘well, I guess you are going to have to quit your job’. Thanks, thanks, that was really helpful. She was a horrible person, to be so insensitive to what was going on in our life.” Here we see the how the medical system could be better at providing emotional support and collaborating with families facing life-threatening tragedies and the difference it could make with these families, especially in not feeling alone, abused and abandoned by the system.

Alicia clearly reflects on the compounding of difficulties caused by a “broken” system that creates additional distress instead of alleviating it during extremely traumatic life events.

Not only are you dealing as you know, with the actual injury and the person and the loss of your life and dreams and time and their craziness and trying to help someone, you are dealing with a system that is broken beyond belief.

Nancy also reflects on the traumatic nature of her partner’s injury. “Well, ok, so Walter’s brain injury itself, well, I mean, what happened to him, that was traumatic, I’d say.” She goes on to describe the beginning symptoms of a stroke, and being discharged from the
hospital after inappropriate tests revealed no problems. They were going to have more tests done the next day closer to home, but,

then, the next day, I mean, that was when our whole life was changed, completely…. he was my partner and now he isn’t anymore so that is hard and it took me a while to realize that this is going to be like this probably for the rest of our lives.

All of these examples speak to the unmet need for responsive, attentive and competent emotional support immediately after an injury such as this, with significant loss and the threat to life. It is these initial and longer-term interactions, emotional support and collaboration, which could be the difference between PTSD and post-traumatic growth in family caregivers, as is suggested by research specifically with people with brain injuries (McGrath, 2004; Sohlberg, 2001).

**Re-traumatization When Interacting with Service Providers**

One of the problems is when I’ve called the agency and I’ve tried to get them to say (pause) the rules were originally that they would send people out and we would interview them and we could talk to them and say, ‘this is what we want, can you do this?’ But, there is no interview process, not at all, they just get sent.

You call them up and they send you someone and when you say ‘I have to interview her’ and see how they get along together, they say ‘oh, well if you don’t like that person we’ll send you somebody else.’

Beyond services simply seeming to be an inconvenience, as shown in the commonly expressed examples above of in-home providers showing up without notice, evidence from this research revealed physical and emotional trauma responses as well as language steeped in traumatic experiences. This suggests that interactions with social services can be re-traumatizing for family caregivers as service users. For example, Rose describes the first providers, who came to her home soon after her baby, Nathan, suffered

---

12 We will see in chapter 5 the difficulties caregivers experience with service providers invading their homospace.
a severe brain injury as an infant. There wasn’t any acknowledgement of the emotional trauma she experienced when her son became ill.

They didn't call and say ‘we’re going to come’, they just showed up so I was trying to figure out ‘what are these people doing here?’ Do I have to have them come? Cause they would walk in and say, ‘well, what do you need?’ and I was going ‘well, I kind of need my baby to get better’ you know, that’s what I need and I don’t know how to make that happen, if it’s even possible?

Instead of meeting this mother where she was and discussing the difficult experience the family was faced with upon the near death of their son, they wanted to provide services before the family was ready for them. In a way, these services were forced upon this family in an insensitive way, creating an unhealthy power dynamic that favored the professionals instead of being responsive to the needs of the family.

The language of fighting, “you are fighting the world by yourself”, destruction, “they had a lady who was supposed to be working with the family, who was so destructive to the family that she almost ripped us apart”, lack of trust, and survival used by interview participants further indicate traumatic experiences. For example, in discussing how her partner gets his care needs met, Alicia states:

…if I don’t, no one else is going to do it and this person will die. And, it is hard for me to watch a human being that doesn’t need to die die and that is what will happen, they will die.

Rose also used language of survival in describing the experience of leaving her young son at a summer camp for the first time. “We just kept calling in ‘how’s he doing?’ … He was alive and that was the biggest concern.” In describing the difficulty in getting her partner’s needs met, Alicia has learned that,

[t]here is always a way. What you learn is very much like Ed Harris in Apollo 13, ‘don’t tell me what we can’t do. This is what I have, how’s it going to work? Because we have to save a life.
A preoccupation with death and survival is indicative of responses to trauma, as seen here. Taking this further, caregivers learn that they can’t depend on or trust services to provide the care necessary to the care recipient, as shown here: “they have to be with somebody you really, really trust and that’s really hard to find.” Finding responsible and trustworthy services was a difficulty repeatedly reiterated by the caregivers in this study. Furthermore, trust was easily eroded with families as service providers repeatedly behaved in ways that undermined the building of trust in these relationships.

Sevenhuijsen posits that an ethic of care presupposes an ethic of trust where trust is “letting other persons (or institutions like firms or nations) take care of something the truster cares about, where such “caring for” involves some kind of discretionary power” (Baier in Sevenhuijsen, 2003, p. 185). It is easy to see how lack of trust exists for caregivers who have had repeated difficult and traumatic experiences with service providers and the implications on this for the provision of care.

Brown takes the idea of trust further to discuss the notion of ‘bond strength’, the level of the emotional bond between caregiver and care receiver. In cases of high bond strength, caregivers may experience distress when having outsiders in to assist the care receiver (Brown, 2007). This may occur because people who are highly bonded may have greater concern with the needs of the other than of the caregiver’s own needs for assistance in providing care. In this case, having outsiders in to assist may cause distress in the care receiver and/or the caregiver, which is then avoided by the caregiver, as they express their empathy for the care receiver and lack the trust necessary to hand care over to a social service provider. In these cases, interactions with the formal care system may be avoided, as the caregiver provides as much care as possible without outside assistance.
Some people are aware of being traumatized by interactions with service providers and use this language directly. For example, Rachel discusses how traumatic it was for her to have providers in their home:

I don’t particularly want home care services, it has been nothing but a pain in the ass and a traumatic experience almost every time. I can’t even go into some of the horror stories. One of ‘em was sitting out here talking to me and he went into the bathroom and fell backwards into the tile tub and hit his head.

On the flip side of services being provided when they aren’t wanted, are instances where caregivers attempt to access services, but are abandoned in their attempts at support. Rachel tried again and again to get services for her husband, but in the end has experiences that make her question whether they are worth it. Below, we see Evelyn reach out, only to be left alone with her anxiety due to lack of appropriate services.

I couldn’t sleep and my heart’s pounding you know, my blood pressure’s out of control, ok and I just don’t know what to do and so I try to call the mental health line, the emergency one and say ‘I’m scared for him’ and they say ‘well, we’re going to have to file a police report’ and I say ‘I don’t want the police’ and they say, well either you have to file a report or hang up’ and I said, ‘I’ll hang up.’

We see clearly here, that these families were not supported when the caregivers reached out for help. Evelyn ended up opting out of what was offered during a crisis situation because it was inappropriate for what she and her family needed. Responsive and competent assistance was required, but all the professionals were going to do was inappropriately send police, which Evelyn knew would escalate the problem and make things worse.

Alicia states directly that it is the service providers who are more the problem than her partner, who requires care, “The services are the bulk of the problem. I don’t need respite from Cody, I need respite from these crises, these other things… Well, the services you provide are inadequate, poorly run and hostile.”
Furthering the evidence of interactions with providers as re-traumatizing, in another example of an attempt to access services, although it goes as it should, with all connections with the service provider going well, Eleanor experiences physical symptoms of trauma, as pointed out to her by someone who picked up on the emotional response she was having. This caregiver reflects on an experience of recognizing trauma responses she had after Tabitha had a minor medical procedure.

It was too much for me to handle and now, looking back, I realize that I have responses that are appropriate for traumatic situations. The problem is that they are so automatic now, that I have them at both appropriate and inappropriate times. Maybe not all together inappropriate, but not necessarily when a trauma is actually occurring. Unless interacting with the medical system is in itself a traumatic experience?

I was first made aware of my PTSD-type response when dealing with service providers by [name of professional]. After dealing with the social worker at [senior center] she pointed out that I was very emotional and talking fast. With that comment, I realized that I was breathing quickly, my heart racing and I was so stressed out, even though the interaction, technically, went as well as it could have.

Here Eleanor is referring to her attempt to access services at a local community center. She had a surprisingly “good” interaction with the social worker, who actually returned her phone calls quickly, which in itself is unusual. But in the process of trying to get a volunteer to visit Tabitha, she realized that she was opening the family up to “invasion” by the service provider. In order to access even basic services, the agency required an in-home assessment. As Eleanor asked questions she realized that they wanted to do this assessment alone with Tabitha, who has severe short-term memory loss. She became protective of her family and decided not to allow the assessment, and thus was unable to get a volunteer in for a social visit. It was at this point that she was told by someone who knew her that she was responding emotionally and realized that she was having a “PTSD-
“type” response that all began with this “good” interaction with the social worker. In this case, even when attempting to access services seemed that it would have been successful, the family would have had to undergo inflexible rules and assessments in a manner they were opposed to, which led them to opt out and so were left without simple, yet needed supports.

Caregivers in this study make direct references to torture, anxiety, fear of abandonment, and physical responses to re-traumatizing interactions. Using direct language of abuse, Elizabeth recounts difficult interactions while at the hospital as similar to a military detention center: “It’s like Guantanamo in a hospital and you also have to do the co-pays, like you pay them to torture you. It’s just unbelievable.” This was a description she gave in relation to doctors wanting to do emergency surgery on her son that she knew, based on his medical history, he didn’t need. The onus was on her to get old medical records to prove to the doctors that he wasn’t in fact worse than he had been, which she was able to do. But in the meantime, she felt trapped, as she was trying to protect her son from unnecessary medical intervention. We will see additional responses of protection from the system in the ‘Responses to Re-traumatizing Services’ section below.

Rose, who has been taking care of Nathan for more than two decades, discusses the difficulty she had with anxiety.

I always knew something bad was going to happen. Just one of the side effects of too much stress for too long and that was awful. It got to a point where I was suffering PTSD. Just always anxious, every little sound… we have this massive fire in our house in the middle of the night and we almost lose the kids and it’s just like always another thing, big huge seizure, a big you know, this. Always, uh, his wonderful teacher leaving and I’d have to start all over from scratch, staff who have been with me for years leaving, starting all over, always waiting for this other shoe to drop and tremendous anxiety. I don’t know so much that it was
depression, as it was anxiety and it came to be that I realized I was terribly paranoid about certain things.

She goes on to explain the dedication she expects from her paid caregivers:

one of my staff, she sits here during the meeting, several, maybe 10 years ago now we were at a meeting, a team meeting and she said ‘well, I just recently realized that when you come to work here you really are being asked to marry this family’ and I said ‘oh, you weren’t supposed to figure that out’. Because yeah, I don’t ever want you to leave me. If you come in here and come to work, it’s not a casual commitment, it’s not something that I’m willing to put in any time on you if you’re not going to just say you want to be here for a while and by a while I mean 5 to 10 years.

Here, we see a fear of abandonment and desire for people to stick with her in her life as a caregiver. Abandonment, as mentioned above, is something trauma survivors fear, and providers leaving people alone with their difficulties is common with providers who are not trained in trauma-informed ways. The result is that people are abandoned, which they fear, which perpetuates the trauma, instead of being sensitive to it and easing it.

**Lack of Humanity**

Supporting the thesis of this project, that there is insufficient *care* in the provision of services, family members often spoke of the lack of compassion with which providers in the health care system treated them.

What bugged me most was the lack of compassion, the um, the business-like way of dealing with these kind of things, that was the first thing and then something else, which I think, yeah, these people are, they don’t take a minute to let you know that they can somehow imagine what you are going through and the reason probably, is that they can’t.

She continues, saying that professionals should behave less “business-like” in order “to make you feel that somebody is actually thinking of you also.” Here we can see how an incorporation of an *ethic of care* could go a long way in helping family members not feel so abused in their interactions with the long-term care system.
Caregivers who were partners were often told to leave and abandon the person they care for when they got sick. One woman, whose boyfriend sustained a brain injury, decided to move in with her partner after his injury because she wanted to help him through his recovery. In the midst of her trying to figure out the best way to help him, and with the initial medical trauma ignored so also dealing with the difficult emotions involved with the change in their relationship, she was told by a social worker that she should leave him.

….he won’t be able to walk…so I said I have to see whether we can find an apartment where he can get a wheelchair and she was telling me people like that end up in a nursing home and she was basically telling me ‘get out of it’. She was telling me ‘get out of it now’…. Of course, I wasn’t ready to do that (laughing). I’m still not ready…

Years later, he is back to work and they continue to live together and enjoy their relationship, despite their challenges. During the interview she was laughing in disbelief when she said this statement because she was “amazed” that someone would recommend such a thing so early on in such a traumatic event. This woman, as well as others had many instances of being treated inhumanely during the course of their interactions with service providers. This is common and unwanted advice given to families, often soon after the initial medical event. Alicia was told something similar after Cody’s injury:

[j]ust get rid of them [social workers]. They have no clue what the caregiver of a brain patient is going through and their stupid platitudes and ideas, they all told me to leave Cody… ‘Take care of yourself first’, bite me…. It’s patronizing when they say it. The reality is, you can’t.

Elliott also indicated similar advice from a variety of sources, but ignored them “I love this man and I am completely devoted to him and I never felt that, I mean people used to say you know ‘find him a place’ and I wouldn’t hear of it.”

Parents are treated in similar ways, with professionals advising them that
institutionalizing their children is in the best interest of the rest of the family. Below, Elizabeth recounts being told that she should put one of her ill children in a nursing home:

One therapist had tried to get me to place [daughter] in a nursing home because she said it was going to destroy my family’s life to have her at home. You know, people really are amazing. They don’t say ‘how are you feeling, how are you doing, are you aware that there are options?’ Instead people feel the need to tell you the option they think would be best.

Here we see judgments coming from professionals about what they think would be best without being responsive to what the family wants and needs. During another part of the interview, in talking about what others think about how her family should live, Elizabeth was also amazed that people tell her things like “well, it’s time for you to boot him out” like, time to get on with your life.” Families in this study uniformly expressed disdain at receiving this advice, nor did they think it is appropriate. What they want and need is information about where to go for help and how to best meet the care needs of the care recipient, as a part of the whole family. They need care, operationalized.

The lack of humanity in service provision presents itself in many ways. Here Elliott is discussing her difficulty in hiring paid caregivers through an agency. “They had rules about what they could and couldn’t do, um and I can’t even remember what it was b/c it was so long ago, but they were very limiting and they weren’t about a human relationship.” Here, we see lack of flexibility; rigid rules, as opposed to flexible guidelines, as was discussed above in the characteristics of trauma-informed services, as a reason for not utilizing agency services. As we will see below, this lack of sensitivity to the “human relationships” that make up families in need of care are a shortcoming of in-home services that impact family caregivers and create situations where they feel the
need to tightly control the care of the care recipient, as well as protect them, often by opting out of service use from an insensitive system.

**Positive Interactions with Providers**

While descriptions of positive interactions with providers were rare during these interviews, there were instances when families reflected positively on interactions they had. When they did, it was usually because the people they were dealing with treated them with kindness and concern and as connected to the person with the injury, as opposed to an inhuman cog in the machine of the medical system. This was true even when the information being provided by the professional was incorrect, as evidenced by Alicia’s positive reflection of the kindness of a professional. “I was really happy and a really nice guy, [name of provider], told me that we could get Medicaid and food stamps and uh, transportation help and he was totally wrong.” In contrast to the incorrect information given to Alicia, Nancy explained a “positive experience” at an appointment with a service provider about eligibility, “we went there and went through it and then this happened fairly quickly [he was approved for services] so you didn’t have to nag, they were telling us the right thing so that was actually a positive experience.” Nancy indicated it was a positive experience because she didn’t have to “nag” or struggle to get what Walter needed. In addition to simply being kind, eliminating the perpetual struggles with the system provides caregivers with more positive interactions.

Evelyn’s positive experience came after a negative, traumatizing one with a social worker who was “so insensitive to what was going on in our life” that she needed additional advice. Upon contacting the head social worker for the rehabilitation unit her son was on, she had a wonderfully positive interaction that remains a fond memory.
… that woman had had a brain injured child and she understood and she told us about different places to go and she was kind and she didn’t make us feel scared. She gave us hope and that woman was wonderful.

With services that were provided at home, there were some indications of positive interactions. Elizabeth mentions her son’s helpers in a positive, but mixed tone: “there were therapists who were amazing helpers, who saw we were in this as a team, but there were other providers in the house who I really felt were mischief makers…” Here, as in the above example, the positive is mixed with the negative, indicating the “mixed bag” that in-home services are for families.

It was a mixed bag [in-home assistance] and has been all these years. Um, at a certain point, I had to say ‘this is way more than I can do, it’s more than our family can do’ and so I’m really glad for the help. As above, not being fought against was another reason people indicated that an interaction was positive. Alicia, in referring to arriving at the hospital after visiting hours was relieved when “[t]hey would actually let me in to see him, that was very nice, because I couldn’t make it at any other time.” She worked several jobs and couldn’t get to the hospital during visiting hours. For this entry without a battle, as many things were for her, she was grateful. This is a case where the hospital was responsive to individual needs and flexible with their rules, which had a positive impact on the caregiver. Here we can see how an ethic of care was present, as the hospital was attentive and responsive to the needs of the family while both were caring for the patient.

These positive interactions indicate that it is possible for families to be treated kindly in their interactions with the long-term system and the professionals who work in it. While rare, the examples provided indicate that it really doesn’t take that much beyond care and consideration for people to reflect positively about interactions with
providers. As seen above in the caregiver/care receiver dyad section, it is possible for caregivers to be attended to in relation to and along with the care receiver. The ultimate recognition of and care and concern for the dyad translates into support for the individuals in relation to one another, as opposed to only the individual to whom the services are directed. We can see how the framing of service provision under the ideology of the individual is problematic and often leaves the caregiver feeling undermined, excluded and even pushed out of the relationship of care. Recognizing the importance of the dyad and responding to it could have a major impact on how services are provided and experienced by caregivers.

**Support, Not Services. Services, Not Support**

As seen throughout this chapter, it was common for the families to be receiving services, but not necessarily support. This was reported to be the case in all of the families in this study who received in-home services. The notion of the ‘savvy caregiver’ emerged here as some caregivers were aware of and eloquently described their ability to know what needed to be done and how to go about getting the care recipient the care they needed so they could be relieved of the entirety of the care.

I’m a caregiver extraordinaire and I know it, I’m good at it … I’m so good at it and I know just what to do… I know how to talk to a doctor and not be intimidated, I know how to call a doctor and say ‘this is going on, what should we do’, I know how to arrange the environment for success.

The four most savvy caregivers were those who had been providing care for the longest amount of time and also retained high levels of control of the care, including hiring and training the paid caregivers. These caregivers only minimally expressed the sentiment of services, but not support, especially in cases where the paid caregivers were with the family for long periods of time and/or paid by the caregivers directly. These caregivers
also expressed involved and intricate relationships of care that took the paid caregiver into account as well as the care receiver.

Services, not support, was also indicated to be a reason why one family who didn’t receive in-home services chose to avoid them.

I know that many of the caregivers [from the support group] have aides, but the aides don’t show up always or they get sick or they don’t want to work and they leave so I said ‘no, I don’t want any aides 24-hours.’

This example indicates that caregivers don’t want to even attempt to engage with services, as they have heard too many stories from other caregivers about the difficulties they face when using them.

While all caregivers in this study discussed this lack of support from services, there were instances when they discussed support in daily life as coming from people other than professional service providers in the health care system. “It’s like from the weirdest sides where you get support, not from the health professionals.” Some of these supports, that might be considered “amenities”, like a doorman, were discussed as necessary to keep the care receiver safe.

I’ve got a doorman here so when Cody goes downstairs delirious they stop him or when he wanders off they tell me which direction he went, if they can’t [stop him]. I’m working two jobs I come home at 9:30, Cody is sitting in the lobby of this building, it’s July, he’s got a jacket on and his face is covered with blisters. I was like ‘oh god, no’ and he’s delirious. So, and thank god this building has doormen cause they wouldn’t let him leave… I don't consider it an amenity. I need that.

While not a service, this is an aspect of daily life which has the potential to make a difference and provide some safety net to the caregiver knowing that there is someone at home to keep an eye on the care receiver in case of an emergency. This is a case of an
individual going above and beyond their professional role, and providing significant support in the process.

Food was mentioned both as a form of support, but not services as well as in discussing services, but not support that caregivers received. As expressed by Nancy, food provided by friends and neighbors was very helpful. “The most helpful things were when someone would do something that they think ‘what would she want?’ And then someone brings me some food and I didn’t have to ask for it and that was better.” In-home paid caregivers not feeding the care receiver came up several times in terms of services, not support that involved family caregivers having to prepare food and feed the care receiver even when services were in place. Elliott reflects on this: “they did nothing except be with him… well they fed him lunch, but I did the cooking everyday.” This lack of food related support was reiterated by Rachel: “[t]hey are supposed to be able to prepare a light meal, but that doesn't mean that they’ll cook or that they’ll fix Lee a sandwich or that he’ll eat it. A lot of them won’t do anything like that.” Here, food, a major aspect of providing care, is an area of difficulty, which was not often helped by the presence of service providers.

Sometimes this kind of support came from home care workers when the worker did things that were above and beyond the duties of their job. For example, the following shows the appreciation of the additional support provided by an agency employee who was staying to provide additional support upon a hospital admission.

We went to the ER and got there about 8. [PM- the time the aide’s shift was supposed to stop working]. She was still with us. She would stay, even though her shift was over and she wouldn’t get paid for it. Her husband would pick her up later. I wanted her to go home because she deserved it, but I was also so glad she was there with us. A comfort and bit of help, so we weren’t by ourselves. She left at 10pm.
The aide being at the hospital with the patient is something that is not allowed under this program. When a person enters the hospital, the home care staff is no longer paid, and are supposed to inform the agency and stop working immediately. In these situations, where the worker is hired through an agency, the worker is at risk of losing their job and the care receiver of losing their services, because the worker is going beyond the scope of her duties, but it is in these caring relational spaces where family caregivers feel supported and not abandoned, as is expressed here. In this example, we see care on the part of both the paid caregiver, in staying at the hospital to provide support, as well as from the family caregiver to the aide when she states that “I wanted her to go home because she deserved it.” Some realization of the different flows of care within the caregiver/care receiver/paid caregiver triad, along with the facilitation of this kind of caring relationships between families and the home care workers can go a long way in helping family caregivers feel truly supported in the work that they do. In this example, the service transcends simply being a service, and becomes a caring relationship in which there is humanity between the people involved. This kind of caring personal relationship acts as a corrective to the problem of lack of humanity present in service provision, which was discussed above.

**Conclusion**

This chapter has explored the provision of services within the long-term care system and presented the problem of the ideology of the individual that is present within home care service provision. Trauma-informed services that are compatible with an ethic of care framework are offered as a corrective to the current nature of trauma inducing services offered to people with brain injuries and their families in the long-term care
system. Specifically, services developed and provided under an ethic of care framework could intervene to reduce the burden caregivers face in interacting with providers on the care recipient’s behalf.

As we have seen in this chapter, these families were often treated badly and traumatized by interactions with social services. We see also that they often found emotional support in places outside of the formal service sector. The ‘support’ that they describe is tangible (people providing food, doormen not letting a person wander) and emotional (professionals “getting it” and treating them kindly), but was not often found in in-home services unless the caregiver was savvy and intimately and actively involved in nurturing and sustaining the relationships between the caregiver dyads and triads. It seems that the nurturing of these triads offer great possibility to transform inadequate and neglectful services into services that foster connections and care among those most intimately involved in these relationships- the care receivers, the family caregivers and the paid caregivers, simultaneously.

Not all caregivers have the luxury of the time required of them to nurture these relationships to the extent that many in this study have. These ‘savvy caregivers’, with a combined 80 years of caregiving experience, have learned what they must do in order to have the care recipient’s needs met, and for them this can be both rewarding and “an extra burden” they must tend to, while being utterly exploited by the medical system. The next chapter will provide a discussion of the responses by family caregivers to the re-traumatizing system.
Chapter 5: Responses to Re-traumatizing Services

What it feels like is, you don’t want to help us. None of these organizations really want to help us. They want us to go away. Be helpful. What’s the change, what would I want in my perfect world? That the organizations that are supposed to help me are helpful. Social workers - re-educate them.

Throughout the interview process there were many themes that emerged when caregivers spoke about their interactions with the long-term care system and social service providers. As I listened to the narratives, I realized that the themes had something in common - each of them was a response to something specific beyond the difficulties they were experiencing with the care recipient’s injury. The responses were not directed at the person with the disability, but rather toward the system they were trying to get help from. As one participant stated directly, “the services are the bulk of the problem. I don’t need respite from Cody, I need respite from these crises, these other things… the services you provide are inadequate, poorly run and hostile.” In the following section I present the following themes that emerged from interviews and are related to caregiver responses to traumatic experiences with the system: management (of services and the system), control (of the care of the care receiver), protection (of the care recipient) and ‘opting out’ of services.

Hypervigilance, an alteration in arousal and reactivity, is a documented response to trauma and was present in many of the caregiver responses to the provision of services and care of the care recipient (American Psychiatric Association, 2013). Especially in terms of control of the care of the care recipient and protection of the care recipient from inhumane services and even from death itself, as is seen below. I discuss below the responses by caregivers to the difficulties they experience in interacting with the social services system.
Management

Caregivers in this study reported significant levels of care and responsibility despite the use of paid in-home services. Furthermore, significant management of these services is required because these formal services are in place. This adds another dimension of care that is required of family caregivers, but not adequately accounted for in the literature. In addition, we see how an ethic of care is present in the caregivers care of the care receiver, but absent from the provision of services these families receive. This speaks to the unquestioned assumptions that when services are in place, caregivers have reprieve and also problematizes the delivery of home care services as well as in-home respite services, which are a main service designed to give family caregivers breaks. With respite services essentially being the same in-home services available to people who need home care services, they often fail to actually provide this much needed break due to the extensive work involved in accessing and managing these services by caregivers. Here exists a paradox; services are offered to provide support, yet management is required if they are to work. As indicated in a quote above, Alicia didn’t want respite from Cody, the care receiver, but from the problems with the system that she routinely faced. In addition to the management aspect involved, respite services, being developed as home care services have been criticized for not providing the respite they intend. It has been suggested that respite be viewed as an outcome, rather than a service. (Chappell, et. al., 2001) All of the caregivers in this study indicated high levels of day-to-day management of services and benefits. The families without in-home services managed the overall benefits on behalf of the care receiver, and those with in-home services managed those services as well as the benefits the care receiver is entitled to.
Elizabeth, the mother of a young adult with a serious brain injury speaks clearly throughout the interview to indicate that she is the person who manages her child’s care, even though there is significant paid care in place.

Right, so I’m clearly the service coordinator… he had really good case managers. I still was always the service coordinator, but they were nice people who were clued in. When he switched to adult services, we went through 9 case managers, 9 service coordinators in 18 months. They kept quitting. It wasn’t that they just quit us, they quit the profession, they moved on, someone stole, someone, whatever. Recently, I’ve changed service coordinators and gotten this young woman, who I think at least is open to helping me recruit other young people. So, whereas she can’t do almost anything else, she can help me with that, so I switched to her. We’ll see... We are unbelievably lucky that our financial situation is that I can be the unpaid service coordinator.

Another mother, Rose, refers to herself as the “manager of the program.” She has coordinated care for her son throughout his life and estimates her weekly management time to be

…probably 80 hours a week. I figured I was working 16 hours a day, minimum and sometimes more than that depending on, b/c I was always there even when the staff was there” (emphasis added). There are scripts that they have to learn: ‘touch me gently’, ‘first this then that’. Tell him what you want him to do, not what you don’t want him to do. There are strategies, that’s all broken down in that nice little 100-page book and they have to learn all that stuff. It’s totally different and so for me as the manager of the plan, I have to, in this field turnover is every couple of months, you don’t have long-term staff. I’m way out of the realm of normalness because I have staff who, Eve (paid staff) has been here over 20 years…

The 100-page book that she references is an extremely detailed instruction manual on each and every aspect of her son’s life, abilities, deficits, etc. Over the years she has added to this manual and updates it regularly based on changes in her son and his situation. It contains very specific instructions on how to handle myriad situations which could literally be the difference between life and death for him. All new staff read this book as part of their training and she regularly spends time working with staff, new and
old, on training, especially, in relation to every detail and nuance of Nathan’s special needs.

The management Rose has provided to her son through his life is consistent, but also always changing in that she never knows when there will be an emergency of some sort needing attention. She mentions that staff turnover is high, but also that she has had paid staff for many years. When staff leave and she has to hire someone new, it takes months to get Nathan accustomed to a new person, but also it can take staff years to really get to know her son in the way needed in order to meet his care needs. Each time someone leaves, Rose is left to find and train a new person so that Nathan will have suitable care. These instances of staff turnover or illness and things such as agency policy changes that can impact his care are unpredictable and so she is always on edge, “always waiting for the other shoe to drop.” Even when things become routine, she is preparing herself for the next emergency or next time that she will have to drop the rest of her life to tend to the management of Nathan’s life and care.

Elliott, a spouse, talks about having respite services come in so she could go to work. “They did nothing except be with him. They didn’t change his diapers, they didn’t shower him, they didn’t, well they fed him lunch, but I did the cooking everyday, I did everything in caring for him.”

In addition to paid caregivers not providing the appropriate supports, participants described in-patient settings as being problematic, as well. This is important because in-patient care is also viewed as a respite service, with family caregivers being encouraged to use these in-patient settings (nursing homes) as temporary respite so they can get breaks. Below we see that even when the care recipient is in a facility, the caregiver is
required to manage the care of the person when they are in-patient in order to avoid serious problems. Below Rachel discusses the inadequacies of both in-patient and in-home care provision.

So one reason we don’t have at home services, I’ve gone in the hospital several times with surgeries, I’ve gotten sick since I’ve been a caregiver, serious sick. They are not allowed to take his blood sugar, they don’t make him eat, they let him sleep, they don’t give him his medicine on time and he’s almost gone into a diabetic coma low glucose, twice …. Even when he was at the nursing home I heard him very confused and called them. Called the nurses station from my hospital room. I had this much of my colon removed a year ago. I said ‘my husband’s very confused, are you taking his blood sugar?’ They said ‘it says three times a stay’. I go, ‘it should be three times a day’ and they go ‘oh, that intern wrote that’. I go ‘that intern wrote that wrong, would you please go down and check it?’ and they did. It was 45…. it took them a week to get it up to 100. They go ‘he won’t eat a snack’ I go, ‘this is what you want to do’ I’m telling them this from my hospital bed, ‘you want to take some applesauce and just spoon it in his mouth. He’s gonna tell you no, he won’t if you just say ‘do you want to eat?’… he’ll say no. I say ‘you just start chatting with him, he’s very friendly, very outgoing’, you saw that. Just take a spoon, put it in his mouth, he’ll eat it, just keep chatting and then eventually he’ll start eating it.

From the above example, we can see the difficulty in interfacing with services and the extensive management required of caregivers, even when the care receiver is in an in-patient setting. Although providing care at home is difficult, one can see the appeal of not wanting to manage services, in addition to providing direct care to the care recipients. This is particularly problematic, as in-patient settings are offered as respite for caregivers, but if their experiences with these settings are negative, they will be unlikely to trust that they can depend on them when necessary. Due to past experiences like this one, Rachel has decided that she can’t leave Lee in these facilities to be properly cared for. Not only does she no longer take vacations to visit her family, but, of even greater concern, she has neglected her own health because she is unwilling to admit Lee to these institutions for fear they will not adequately care for him.
In addition to the lack of trust that Lee would be taken care of, she mentioned that this option was no longer available to her because he had recently been hospitalized for a fall resulting from a home care worker moving a piece of furniture in the bedroom. He was in the hospital for another concussion and said that he wanted to kill himself because of the damage to his brain. The hospital admitted him to a psychiatric unit due to his statement. The next time Rachel called about having him stay in the nursing home so she could go visit family, she was told that “because he had been admitted to the psych unit that he was no longer medically stable therefore they couldn’t take him.” Here, a fall that was caused by in-home service providers ultimately led to her options for alternative care being severely limited. In the end, without assistance, she is again left alone to care for her husband, as well as to figure out how to get the needed help, which at the time of the interview, they were not receiving. Rachel indicated being tired and throughout the interview vacillated between wanting services to be available yet recognizing that they often make things more difficult, as opposed to making things better. An ethic of care is absent as professionals’ lack of response to the needs in their lives has become standard practice.

**Fudge Factor**

I work it so that I can get what I want, which is what he needs and I figure out how to do that and I’m smart enough to do that and there’s only been maybe a couple of things that I haven’t prevailed on over his lifetime and it’s really shocking to me when I don’t prevail.

While managing the services of the care recipient, there are many methods people may use in order to get the needed services for their loved ones. Among them may be developing meaningful relationships with professional care providers or manipulating services in ways that are not allowed, but that make the conditions for meeting the care
recipient and family’s needs possible. Rose spoke at length about the dizzying task of managing her son’s care and the lengths she must go to in order to make his services look like one thing on paper, but another in practice. This is because what he needs is greater than what he is eligible for and so she must do a “big mathematical equation” in order to manage his services in a way that provides him with the care needed, but at the same time adhering to State and service provider rules and regulations.

One approach to this “massaging” of the system or the “fudge factor” utilized by families may be including professionals in their creative arrangements in order to get what they need, but not sharing too much information, as to put the provider in a compromised position. This may be essential, as the professional, if sympathetic, may be useful to the caregiver in helping to determine what information must be passed on to the State or other entity ultimately in charge of making decisions about the services the care recipient will receive. Caregivers must determine what information must be shared and which is best omitted. There is a range in how much ‘privileged’ information is shared with professionals. This sharing is not done impulsively, but with much caution and contemplation, as it has the potential to cause trouble for all involved.

Rose, protecting the agency care manager from knowing the complete truth, so as not to put her in a compromised position by sharing too much about how the family goes about getting the care necessary for her son, shares some, but not too many of the details about what she “fudges” to get the services he needs to remain at home. “I made one for her to look at [false schedule] and I didn’t have it totally, I’m not going to put her in a compromised position.” The many layers of potential trouble caregivers could get into by “fudging” in order to get what is needed, weigh on the heads and hearts of the
caregivers as they walk a tight rope between getting the needed care for their loved ones, and maintaining the right balance between secrecy and disclosure to attain their goals. If they were discovered, in-home workers could be fired and services could be lost.

In Rose’s case, attaining her goals includes making two different weekly schedules, “actual” and “reported”, for the six paid home care workers who provide his care under her close management. In this instance, she does not want the agency supervisor know the extent to which she massages the truth in order to ensure her son, who is eligible for only 23 ½ hours of home care, actually gets 24- hour coverage, plus necessary (but unpaid by the program) overlap hours, in which the people beginning and ending their shifts have at minimum a half an hour of overlap with each other. This is necessary in order to complete required paperwork and ease away from the young adult slowly, as he has severe disabilities requiring very specific forms of interaction and communication in order to sufficiently and safely care for him.

It is a big mathematical equation… we call them the maps. This is our map [showing me]. We have one for the first week and one for the second week. This is the second week and I pretty much do it and then version 2, version 3, version 4.

These “maps” are color-coded weekly schedules that are mind-boggling to see, let alone understand the complex mental gymnastics done by this mother to ensure that her son has 24-hour care, including two workers at the beginning and end of each shift.

Here, Rose is the protector of many people- herself, her son and the workers she is protecting from the truth so they will not get in trouble because of the methods she used to receive sufficient care for Nathan. Care flows from Rose in many directions as she also engages in self-care by getting her son the care he
needs so she doesn’t have to care for him. Here, appropriate care for the care recipient results in care for the family caregiver as well. Within an ethic of care framework, self-care is the basis from which all other care emanates. Rose attempts to maintain coverage for her son so she is able to provide herself with care as well. She expressed that she would be unable to care for Nathan alone and has dedicated herself to managing and maintaining his services and providers at all costs. Here again, we see that it is impossible to separate care for Nathan and care for Rose. When he is cared for, she is cared for. This is an important point, given the discussion of the lack of care with which the larger system operates.

In other cases, both family caregiver and paid caregiver “do creative things” which are not allowed through the home care agency, but are done anyway in order to make the care situation work for all of them.

There are things we do that aren’t allowed, but that work for she [paid caregiver] and I. I feel like it is a team effort and I help her and she helps me, but I think our arrangement is not typical. I buy her things and try to consider her in our daily lives. She will prepare medication and even keep her overnight when I’ve travelled, which are not allowed by the agency. I know that she will make herself available in an emergency if I need her, even if the agency tells her to go home because we have discussed that. We do creative things that work for us, but not without risk. The agency calls to take attendance and we have creative ways of dealing with that if I’ve given her the day off so she will work when I need her, but outside of her regular hours.

In this example, the caregiver is acutely aware of the time and energy spent nurturing the relationship with the paid caregiver, but also of the problems that could arise if the agency found out. As in Rose’s case, great lengths have been gone to by the aide and caregiver to negotiate care in a way that is useful and accommodating of both caregivers’ schedules, even though, according to the ‘official’ schedule, there is no room for variation based on actual needs which change from day-to-day or week to week.
Control (of the care of the care receiver)

The family caregivers of people who had in-home services and had been in the role of caregivers for a long time, ‘savvy caregivers’, indicated control of the care recipient’s services and care to be very important to them. “It was very difficult, but I was in charge and that has always been the most important thing to me, that I get to be in charge of his care.” Rose, who we see above providing significant care in tandem with paid caregivers, also indicates the importance of control to her. “The only reason I can do it is b/c I am doing the whole thing. I’m in charge and I don’t want anybody coming around and checking me out either.” She reflects on when she had to “rise up” and take control of an otherwise out of control situation:

it’s just torture and I had to, and all these people were coming in, it just did not work for me in the beginning and I had to kind of get to a place where I could just grab it and dominate and become, I don’t mean dominate in a negative way, but rise up, I had to rise up to handle what life gave me.

Here, she speaks of the control she needed to develop so she wouldn’t be crushed by the weight of the responsibilities. In relation to having professionals in her home, she had to take control or else be dominated by them. This indicates a survival mode she entered into for self-preservation, furthering an indication of responses to trauma. Literally, she goes on, “…or be killed by it, yeah, it was either going to do me in or I was going to rise up and conquer it.” This is an extreme example of control by a caregiver whose life has ultimately been full of anxiety and beyond control in such a way that in order to manage it and survive it, she needed to “dominate”. Here we see control as a coping mechanism and response to services not providing her with the support she needs so she has to dominate them in order to get what it.
The issue of control came up for people who managed in-home services, but not to the degree for the caregivers of people who did not receive in-home services, but whose interactions were with the larger long-term care system. They made it clear that they were the ones in charge and were committed to maintaining this control in order to get the best care for the care receiver, as well as to keep them safe.

Although control of the care of the care recipient is highly valued, it also presents another aspect of extra work for the caregiver. Here Elizabeth describes the difficulty in using services through a Consumer Directed Program, which are characterized by high levels of patient and family choice in the provision of services.

But that’s it’s own extra burden because you’re recruiting, you’re, luckily, with each of the programs, the fiscal intermediary with CDPAP and the fiscal services for CSS through OPWDD, they will do the background check, the fingerprinting and make sure they don’t have a criminal record, but everything else I'm doing. You know, checking references and training them, all of that I'm doing, but then it’s more specific to him.

She acknowledges both the negative and positives involved in using this program. On the one hand, it makes more work for her; on the other, her son receives more individualized care that is specific to Evan’s needs.

In contrast to the families with in-home services who maintained close control of the care of the care receiver, Andrea clearly expressed not wanting to take control of Tyler’s interactions with the long-term care system.

You know how some people are kind of like, just take control? That’s not my style, it wouldn’t fit with him so he does what he can, but then he forgets… I feel like I’m not doing as good a job at managing this other stuff and I’m leaving it to him, but that’s not really a great solution either.
Here we see Andrea’s guilt over not doing a “good enough job managing the services piece”, but also not wanting to do it, and so struggling with what she wants to do versus what she thinks she should be doing.

**Protection From the System**

As the caregiver becomes a buffer between the care receiver and others, caregivers take on the role of protecting the care receiver from all things, which could possibly go wrong in life. Sometimes this protection is from the symptoms of their brain injury, from the medical system or, even from death itself.

As seen above in the ‘fudge factor’ example, caregivers sometimes also protect the service providers so as not to implicate others as they do what is necessary in order to receive the needed services. In this role, caregivers become the vessel for anxiety and worry and take on more than their share for themselves and the care recipient. Some of this protection may be the result of the system-induced trauma that caregivers have experienced, as discussed above. When the traumas are not resolved or worked through, but ignored, hypervigilance to prevent future traumas (their own as well as the care recipient’s) becomes a way of life for caregivers who use the language of survival and torture to describe their daily lives. Rose’s dedication and hypervigilance of the maintenance of Nathan’s home environment indicates a level of protection she aspires to always. “Every little detail about what it means for him to be successful in an environment has been thought out and how he can do it as independently as possible.” It is her insistence on the control of his environment, which keeps him safe at home.

Protection takes on many forms. Below, Elliott shares her fears about Thomas ever having to go to the hospital.
He’s had his incarcerations in a hospital and he will never go to a hospital again, whatever it is, we are going to deal with it at home. I mean he is almost 85 and he is terminally disabled with dementia so what is the point anyway of going to a hospital, I mean for what? They torture old people with dementia there.

Elliott is discussing the lengths she goes to in order to protect her husband, Thomas, from the medical system. “My dread is that he will fall in the street and somebody will call 911.” Because she has a paid caregiver who she has hired privately, she can do things like make the paid caregiver Thomas’ proxy in case something happens when they are out in the world. However, she knows the need to closely control his care and that “if I had an agency, it would be impossible.” She knows that the only way to maintain control of her husband’s care and keep him safe is to avoid services over which she would not have control, such as those provided through an agency.

Sometimes protection is seen as a negative thing, as in this case where Alice, the mother of Aida, an adult, shares her reservations about protecting her daughter too much. “I feel that I protect her a great deal and um, and that I am not encouraging her growth, I’m aware of that.” Here, the residual unresolved trauma of the initial accident, where Aida was a victim of a hit and run accident, combined with a lack of appropriate professional supports, may not be allowing her to feel free of the need to protect her daughter. Further, she expresses great anxiety throughout the interview about what will happen to Aida when she is no longer available to her.

**Opting Out of Services**

We can see how even when services are in place, a majority of the care still falls on the family caregivers, and how the frustrating and time consuming interactions with service providers makes opting out of receiving services seem like a reasonable alternative. With an estimated 80% of long-term care being provided by family
members, up to 90% of it without outside assistance by formal providers, we can see why family caregivers might “choose” to do it alone, instead of putting up with the “logistical bullshit”, including the vast coordination of services required by families in our current health care system (IOM, 2008; National Alliance for Caregiving, 2015).

Structural violence refers to the systematic ways social structures harm or disadvantage individuals. While structural violence can be directly violent and lead to death, there are other manifestations of it that produce outcomes not as positive as they could or should be (Farmer, 2004). Structural violence can be subtle to the point of not being able to directly identify the source of oppression and in this form may be less outwardly violent, such as oppression that doesn’t necessarily lead to death, but nonetheless remains an incarnation of structural and systemic violence.

In terms of the difficulties family caregivers have in their interactions with the long-term care system, we can begin to see the structural violence present as individuals’ needs are repeatedly ignored and neglected. The violence perpetrated against families encompasses a wide range, but seems likely to be a factor in their decisions not to use services.

The opting out of the utilization of services may be due to the constraint of personal agency as they attempt to access services, but are unable to either because they are unavailable or inappropriate. The families in this study repeatedly attempted to access services, with various effects. In some cases the inability to access services actually led to brain injuries, in others, caregivers were repeatedly left alone to provide care on their own due to inappropriate choices while fighting against an uncaring system,
often at their own expense. Each time a family tries to obtain a service and fails, or has services forced upon them, their choices of care are constrained.

While a popular reason for the lack of service utilization by caregivers continues to be that caregivers don’t self-identify as family caregivers, this research indicates that services may not be used, even when needed, due to the difficulties families experience while interacting with these providers. Opting out of services may be a resistance to the lack of control caregivers feel in relation to the care of the care recipient or as a response to the “invasion” of the homespace by service providers, and not wanting people in their homespace as indicated by this reflection of invasive and unhelpful in-home services:

I didn’t mind the speech therapy and the physical therapy. That was just an hour and that was great, but to have, they sent home aides who were watching us while we slept in our bed and falling asleep themselves, what was the point? I mean it was like, strangers living with us. Why? They weren’t doing anything. I was doing everything anyway. There was nothing for them to do; he wouldn’t tolerate them. He wouldn’t go into the bathroom with anybody except me; nobody could do anything.

Opting out doesn’t appear to be the first choice of these families, who try and try to obtain services, often to no avail. The ‘choice’ of opting out is the result of the lack of appropriate services, which are unavailable and/ or difficult to interact with, to the point of being traumatizing, as seen above.

Caregivers often reported that between the things that in-home caregivers were not allowed to do or just didn’t do that would be helpful as well as all of the management and oversight required, “it’s easier for me to do it, than to find people to do it.” Two very dedicated wives, Elliott and Rachel, both reflected on a lack of assistance when paid services were in place as well as their inability to get services, although not for a lack of trying. Rachel describes the lack of assistance from paid caregivers:
It isn’t anyone’s job description. People come in and do certain things and many of them can’t touch the meds unless it’s a nurse and then it’s more management. It’s easier for me to do it, than to find people to do it.

Elliott shares this sentiment about the lack of assistance when paid caregivers were present to describe why she ultimately didn’t use agency-based services for her husband after trying them, “they did nothing except be with him. They didn’t change his diapers, they didn’t shower him, they didn’t, well they fed him lunch, but I did the cooking everyday, I did everything in caring for him.” She continues discussing how she diligently tried to find services, but without success:

I tried adult day care. I tried so many things, nothing worked. He wouldn’t tolerate it; he would want to be with me, only with me. He would leave, the alarms would go off then they would try and keep him, he would get agitated, he would get violent and they said ‘don’t bring him back.’

In the end, Elliott arranged privately paid in-home staff\textsuperscript{13} for the care of her husband. This suggests that it is not because people don’t want services, or because they don’t identify a need for them, but because they are unavailable, difficult to use, or ultimately unhelpful, that services remain underutilized. These are clear examples of the extent to which care work remained the responsibility of family caregivers, \textit{even with services in place}. Instead of continuing to have strangers in their homes, it becomes the preference to provide care on their own, instead of dealing with the numerous management tasks required of them when formal in-home services are involved.

There were similar instances reported of people not getting the help they needed in families who didn’t have in-home services in place. Nancy, in trying to find assistance with unmanageable amounts of paperwork related to Walter’s injury attempted to get professional assistance with it.

\textsuperscript{13} A very creative solution to the issue of having paid staff in her space will be discussed in detail in chapter 6.
She [care coordinator] actually did connect me to a lady who came to our house and looked at the stuff and said ‘no, this is too much, I can’t do this’. So, in the end we didn’t find anybody, I had to do it myself.

In all of these instances, families wanted and tried to get help, but were left without assistance, not because they failed to identify that they needed it, but because the services failed to be available or useful. Either way, the result was that families were left alone in their need for help in providing care.

**Conclusion**

There is an assumption that having services in place means that family caregivers have less work to do and that they can sit back while the professionals do the work. Implicit in this assumption is the notion that services are easy to access and use, helpful to the family and caring in their provision of services and, thus, care. Hidden from the concept of in-home caregiving services is the extensive work required by the family in order for these services to be accessed and, once accessed, helpful, safe and caring. There is no acknowledgement that the services in themselves may be stressful, inadequate and even abusive toward families, thus increasing, not decreasing, caregiver burden, as they are intended to do. As we can see from the examples in this chapter, having services in place requires extensive and frustrating interactions with providers who need to be carefully managed. Even with this extensive management, things don’t always work out positively for the family and they engage in protection and maintaining tight control of the care of the care receiver in response to the re-traumatization they experience while interacting with various aspects of the long-term care system.

For many families, structural violence, including the extensive management and oversight of services, combined with traumatizing interactions was a major reason for
avoiding home care services, for keeping the services they used to a minimum, or hiring privately so as to have more control than is possible when paid caregivers are provided by agencies. There is an exploitative component to this kind of work required by family members in order to maintain appropriate services. Family caregivers are the most exploited members of the long-term care system. They work unpaid, sometimes around the clock providing constant and consistent care, while being neglected by other members of the long-term care system. The fact that this behind-the-scenes work goes on unrecognized only serves to continue the cycle of abuse and exploitation, where family members routinely do work that if done by others would be paid. I frequently heard caregivers say ‘it is just easier to do it myself’ when contemplating engaging with additional services. Much of that notion was a direct result of having experiences which were difficult and at times re-traumatizing, as providers acted in ways that were against their family’s best interests. Management, control and protection from the system could be reduced, with more people opting in to the use of services, if in fact they are easy to use and achieve what they set out to do- provide respite from the difficult tasks of providing continuous care to the people caregivers live with.
Chapter 6: Microgeographies of Care in the Home

“The increasing porosity of the boundaries between who cares and where, thus calls for a more dynamic theorization of how different individuals are enmeshed in the care/home landscape.” (Milligan and Power in Brown, McLafferty and Moon, 2010)

I'm Tired of Having People in my Home

At five o’clock we don’t have care for him. So, I turn into a pumpkin at five o’clock and a lot of providers don’t understand why we don’t use, in their mind, our limitless wallet, to purchase more care…, but, I'm tired of having people in my home. I can’t stand the thought that there would be someone home at the same time that my husband and I are home. I have no interest, frankly, because I have a daughter with mental illness, I couldn’t stand the pressure of [paid] caregivers as they began to realize what was wrong with my daughter and then how they treated my husband and I and my daughter, while caring for my son. It’s a very ugly experience… It’s very difficult, the consistent [long pause] life with other people sharing care is very tough. Being an employer in your own home is very tough; having to be extra pleasant because your family member is not is also very difficult.

Within human geography, space and place are essential concepts. Space is abstract and void of meaning, while place is space with meaning attributed to it (Tuan, 1977). Spaces are “marked off and defended against intruders.” Places are “centers of felt value where biological needs…. are satisfied (ibid.). According to Tuan, meaning can be ascribed to a space directly and intimately through the senses, or indirectly, mediated by symbols. “Place is security, space is freedom: we are attached to the one and long for the other” (Tuan, 1977, p. 3).

In the case of care, the places of care created through caregiving, both the intimate physical tasks of care, as well as the relationships involved in caregiving, need to be recognized as important to the creation of caring spaces, in this case the homes where care is provided (Andrews, et al, 2013). A look at the microgeographies of the
homespaces in which caregiving takes place reveal a variety of spatial and social interactions which impact caregiving experiences.

Geographers have exposed the importance of space and place in framing the experiences of care (Conradson, 2003; Milligan and Power, 2010; Milligan & Wiles, 2010; Wiles, 2003). Without the recognition of the importance of social relationships, and hence meaning, places of care will be seen as spaces of care that are devoid of meaning. Neglecting to see the importance of the social relationships resulting from the place-making occurring in the process of providing care in the home, we fail to capture the full meaning of these places of care that result in intimate relationships due to geographical proximity within the space of the home. This abstract space becomes a meaningful place as care is provided to and people cared about within the home (Milligan, 2009).

In previous chapters, the provision of services and caregiver responses to those services was discussed and provided a context for the discussion here about the microgeographies of the homespace in which care is provided. The difficulties caregivers experience while interacting with the long-term care system and in-home services, in particular, provide a foundation to consider what occurs in the home and to the family relationships when these problematic interactions happen within the private space of the home. The collision of public and private in the homespace create problems for caregivers which go beyond simply providing hands on care and infiltrate every aspect of their lives, as their homes become sites of care, whether they like it or not. The ultimate household negotiations that result are the focus of this chapter.
“Living Together”

The only requirement in order to be included in this study was that the person be a caregiver who lives with the person they provide care to. I immediately ran into decisions that had to be made regarding this eligibility criteria, as one third of the interviews I conducted were with people who didn’t technically live with the person whose lives they manage and who they provide care to.

My study focuses on family members who live with the people they provide care to because I wanted to focus on this kind of caregiving, as opposed to long-distance caregiving or people who lived close to, but not with the people they care for. At the beginning of this work I didn’t realize there may be alternative kinds of ‘living together’, where people have different versions of living together, and for various reasons (i.e.- “saving face”, getting the services they need, or preserving one’s own sense of space and separation) live in ways where it might not appear that they are living together although the caregiver is the main person responsible for the well being of the person in need of care. My initial assumption that there is something which happens specifically when we live with people, an intimacy and knowledge of the daily life and routines, and personal interactions with the people who help them (service providers, paid caregivers) which may not be accessible to or known by caregivers who do not share space with them. Additionally, I was working under the impression that there is a level of interaction and relationship with service providers (i.e.- in-home paid care workers) unknowable by people not living in the household of the care recipient.

It was immediately apparent that I had fallen into a trap, one that I am routinely critical of, but missed as I accepted many of the existing assumptions about who family
caregivers are and how they live. Currently, the distance caregivers live from care receivers are looked at in terms of in-home, in close proximity to, or long-distance caregivers. There is little distinction of the family caregivers who provide as much care as live-in caregivers, but who may not actually share an address, front door or kitchen with the care recipient, but live in very close proximity to the care receiver. This brought up very interesting questions which shook the foundations upon which my assumptions of in-home caregivers were based and revealed important questions about what it actually means to live together. It also rendered visible another level of household negotiations, the need for caregivers to make difficult decisions about what households look like and who they are made up of. Sometimes, as we will see below, these decisions are made out of necessity, so as to maintain essential benefits allowing care recipients to remain in the community and out of institutions.

In the cases of alternative forms of living together in this study, families developed intricate living arrangements allowing them to be in close proximity (i.e.- the studio next door, an apartment attached to the family home, and a house down the same driveway and within feet of the family home), but also allowed for private space for the caregiver in which to live and work. Sometimes these arrangements were made so the care recipient could maintain formal long-term care services, which they would have been ineligible for had they remained in the family home. The very notion of what it means to live together provides yet another layer of complexity within the care relationships families must engage in to get the care recipients the care they need. In the end, I included these families in the study because they each were actively engaged in the
lives of the care recipient, with similar levels of intensity and responsibility as people who actually share the same front door.

**“He Does Not Know this House Exists”**

This idea, ‘living together’, began to get complicated when I was faced with the question of whether Rose, a mother with an otherwise appropriate caregiving situation who I wanted to interview, seemed ineligible for my study because she and her husband do not share living space with their son, Nathan. Everything about their situation resembled a family who lives together, except for the fact that they actually have separate houses, a few feet away from each other on the same property in the rural northwest.

The family in question is made up of a mother and father (the caregivers) and their 20-something year old son, who has been severely disabled (non-verbal and blind, with severe cognitive impairments) since he was several months old. They all lived together in their family home until the boy was turning 18, at which point if he had stayed living with the parents, would have “aged out” of the services he was receiving which made it possible for him to stay at home. The formal services would have ended and his care would become the sole responsibility of his parents.

The case manager said to me ‘I just need you to know that on the stroke of midnight on his 18th birthday, if you are still living with him, you will be required, the state will take that as you saying ‘I want to continue, long-term doing 8 hours a day of his care.’ I already couldn’t do 8 hours a day of his care, but I was having to and I said to myself, I’ll do it till he’s 18. So he started telling me that when he was 18 we were going to need to be in a different home or I was going to need to move or whatever.

Rose knew that they would, under no circumstances, be able to provide for all of Nathan’s needs without help.

He had to be living on his own in order for me and [husband] to be relieved of duty cause in law, if he's living in the family home with the family then the
family is required to do 8 hours a day of his care and how they’re interpreting the law now is that that 8 hours a day of care, I was told at the time that that would be his sleeping hours, now they are saying ‘oh no, everybody sleeps 8 hours, this is 8 hours a day of his waking.’ So, basically, you are in charge of 16 hours a day, which would have killed me, I couldn’t do that. I can’t do it anymore. So, he had to have us move out so that we wouldn’t have to do any care and he could have 24-hour care.

Her solution to the maintenance of necessary services was to leave him living in their current family home and build another house next door for she and her husband to live in. This family lives in a rural area and owned property where they could do this and still remain closely connected with their son. They have the same driveway, share the same outside space, the parents orchestrate and oversee all of Nathan’s activities, manage his paid caregivers, have team meetings in their home and see and interact with their him daily. He, however, does not enter their home and they aren’t even sure if he is aware that it exists even though it is visible (he is blind) from and within steps of his own house. They made a conscious decision that he would stay out of their space so they would have a space of their own outside of the trappings of the carefully engineered space required to keep him safe and engaged in the world.

He does not know this house exists… That’s where blindness comes in, taking full advantage of that. It’s very important for me to not have him come over. I want to see him on his turf… Yeah, we have this space that’s not his and maybe at some point I’ll decide that it’s ok if he comes over, but I just keep going ‘eh, why?’ Cause he’s not fussing, he sees us all the time.

This points to the importance for the parents to have a private place for themselves and does not fall under the extreme control needed in his own house for his safety and well-being. “I need to have some time in my life where I can put something down and I can come back six hours later and it’s still there.” This separation of space, even though they are intimately involved in all aspects of his life and care is important for them to maintain
some normalcy in and control of their own lives and living space. This represents an aspect of self-care, in that the caregivers need their own space in order to have some refuge from all that is involved in the caring situation. Self-care is an important component of an ethic of care and is seen here as caregivers navigate their need for personal space, which may be difficult to have when living together.

“He Lives in Another Room”

The next time I had to consider the notion of whether or not the caregiver/care receiver dyad ‘lived together’ was with Elliott and Thomas, a husband and wife couple who live in a large urban city. She had been caring for her husband since a severe brain injury due to a fall several years before. She worked from home and at a certain point after his accident she realized the studio they shared, with no walls or doors except for the bathroom, was an impossible space to share as it was, if she were to be able to work again. After buying the apartment which shared a wall with their current one and having architects draw up the plans to combine them into one large apartment, but with a separate room with a door so she could close herself off from his disturbing behaviors so she could work, she, in an enlightened moment realized the implications of this and how difficult it would actually be to keep him apart from her while she worked. Due to some difficult post-TBI behaviors, if they had a door within the apartment accessible to him and capable of being opened like any other door in a home, she realized that there was nothing to prevent him from opening it in order to be with her wherever she was in the apartment.

We got this apartment next door and even actually hired architects and stuff so that we could break through and just make it so, because this is a loft, we don’t have a separate space, there isn’t any separate space. If you turn around you’ll see, that’s our bedroom. There are no doors. So, we got that and I was going to
break through and then I thought ‘oh my god, how stupid. I have this perfect separation.’

At the last minute, she called off the renovations and thought they could maintain the apartments as separate, having to walk down a hall, unlock, and open a front door, rather than making one large apartment. In this way she was able to maintain some of her own space, while remaining intricately involved in all aspects of his life. She does all of the household maintenance and management of both apartments as well as the shopping, managing and overseeing of his care. They go out together frequently. He visits her, and she visits him several times daily, but she has her own space which she can control when he comes into it. This has made it possible for her to resume her work life with success. Instead of a door on the shared wall that connects the apartments, they both have front doors and have to go into the public space of the hallway in order to access the other’s living space. Does this difference in a door change the answer to ‘do they live together’? As Elliott said, “you could say he lives next door, but he doesn’t, he lives in another room…another room, right and it’s closer [than another room might be in a big house elsewhere].”

“He has a Bedroom, a Kitchen, and he has his Own Bathroom”

In another family, Steve, the adult son and care receiver lives in an apartment attached to his mother Evelyn’s house, in a small rural town. Just inside of the front door, there is an entrance into this apartment, into which Evelyn rarely enters. The main part of the house is left open and is shared by Steve, Evelyn and other members of the family. Although Steve has this separate apartment, he ventures into his mother’s kitchen in order to eat and they often visit together in the living room of the main house.
Every morning I put breakfast out cause he comes looking for it, alright. And I’m sure he could get breakfast, but he comes looking and he doesn’t usually eat lunch. Every night I try and have a nice dinner... some produce and protein and you know stuff that’s balanced out. I try to keep food on the cabinet you know, nuts or some sweets, or fruit or something and cheese like crazy. Always gone. He doesn’t ever cook for me.

She allows him unrestricted access and enjoys when he visits with her, but she also realizes the importance for him to be able to tell others that he has his own place. This “saving face” she believes is important to his view of himself as “independent”, even though he doesn’t take care of the apartment well and depends on her for a majority of his meals. The above quote speaks to her maintenance of the household, as well as the fact that he doesn’t contribute to their mutual home, or reciprocate by doing things for her at the household level, as indicated by her mentioning that “[h]e doesn’t ever cook for me.”

Here again, the caregiver maintains the home in which the care receiver depends on and lives in. The boundaries between living spaces are blurred and unclear, which speaks to the nuances present in and which must be carefully considered when thinking about whether people live together or not.

So, do they live together? In the above three cases, the caregivers answered, “yes” to this question. In the case of the two apartments, they have different addresses, as indicated by apartment numbers. Is this arbitrary designation enough to exclude them from the definition of living together, even though the wife maintains the household and manages the entirety of her husband’s life? Do two kitchens mean they don’t live together? Does the fact that the Nathan may not even be aware that he and his parents don’t share space in the same home impact whether they ‘live together’?
What it means to ‘live together’ and whether it can take on different forms seems an important aspect of relationships of care. If people are responsible for the activities and well-being of another who lives in very close proximity, but they do not share a bed or a kitchen or cohabitate in a ‘typical’ way, can they still be said to be living together?

At the beginning of this work I didn’t realize that there were various kinds of ‘living together’, where people have different iterations of being involved in each other’s lives, and for various reasons (i.e.- “saving face”, getting the services they needed, or preserving one’s own sense of space and separation) live in ways where it might not appear that they are living together although the caregiver is the main person responsible for the well being of the person in need of care. My initial assumption was that there is something which happens when we live with people, an intimacy and knowledge of the daily life and routines, and personal interactions with the people who help them (service providers, paid caregivers) which may not be accessible or known if caregivers do not share space with them. Additionally, I was working under the impression that there is a level of interaction with service providers (i.e.- home care workers) that is unknowable by people not living in the household of the care recipient.

**Space**

There are many implications of this contested nature of ‘living together’ needing further exploration. One important aspect, which presented itself, was the importance of “space” in the lives of live-in caregivers. In the three cases where there was some actual separation of space, the caregivers felt a sense of greater control over the situation as well as more positive overall outlooks about their caregiving situations. All of the three caregivers directly discussed the benefits to both themselves, as well as the care receiver,
of having space of their own. Rose discusses the benefit to Nathan of having his own space:

I want to just provide him a space that’s sacred, a sacred space where he’s good enough just the way he is. That’s what I’m doing, giving him that and I can’t figure out anything else that I could be doing with my life that would be more important than that, there’s really nothing more important.

In addition to Rose acknowledging the importance for Nathan of having his own space, she also indicated a need for her own space. Discussing the decision to have Nathan live in his own house, she reminisced on her feelings about her need to live separately. “I need to have some time in my life where I can put something down and I can come back six hours later and it’s still there.” The need for separate, but very close, spatial arrangements are indicated here.

While this is no longer an issue for them because Nathan doesn’t enter their space, it is indicative of the importance of a separation of space, regardless of how close the caregiver and care receiver live to one another. This need for space, but lack of it is an aspect of care and possibly caregiver burden for caregivers who live with the care receiver in a way that doesn’t exist for caregivers who live separately from the care receiver. This became apparent during the course of this research and is an important potential area for intervention of behalf of the caregiver.

Caregivers in this study who lived with the care receiver, in the traditional sense, all expressed a desire for more space for themselves, but again, had a desire to remain in very close proximity to the care receiver. Alicia talks here about what her ideal living situation would be:

I do need a little space for myself, as a caregiver, I need a little space for myself. I need a space where I can go ‘Cody, no’ or I can’t do this… What would be ideal, he would have a one-bedroom and I would have a studio apartment in the
same building so when he would be acting up I could say ‘you know what, I’m going to my place now’, but I could still come back, when he calms down to check on him, but it has to have a separate door that locks…. So, my ideal world, separate space, but close, in the same building.

Her desire for some space she can retreat to is clear, but so is her desire to be close enough to “check on him” quickly and easily. At one point, Alicia tried moving out of the shared apartment, but found that the time and energy required of her to meet his needs from afar was not worth it. She went on to reiterate what would be ideal:

The only way that [living separately] would work is if I had an apartment in this building so that I could come and go and when you’re crazy, I can leave you and when you are calm, I’ll come back…. ‘why, without the benefits of the marriage, would you do this?’ To live someplace else and take care of someone, fuck no!

Although Alicia indicated the desire to live close, but separately, she also contradicts herself by indicating the desire to live together and have “the benefits of the marriage.” It seems as if living in the same building might be close enough to still be considered ‘living together’, even if they had separate apartments, which is interesting given the above discussion about various constructions of ‘living together’. Andrea shares a similar sentiment about the desire to have a different living arrangement with her partner, Tyler.

A two or three bedroom apartment would definitely make it easier, yeah, that’s what comes to mind, like I imagine, we could just get some, or living separately might make it a lot easier b/c a lot of this stuff happens around the apartment and around stuff with the apartment… yeah, ideally, if he could live on his own that would be great ideally if there was some residence where he could live, you know where he could be ok on his own and I could have my own space that would be fantastic.

Andrea starts out saying that another bedroom would be useful, but then goes on to indicate that she would like to live separately. Throughout the interview she mentioned that there were no appropriate places for someone like Tyler to live, but that if he could have his own place in close proximity to her, that would be her ideal situation.
Alice also expresses a desire to live separately from her daughter, for example in a different apartment in the same building. “You know what I would like? I would like Aida to have her own place and I live here and just supervise her, but I don’t want to live with Aida. I’m very tired.” Alice’s desire for separate living spaces came up several times throughout the interview and she also indicated Aida’s interest in living separately, but ultimately that she doesn’t think she would move out. “She’s comfortable, I cater to her needs, I think Aida loves me dearly and I also love her dearly and she has no social life…” This idea of the care receiver being alone if one were to move came up in many of the interviews as a reason to stay living together. This speaks to the relational component involved in the care relationships that would be disturbed if one person moved. Each of these caregivers also discussed the impossibility of being able to afford two apartments. This provides insight into the dedication of the caregiver to the care receiver and the assumption that even if one of them moved out, the caregivers would shoulder the cost of maintaining the households. This is significant, as it speaks to the interconnectedness and desire to maintain the relationships, even if they were to live separately.

Rachel talks about how having another bedroom, like in their previous apartment, would be a way to get more space in order to be able to get away from the paid caregivers when they are in their home. “Our other apartment was different, it was better in a way…it was 2 bedrooms and we could get away from it [home aides making noise] more, whereas here it’s just you’re right on top of each other”. This example provides insight into the invasive nature of services on the homespace and the desire by caregivers to be able to avoid forced interactions with paid caregivers when they want to.
**Positive Aspects of Providing Care**

Many of the caregivers in this study indicated positive aspects of providing care generally revolving around their love for the person they care for as well as the personal growth and deepened relationships that came out of the caregiving situation.

There have been some gifts. I think this brought us closer faster. He loves me and is incredibly appreciative. And that’s why when people say ‘well, why don’t you live someplace else and still take care of him?’ It’s like, no, and [social worker] said it, ‘why, without he benefits of the marriage, would you do this?’ To live someplace else and take care of someone, fuck no!

The above quote indicates the importance of the reciprocity present in the relationship even though it has changed to one with more than usual care needs. Alicia doesn’t think of Cody as a ‘care receiver’, but as her partner, with whom she shares her life.

Rachel also speaks of the benefits of her relationship with her husband, even with all the difficulties they experience. “I like him, as a person. I love him as a man and a husband and um I enjoy his company. He had a wonderful sense of humor that he’s losing, sometimes it comes back.” Lee is less able than many of the other care recipients to reciprocate in the relationship with his wife, which creates household level complications that will be discussed in the next section.

Andrea, one of the least experienced caregivers in the study, with less than two years of caregiving behind her, reflected on the spiritual level of providing care in relation to her relationship with her partner.

I think going through this you know, especially when he was in the hospital and in the rehabs brought us much closer, you know he was kind of dependent on me in a way he had never been before…. and we got much closer and um, and I think just being in the caretaking kind of role with him, there was a lot of tenderness that I felt toward him and a lot of just really wanting to take care of him…. on a bigger, I guess more humanistic or spiritual level you don’t just abandon people… You know, here we are, this is what we’ve been given, this is what we’ve been dealt you know, I guess you could just walk away, but you know…but can you, or
should you or do you want to or why not just step up to what you’ve been given? You’ve been given a huge challenge, like life’s dealt you a huge challenge and you know and I love him. The romantic piece is you know starting to really fade, but I love him and I always will love him.

Even as Andrea questioned how long she could sustain their relationship and whether or not their relationship would endure the stresses of his injury, she still indicated a deep desire to be there for him through his difficulties. “Love” was mentioned directly in each interview and forms the basis for the care people provide to each other.

Each of the above quotes are rooted in an *ethic of care* in that they acknowledge the interdependence between caregiver and care receiver. This interdependence gets artificially erased as services enter the home to provide services to the care recipient only, which is problematic when the care recipient lives as a member of a household and family. We will see below how neglecting to acknowledge this interdependence creates hardships for family caregivers who are left to do more than their fair share of household work, material and social, even though they share their home with another person. This is especially problematic in relation to the theory of ambiguous loss, which is discussed next.

**Caregiving and the Theory of Ambiguous Loss**

Boss’ Theory of Ambiguous Loss came out of a desire to understand and preserve family resilience in the face of crisis and is useful in looking at the family situation of people providing care to people with brain injuries, especially those with severe cognitive impairments who are unable to direct their own care (Boss, 2008). Specifically, the *psychological absence with physical presence* type of ambiguous loss can be identified in families where the person who sustained the injury is physically present (along with their needs), but psychologically absent in their ability to reciprocally contribute to a
household or care for or be in relationship with those closest to them in their families.

This is often discussed in terms of confusion over mourning for the loss of a person who has not died, yet has changed from who they were previously. We see this clearly in the quote below:

Because of her impaired memory, I became the vessel for all the thoughts and emotions I was having as well as the ones I anticipated she would have been having, if her brain were still in tact. And even though we were together so much, I remained alone. I couldn’t engage in conversation with her, reminisce with her, problem solve with her, do anything that required recollection, reasoning, judgment or executive functioning of any kind. This is a certain kind of hell-being with someone, but being alone. It can be very sad.

With relationships forever changed, there is simultaneously a trauma that occurs and a closure that cannot, as people with care needs, as well as their families are dynamic and ever-changing. The ambiguity involved in this type of loss can traumatize and immobilize individuals operating in these situations. Ambiguous loss is a relational disorder, rather than a psychic dysfunction (Boss, 2007). Therefore, it must be intervened upon within relationships, not at the individual level. It is this distinction, which makes it of particular interest here, especially given the discussion of the ideology of the individual that is overwhelmingly present in the provision of in-home services.

Another relevant aspect of the theory of ambiguous loss is that there is an assumed natural resiliency in families. The challenge in caregiving then, is to figure out how best to nurture this resiliency in order to create healthy family dynamics, even in the face of psychological absence with physical presence, which renders a family member in need of care and often unable to contribute (equally or sometimes at all) to the household of which they are a part. In order for services to be more helpful to caregivers, families must be seen as cohesive units in relation with one another, not separated and treated as
individuals without emotional connections and the resulting complex relationships. Service provision that assists people with brain injuries in contributing to their households could go a long way in reducing the strain caregivers feel in having to do everything to maintain a household in addition to providing care to the person with the brain injury.

**Scale of the Household and Household Negotiations**

Taking further the importance of acknowledging the interdependence of people within their families, there must also be recognition of the households in which people in need of care live. Home care services provide care in the ‘home’ in order to keep people in ‘the community’, but in this conceptualization of home care, the scale of the household remains a taken for granted aspect of people’s lives. The people in this study who were receiving home care services contributed very little to their households. As a result, family caregivers were left to manage the household on their own.

People who live together must discuss the household and negotiate myriad aspects of daily life with each other. However, if the care receiver isn’t able to participate at this level of the household, the caregiver easily becomes overwhelmed with the level of household responsibility they must maintain in order to sustain the home where they both live. This component of life as a caregiver is not necessarily helped by the presence of in-home services and may even be made more difficult as they have to interact and develop relationships with new people who will be in and out of their homes in order to provide daily assistance to the care receiver. Not only do caregivers have to negotiate a new relationship with the person with the brain injury, but they are also required to interact with service providers. Many caregivers in this study learned that in order for
these services to work, they needed to put in time and energy developing and nurturing their relationships with the professional caregivers there to assist the care receiver.

The current framing of caregiver burden ignores the complicated relationships resulting from the in-home provision of services and impact on the existing familial relationships in ways that are difficult for family caregivers. Community-based, in-home services are services provided to individuals in the ‘community’ so they can remain at home for as long as possible.

A problem with these services, which emerged during the interviews, is the fact that as services are provided to individuals at home, there is a disregard for the household in which these individuals live. When people who do not have special care needs share households, there is an interdependence they share, with each member contributing to the overall running of that household. Whether it is a 50/50 arrangement, with all household chores being shared equally, or a 60/40 or 80/20, the members of the household must negotiate these responsibilities in ways that work for them, as a family unit.

When a member of a family becomes ill or disabled and is unable to contribute to the household as they previously did, a renegotiation of the contributions to the household must then occur, but often does not, leaving the entirety of the management of the household the responsibility of family caregivers. If the person with the brain injury is no longer able to participate in the household at the level they once did, there must be some mechanism in place to assist that person in contributing as much as they are able, so as to relieve the caregiver of the responsibility of maintaining the household completely.

In-home services, by not acknowledging or intervening at the scale of the household, do not ease the ‘burden’ of managing and maintaining the home where the
person with the injury ultimately lives, and may actually contribute to an added burden of having to manage relationships with in-home service providers, in addition to the other management tasks that increase when a member of the household becomes disabled. Here, the theory of ambiguous loss is relevant at the level of the household both in terms of the material requirements of maintaining the home, as well as the negotiations of familial relationships and those with paid in-home caregivers.

**Social Spaces of Care: The Importance of Relationships**

The opening quote speaks to the blurry lines and unknown spaces among and between the actors involved in caregiving situations. These social and relational ‘spaces’ become the geographies of the relationships existing in the home between caregivers and care receivers and acted upon by outside (paid) services (Cloutier, et al, 2015). Here, care can be seen as “a form of relation” existing within these relational spaces, with the social interactions between caregiving dyads and triads being essential components of care within the spatial domain of the home (Conradson, 2003).

Relational activities of daily living (RADLs) are social and relational aspects of care provision existing between families and formal services providing care within the homespace. These services act on the homespace in ways which go unnoticed and ignored by professionals and researchers, with family members having to defend against, work with, do for, and ultimately keep all the pieces together while at the same time there is an assumption being made that their lives are easier because these very services are in place. A relational ethics framework, rests on four fundamental principles: engagement, embodiment, mutual respect and environment, and suggests that relationships between care receivers and care providers must be preserved as the heart of the health care
experience (ibid.). Furthermore, relational ethics have been suggested to be useful in the general home care context in order to ground relationships as important elements of home care (Cloutier, et al, 2015). Findings from this study indicate that relational ethics frameworks were not utilized by the service providers these families interacted with. In addition, the relational aspects of the social interactions between families and the long-term care system remain unaccounted for in caregiver burden research, but were important to the caregivers in this study. For this reason, as stated earlier, RADLs should be included along with ADLs and IADLs in order to more completely conceptualize “caregiver burden.”

This work illuminates the disconnect between the relational aspects of service provision within the physical spaces of care, indicating that they are not one in the same, but act upon each other. The manner in which the interpersonal negotiations take place, who has control of the services, and the care with which they are provided, all play a huge role in how the services work (or don’t) and are perceived by the family caregivers and the caregiver/care receiver dyad. Additionally, as we will see below, beyond the importance of recognizing this dyad, we must also recognize how this dyad is impacted, when a third entity enters the relationship. Here, paid in-home service providers and community-based providers weave their way into personal relationships of care in ways that are unrecognized and often unwelcomed.

This ‘space’ discussed here is the ‘relational space’ between the provision of services and the relationships of care that are created by these services. There is a widespread assumption regarding the positive nature of in-home and community-based services, which remain unquestioned in the general public. For example, the mother of a
young adult with multiple severe disabilities who has been managing her son’s care for more than two decades provides insight into these unquestioned assumptions that the paid services her family receives are purely positive. This family unit has the assistance of six paid caregivers, whom the mother manages on a close and daily basis. In discussing the judgments made about her family’s life by the manager of the program who pays these workers, we can see clearly the disconnect between the professional manager and the family manager:

…the manager of the program said to me ‘well, you’ve got it made, you’ve got all this staff in there all the time, you don’t have to do all that’ and I said ‘you are clueless what it takes to not only have staff and train them so that they are doing Nathan well, but they have to be supported so they don’t just flippin’ walk off their job’. This is a hard job… I remember this one staff coming out of Nathan’s room with her hair sticking out and going I’m not getting it, am I? I said ‘you’re doing great, great, you are doing so good’. I mean in the early years when they were all new it was not at all unusual for them to stay for an hour or two after their shift and defuse with me. ‘Well, he just kept doing this’ and I go ‘ok, now what you have to say is…’ there are scripts that they have to learn.

She spends significant time and energy developing her relationships with all of these people because she knows that it is through her relationships with them that her son gets the care he needs. In this situation, the extent to which the family and paid caregivers become important parts of each other’s lives becomes clear. Not only are the paid caregivers helping care for this woman’s son, but she takes “them on”, cares about them and nurtures those relationships in order for her son to get the care he needs from them. This extensive emotional labor is necessary, but also exhausting, and remains hidden to all but those closest to this family.

It’s bad, it’s bad and we’re all at a point and they’re [paid in-home caregivers] all wounded. They all have their own journey, you know, several of them were abused as children…. I’ve taken all that on. I’ve had to love these people and support them.
She works hard at these relationships so her son gets what he needs, but also so she gets what she needs from the relationships with the paid caregivers through their care of her son. It is a striking realization that it is possible for services to be good for the family caregiver as well as for the care recipient, but, as seen here, this requires an extreme level of dedication to these relationships, one similar to any other intimate relationships we have in our lives. The difference here though is that family members don’t often get to select the individuals who work in their homes for the care recipient, unless they arrange for and privately hire professional caregivers themselves.

This situation is similar to a pre-arranged marriage, where strangers are thrown together in awkward situations and expected to be part of a team, although, as one mother noted, “not a team you feel like being a member of”. From the family caregivers’ perspective this is uncomfortable and awkward because you find yourself in the position of employee, but unless the person works for you directly and not an agency, this is not actually the case. You have to allow strangers into your home, a place that is often reserved for people you want to have around, not strangers who invade your space and, as seen in the quote below, can be disrespectful of your family, things and insensitive to how your household is organized and run.

The fishbowl, the whole fishbowl thing. Having people in your space, everyone lives their life, right. Everyone can have a messy house or a neat house, a dirty house or a clean house. Be nice to their other children, scream at each other, but no one knows it, because usually you only invite in the people you want, when you want, when you can have the fruit cut and everything’s nice. Instead, all of these helping professionals come into your home and you are under a magnifying glass, and not only that, these little 24, 27 year olds who haven’t had children yet, who don’t know the pressures on a marriage that was under tremendous pressure or the financial pressures or frankly, they make comments. And put in social reports. What your house looks like, what you’re feeding your kids and each other, what relationships are like, you know, instead of understanding that they
are a service provider vendor that I am choosing and hiring and bringing in to provide a service as a member of my child’s team. They see me again, deficient, defective parent, right, who clearly the way they treat the family, it’s their job to fix us. Not to do their piece and make sure to communicate effectively with the other team members. It’s as if the judgment is part of what they went to school and got their degrees for, is to actually make these completely uninformed judgments.

This invasion of space that occurs due to the provision of home care services is an aspect of caregiver burden that remains buried under the dominant discussions and near complete focus on ADLs and IADLs\(^\text{14}\), which are the prominent focus of caregiver burden.

From the perspective of the in-home worker, they are in a difficult position as they enter into a stranger’s home and have to adjust to different ways of doing things and interact with people who may act as their boss, but not actually be their boss. Their boss is actually an agency supervisor who never enters the home nor has any idea of how their decisions impact the relationship between the care receiver and caregiver, as well as the new relationship between the caregiver, care receiver and in-home paid caregiver (the triad). These messy and complicated negotiations become the private domain of the family caregiver, who must navigate them alone within the confines of the home.

**The Material (household chores)**

Within the household, the material aspects of it must also be negotiated along with the social. Prior to the medical event that caused the brain injury, there were negotiated divisions of labor, which existed within each household. After the brain injury, it is likely that while the person was initially hospitalized, the caregiver took on complete responsibility for the maintenance of the household. This maintenance includes the protection of the home itself, keeping it maintained and paid for so the care recipient has

\(^\text{14}\) See page 14 for an explanation of ADLs and IADLs.
a place to ‘go home’ to. As Rose stated above, “we’re running two houses.” She and her husband maintain two households in order for the family to be in close proximity to each other. In addition, there are the domestic activities that are required to keep a household running. These are the traditionally ascribed “women’s work” that go into keeping a home running smoothly—cooking, cleaning, laundry, etc.

Upon the return home of the care recipient, these household negotiations often remained the domain of the family caregivers in this study. This may be due to the fact that the care recipients were no longer able to contribute as they had previously or because no one actively negotiated the roles within the household. New patterns emerged, often with the family caregiver maintaining sole responsibility for the running of the household, whether or not the care recipient could assist in any way or not. Any reciprocity that existed in the household prior to the injury often disappeared. This creates another layer of responsibility that falls on the shoulders of the family caregiver. Now, however, they are also negotiating a new life with a care receiver who has various levels of needs requiring attention. In some cases, these needs are significant and all-consuming, in others, they are less consuming, but present nonetheless.

**Families Without In-home Services**

Half of the families in this study did not have in-home services at the time of the interview. In these families, the care recipients were more independent, being able to leave the home and travel independently, and negotiate their own dealings with the various aspects of their daily lives without close supervision.

In these cases, family caregivers often helped manage various aspects of the care recipient’s long-term care needs, such as through interactions with public benefits.
agencies, doctors, insurance companies, and community-based social service providers. These interactions, although not with direct in-home providers of services, required immense mediation by caregivers and often very time consuming and sources of stress for caregivers. For example, Alice, the mother of Aida, a survivor in her late 30’s describes “being totally overwhelmed” by the management of “everything” for her daughter. She discusses “the amount of paperwork, the inefficiency of the different agencies, the insurance company, the trust, the lawyers…” In addition, Social Security issues and Access-A-Ride (transportation for people with disabilities) eligibility and access issues came up several times throughout the interview as a problematic aspect of the management of Aida’s life. In addition to these service related managerial tasks, she does everything to maintain their home as well.

I mean I do everything for her now, but when I say everything, is I prepare her dinner, I take her places, if I have time I say ‘no, don't take the subway, I’ll take you there’, um, I do many things with her and for her because I don’t want her to, I don’t know, it is like making up for what she had lost.

In this example, even though Aida is relatively ‘independent’, Alice still does many things for her that members of households do for each other. The difference now is that Aida contributes to the household very little, even though, in this case she appears to be able to. When she does contribute, such as in doing the grocery shopping, Alice is very grateful for it. We see in the following that although Aida is able to contribute, she doesn’t necessarily do so.

Aida can do the laundry, no doubt. Aida does her banking, Aida does the shopping for me, she remembers what I have to buy, um, I mean she’, but maybe she needs someone like to do the cleaning of the apartment. It’s not a big help that she needs.
Here, the “caregiver burden” has a lot to do with the management of these systems, as well as the overall maintenance of the household. The family caregiver could benefit from help negotiating the new household dynamic present for this family. They don’t want in-home services because of the perception that they are for people who need more assistance than Aida needs. However, on the other hand, Alice explains being “tired, tired, tired” because of living with and supporting Aida as much as she does. The maintenance of their home is repeatedly expressed as difficult for Alice, both because it is expensive and not where she currently wants to be living, but remains there so her daughter can keep her home. Continuously putting into a household and not reaping the benefits of the relationship or co-habitation experience is exhausting, devastating and I suggest a huge part of the burden caregivers face.

In relation to the Theory of Ambiguous Loss, caregivers ultimately feel like they are living alone together with someone who needs more from them than they get in return. This is evident throughout the interview with Alice, but especially poignant in the following comment about how alone she feels, even though she lives with her daughter: “if something happens to me, poor me and poor her because… I am here by myself.”

In another example of a family who does not receive in-home services, Nancy describes her partner, Walter as “recovered enough so that I can handle him. That sounds awful, but I mean vacuum and cook for him and I have to like remind him that he’s taking all of his medication, I take care of that.” He isn’t able to buy things he needs for himself so she also needs to do these household level maintenance activities. “He tried to go shopping for himself and he came back with all of these things which we had to return so I need to help him with all of these things.” Here, she has to take care of these things
because otherwise she has to correct his mistakes. Continuously putting into a household and not reaping the benefits of the relationship or co-habitation experience is exhausting, devastating and, I would argue, a huge part of the burden caregivers face. This was made evident as Nancy spoke of the division of labor in their household since Walter’s injury and whether she could sustain this for the rest of their lives.

Living with somebody with brain injury, um, if you were thinking you have a partner and you could say that you support each other equally so it’s like 50/50 shared responsibility and everything, it’s never really 50/50 in the first place, but with somebody with brain injury it’s 80/20. 80/20… is that really something you want to do? Does it have to be 80/20? maybe it’s 70/30.

Caregivers, such as Alicia, with family members who are able to participate in some way in the life of the caregiver, talk more about the positive aspects of the relationship and that they also get something out of the relationship. “If you can’t enjoy the benefits of loving each other, why would you do this?” For example, Nancy speaks of this directly in discussing her relationship with her partner as one she values and is grateful for.

One of the things that is really awesome about him and this is what the others sometimes are envying me for, he comes up with things to do. He has organized a couple of trips. So, he booked the tickets and he just e-mailed me earlier and said ‘I think this is what we can do this weekend’ and so, and we have a good time then…We do have a good time, otherwise, it would be entirely unbearable and fortunately he is extremely sweet and um, never gets upset… He is affectionate and sweet and it’s most of the time it’s nice. I’m getting angry with him and he’s just sitting there reading his book and I have to do everything else, but I don’t know. He said he’s going to cook some dinner. We’ll see if that happens, but every now and then he’s trying. It’s still totally worth it… I do get something back. Walter is getting better… Walter is definitely appreciative of this. He is telling me he is glad to have me and he loves me.

Here, we see the difficulty of being the sole contributor to the household, but also the benefits to the relationship when there is reciprocity from the care receiver. This speaks to the need for caregiver/care receiver dyads to have ways to return to their previous...
relationship roles and not only remain in the caregiver/care receiver roles in their day-to-day lives.

In talking about what was most helpful for her in the beginning, she reflected on the household level of things such as food. “The most helpful things were when someone would do something that they think ‘what would she want?’ and then someone brings me some food and I didn’t have to ask for it and that was better.” Here, “the most helpful things” had to do with food just showing up, which is a household level contribution that can be difficult for people to manage or ask for when they are dealing with the initial medical event and resulting serious injury.

In the families in this study without in-home services, family caregivers remained responsible for the majority of household tasks, even though they shared their homes with the care receiver. This highlights the experience of living alone together, and reinforces the Theory of Ambiguous Loss and the difficulties it presents at the scale of the household.

**Families With In-home Services**

In families where in-home services are provided to the care recipients, there remain two unquestioned assumptions. First, that the management and maintenance of the household rests with the family caregiver, and second, that in-home services are helpful to family caregivers. As seen in the previous chapter, in-home services are not easy for family caregivers to interact with, don’t necessarily make life easier for them, and even at times make life more difficult through processes of re-traumatization.

Because in-home services are provided to one person, the individual with the disability, they are not effective in assisting at the household level and so, caregivers end
up doing everything involved in maintaining the home, even though they aren’t the only person living in it.

I couldn’t even walk through the grocery store I had to use a cart and they would have to shop for me when we first moved here. So we were hoping the aide would help with that kind of thing, but we never got anybody that was really committed.

The question here becomes is this a matter of “commitment” on the part of the paid caregivers, as said above, or a failure of the system to not include the caregiver/care receiver dyad in the provision of services and only narrowly focus on the individual, at the expense of the family?

In addition to being solely responsible for routine household maintenance, the presence of service providers creates another level of management for family caregivers, namely, the social relationships that result from having paid caregivers present within the private space of the home.

Rachel and Lee are a good example of the ways in which services do not adequately support the person with the disability in contributing to the household. By not assisting the person with the disability to make contributions at the household level, the work falls to the family member and so this unrecognized aspect of ‘caregiver burden’ is not reduced by the presence of paid in-home service providers. In discussing the provision of services, Rachel states, “they are here for him, that’s very much the rule, they’ll wash his clothes, but not mine. I mean the rules are really, they’re just not made for people with families.” This reinforces the initial problem with recruitment, which I experienced in not being able to find people with family members present who use formal services. Later in the interview she discusses problems she had getting services to come to their home. “That’s when finally I learned the way it works is if they have a family
member, they rely on ‘em.” She goes on discussing that Lee considers himself a burden on her:

…very much he has a sense of what I do for him and it’s a burden to him. It hurts him. It hurts him that he did this [due to suicide attempt]. In his mind, ‘I did this to you. I appreciate that you’re here and want to be with you and I hope you want to be with me’ you know?

In this case, Lee feels like a burden because of all his wife does for him and it would likely help him and ease this feeling of being a burden if he were able to contribute to and help her in their daily life together, as her husband. This brings us to the question of how services might explicitly assist the care recipient in contributing to the household so as to help the caregiver, who is acknowledged by the care recipient as doing a lot for them.

Also, at the level of the caregiver/care receiver relationship, the larger question is whether and how services can allow people to maintain their original relationship and not only exist in this new caregiver/care receiver space that dominates their post-injury relationship and life together? This suggests that services need to intervene at the scale of the household, not just at the level of the individual within the home. Here, we can see a direct negative implication of services being delivered under the framework of the ideology of the individual when the person lives as part of a larger family unit.

Going further, Rachel has expressed instances where not only do the in-home providers fail to do what they are supposed to do, for Lee, in the process of being unhelpful, they make things more difficult.

There’s rules, right, there’s rules. There are things they won’t do. I had heart surgery, I had to come home in a cab and one of these aides said to Lee, you and me need to go for a walk, she made him a TV dinner, she ate the other TV dinner, which was mine, and he said ‘I want to talk to my wife’. The nut case goes over here and starts praying for me. I said ‘you just need to be quiet while Lee and I talk, you know, you can pray quietly for me if you want, but you have to stop b/c I’m sick’… and the girl is not praying for me b/c she cares, b/c I had come
between her and Lee and he wouldn't go for a walk with her. I call the service and say I’m home, she can leave because right now she’s causing more stress. They said well, wait until the 8 o’clock girl gets there’. I thought oh, so I just go in my room and shut my door and Bill wants to be with me and then they are here. They are more stress, under serious conditions, when they should be helpful, basically helpful and kind, not neurotic.

In this instance, Lee is unable to contribute to the care of his wife when she needs it upon returning from major surgery. Not only did the paid caregiver not assist her, but even ate food that was meant for Rachel. Here, in this extreme case we can clearly see how helpful it would have been for Rachel if the aide had helped Lee do what was necessary upon his wife’s return from the hospital. Not only would it have been tangible assistance for Rachel, but it also would likely have made Lee feel good about contributing to the household as well as participating in the reciprocal care of his wife.

In opposition to the unhelpful and contentious nature of agency provided in-home services, there was only one caregiver who hired and paid privately for the in-home assistance for her husband. She had the most positive feelings about her relationship with her husband’s aide than the other caregivers in this study. Her reflections indicated a positive, trusting and long-term relationship; one that she indicated would be “impossible if I had someone from an agency.” This was the family in which the husband lives in the attached apartment and the aide lives in that apartment with him. The wife continues to do all of the shopping and their outings are mostly together, “yes it’s the three of us. The three of us, we take him to the museums…do you know the Yiddish word kvell? Adele and I, when we take him out, we kvell.” Here we see that the caregiver is actively involved in the life of her husband, with the aide being an integral part of their life in order to assist the wife, as needed.
Hiring people and having direct relationships with them may create a different dynamic, one that may be more caring than one when agencies are involved. Somehow, agencies may disrupt the triadic relationships, with their rules that don’t make sense, are controlling or that are “just not made for people with families” as indicated above. Agencies may even intentionally try to discourage close personal relationships between workers and family members because, as one home care agency executive director stated while discussing the problems associated with one aide being too embedded in the family: “when one aide is the sole person assigned to the person, sometimes things happen where they are so integrated into the family and something happens outside the scope of care and something bad can happen.” Here, “the scope of care” she refers to has to do with the limitations of what paid caregivers are allowed to do under agency regulations. When families have close relationships with the paid caregivers, these regulations may be ignored, as workers and families do things they aren’t allowed to (i.e.- “fudge factor”) in order to provide appropriate care.

In addition to situations where families privately hire workers, similar close relationships also existed when workers were from agencies through programs where the family members retain control and manages the program. As in the example of privately hiring a paid caregiver, these families also maintain close relationships, likely because the agency acts only minimally in the case and so families and the paid workers make the care situations more reciprocally work for them.
Conclusion

In this chapter, we have seen the multiple relationships within care arrangements family caregivers are enmeshed in within the scale of the household. These relationships, ones that are both rewarding and complicated provide the base from which all care emanates. Without an understanding of this base, the dynamic nature of these relationships and how they impact upon each of the individuals in the unit, it becomes evident that the relationships themselves, the relational spaces of care, are obscured as the focus of care of one individual, the “patient” or “consumer”, becomes the main focus, while others in the care relationship (family and paid caregivers) remain hidden, neglected and often mistreated within the context of the care relationship. The importance of these relationships on all people involved must be acknowledged so that everyone’s needs can be addressed so none are benefitting at the expense of others. The level of the household is of utmost importance, because it is the site of care, but also a scale within current service provision, which is ignored.

The relational activities of daily living (RADLs) that caregivers participate in on behalf of care recipients must be paid attention to if we are to transform these relationships in positive ways. With this recognition, the caregiver/care receiver dyad and caregiver/care receiver/paid caregiver triad come to be seen as essential relationships which both impact the provision of care and are impacted by the provision of care. There are relational spaces which, when ignored, can become sites of contention, but when recognized, facilitated, and cultivated have the possibility to be a solid foundation upon which the positive and caring facilitation of care can emanate. Paid in-home caregivers are in the middle, stuck somewhere between professional and family, but with no support
in navigating these difficult relationships with the families they work with. At the same time, family caregivers are in the middle as well, stuck between paid caregivers and care receivers. The importance of these triads in providing responsive, attentive, competent, and responsible care provides a starting point for a radical transformation in the delivery of care. These relationships are already the backbone of long-term care. It is time to recognize them as such and provide supports to make their caring easier and equitable, instead of uncaring and neglectful.
Chapter 7: Concluding Thoughts

The general aim of this dissertation was to explore the interactions between informal family caregivers and the long-term care system, and the preceding chapters have accomplished that goal. Utilizing a lens of an ethic of care to understand in-home care provision and interactions with the long-term care system has shown a discrepancy between the caring by families, on the one hand, and the lack of care with which they are treated by the system on the other. While negative interactions were expected, it was noteworthy and surprising the extent to which these interactions drove the behavior and responses of caregivers to formal services.

Overworked and overburdened family caregivers need easy access to support, which is readily available and does not take additional time, energy and effort to maintain. When will we realize that when we truly assist one half of the caregiver/care receiver dyad, we are ultimately helping both? We need to break down the barrier of eligibility and of focusing services on only helping the patient or in trying to help the caregiver, only providing respite services that separate the caregiver from the care receiver. This could be helped with a simple question of what it is the dyad wants and how do we help facilitate and nurture the relationship. Less about services, more about supported living of the family caregiver/care receiver dyad.

A broad conclusion of this study is that informal family caregivers of people with brain injuries are traumatized and re-traumatized in the process of seeking and receiving care. They are, understandably and almost inevitably, traumatized through the experience of the initial medical event that caused the brain injury. But what is striking and shown in the research presented, is that they are further traumatized as caregivers
interact with service providers and public benefits in an attempt to get what is needed for
the care recipient.

The construction and presentation of what is understood as ‘caregiver burden’
remains incomplete, as shown by the caregivers in this study. The interactions with the
long-term care system, and specifically in-home services contributes to their sense of
burden, not easing it, as these services are intended to do. This is a gap which must be
recognized and filled, both in order to gain a more in depth understanding of the breadth
of the ‘burden’ caregivers face on a daily basis, and on a practical or service level if we
are to begin to provide more helpful support for caregivers.

In the extreme, as we have seen in the cases presented, these services make
additional work for family caregivers and are delivered in a manner that creates
emotional distress, actually involving the re-traumatization of service users. There is a
need to re-locate the origin of caregiver burden in the disorder of the state and the
provision of social services themselves, rather than a simple result of there being a person
with a disability who needs care.

Often overlooked, but shown in this research are the positive aspects of providing
care. These revolve around the increased closeness within families. The relational
aspects of care need increased attention if we are both to better understand it and if we
are to facilitate caregiving in today’s world in a way that doesn't exploit anyone in the
care relationship.

Household negotiations, especially maintaining the household and the social
relationships created when in-home services are in place, must be acknowledged as a
potential source of strain on family caregivers. However, these relationships, if nurtured
appropriately, have the potential to attend to the needs of everyone in the care relationship-- caregiver, care receiver and paid caregiver-- to create more overall care in caregiving situations. An ethic of care framework, as demonstrated in this research, provides a corrective to the traumatizing services utilized by the family caregivers in this study.

**Discussion of Findings**

The findings presented in this dissertation suggest several things. First, that there exists a need to re-frame caregiver burden to include positive aspects of providing care as well as the negative interactions caregivers have with service providers and the long-term care system as a whole.

Second, there are deep social and institutional failings present in the long-term care system, with family caregivers’ difficult interactions an indication of the change needed in the system. Currently, as I have shown, the long-term care system may create more difficulties than benefits for caregivers, despite claims of a desire to assist caregivers in their caregiving roles. We need to be critical of the assumption that if services are in place, things are easier for caregivers. This is a shift from the current prevalent assumptions that when providers are present all must be well in the lives of the family and that they don’t have to be involved in the provision of care.

Providers must also acknowledge the huge amount of work involved for families, even when they are in homes providing services. This work is often invisible because it occurs behind the scenes, and is made up of complicated relationship negotiations between the dyad and triad, is time and energy consuming for the already physically and emotionally exhausted caregiver and remains their responsibility in order to make the
experiences of in-home caregiving go well. Alternatives to the current provision of in-home care must be developed in order to give people, caregivers and care receivers, more options in terms of how they receive care and who provides it. The ways in which support is provided needs to be rooted in an *ethic of care* and be attentive, responsive, competent and responsible to the needs of each person involved in care situations.

A question that remains is whether formal services are where support is most likely to come from, and if not, then other solutions must be arranged that will actually support families with care needs. For example, for people wanting in-home services should be able to pick who comes into their homes to provide care and when. Care provision needs to be flexible, but also non-specialized. Many people need assistance in daily living, and this changes in terms of what ‘care’ looks like on any given day. Therefore, care providers must be able to assist caregivers and care receivers in ways they need it, not necessarily as designated by the rules of agencies.

Importantly, there are other possible ways to assist caregivers and care receivers that are outside of the scope of services. For example, housing subsidies or stipends provided directly to caregivers could provide tangible financial assistance to these families without them having to use services if they choose not to. Food Stamp benefits could be provided to any person providing care to another to help ease the financial strain of caregiving. Lastly, eligibility criteria and requirements in order to obtain necessary benefits should be minimized as much as possible. Enormous time and energy is expended by families engaging in the frustrating tasks involved in proving eligibility for programs and services. Often, these programs require yearly onerous recertification programs. Streamlining these programs and creating automatic eligibility for certain
populations (i.e.- people with permanent disabilities and their caregivers) could reduce family caregiver work on this front, as well as reduce tedious work on the part of the long-term care system, in general. Continuing with the food stamp example, people below a certain income could be automatically eligible, and provided with a food stamp benefit in the same way people are automatically eligible for Medicare when they reach 65, or sooner if they have a disability lasting more than two years.

Third, the triadic relationships that result between the caregiver/care receiver dyads and paid in-home caregivers must be given special attention, specifically in terms of mediation, communication and the cultivation of these relationships in order to develop relationships of care that nurture each of the individuals in the relationship and recognize their ultimate interdependence, so none is taken for granted, oppressed or exploited in the process of providing care to other members of the triad.

Although this project was not specifically focused on paid caregivers, it is imperative that they are given adequate recognition as essential members of the care team and the attention necessary so their needs are considered along with the caregiver/care receiver dyad. Until the long-term care system is able to recognize the importance of each individual within these relationships, we will fall short of supporting the caregivers, informal and paid, upon which our entire system is based.

Fourth, attention must be turned to the scale of the household, in terms of the paid services provided to care recipients. Home care services provided “in the community” fail to intervene at the level of the household. So long as paid caregivers do not help care recipients contribute to their households, caregivers will be left to do all of the work of maintaining a household, in addition to being the sole person ultimately responsible for
the care of the care recipient. Home care services must provide services at the household level, not only to the individual, outside of the context of the relationships that person is a part of and that exist within the household.

**Recommendations**

There is a desire by policy makers to facilitate caregivers’ involvement at home for as long as possible to avoid institutionalization because it is less costly and because it is peoples’ first choice to remain at home. However, this research suggests that families feel they are being pushed out of the caregiving situation by providers who want to “get rid of them.” This is destroying existing family ties when we need to facilitate caregiving through true family support instead of alienating family members from each other by introducing services. We need services in addition to and in cooperation with, not in place of family members, if this is what families want.

Caregiving and the challenges caregivers and their families face are numerous and exhausting. It is up to policy makers to ensure that however caregiver support moves forward, it is the caregivers and their families who are given the power to decide what will work best for them, not service provider agencies who stand to profit from the delivery of these services.

**Re-frame Caregiver Burden**

The recognition and acknowledgment of the difficulty caregivers face in their interactions with the long-term care system and in-home service provider is a first step toward responding to these difficulties in ways that are meaningful to caregivers. In addition, recognizing the positive aspects of their relationships with the people they care for will allow for more complete discussions of the totality of the caregiving experience.
Including positive aspects of providing care, interactions with providers and relational activities of daily living (RADLs) in conceptualizations of caregiver burden will provide for a more inclusive and complete discussion of the issues and how to address them.

These findings yield insights into caregiving practices and the in-depth negotiations are required of caregivers when they interact with service providers to ensure the care recipient receives the necessary care. This study has been critical of the current conceptualization of “caregiver burden” and sheds light on caregivers’ lives, which are nearly consumed by constant difficult interactions, with providers. In the end, much of the discussion around positive interactions with providers were really about people being nice and caring and treating them with a thread of dignity and kindness. The suggestion that caregivers are neglected and abused in their interactions with providers suggests that these negative interactions impact the overall burden imposed on caregivers and that new modes of interaction between caregivers and providers must be developed. The current incomplete conceptualization of ‘caregiver burden’ must be expanded to include the burden placed on caregivers, not by the care recipient and the tasks (ADLs and IADLs) that caregivers do for them, but thorough the direct interactions caregivers have with myriad social services and providers.

**Ethic of Care in Service Development and Provision**

Instead of continuing to focus on the ideology of the individual within service provision, an ethic of care calls for a recognition of the relationships we are involved in and reciprocal interdependence as another way of conceptualizing who needs care and how it is provided. Support comes in many forms, and the findings here suggest that
support from social services is often missing in services provided to families where there is a person with a brain injury present.

There needs to be a shift away from the ideology of the individual toward interdependence in discourse and practice. This is especially true with brain injury, where the discourse follows the larger notion of independence above all else and the restoration of independence after brain injury as seen in the mission of the Brain Injury Association of America\textsuperscript{15}, as well as in the description of the NYS Department of Health TBI Waiver Program\textsuperscript{16}, a state-wide program for people living with traumatic brain injuries.

Including an \textit{ethic of care} framework in both the development and ultimate provisioning of services within the long-term care system would go a long way in attending to the needs of family caregivers, as they exist in relationship to the people they care for. In addition, being truly attentive and responsive, while providing competent services responsibly would offer supports and services to people in ways, which are useful to their specific situations and include each person in the care relationship. An \textit{ethic of care} would have us look at ways which people can be supported outside of the service system as well so that people aren’t only seen as ‘service users’, but people embedded in interpersonal relationships at many different scales- the home, the community, etc. Less of a focus on the development of services and more about the

\textsuperscript{15} \url{http://www.biausa.org/}: “Brain injury is not an event or an outcome. It is the start of a misdiagnosed, misunderstood, under-funded neurological disease. Individuals who sustain brain injuries must have timely access to expert trauma care, specialized rehabilitation, lifelong disease management and \textit{individualized services} (italics added) and supports in order to live healthy, independent and satisfying lives.”

\textsuperscript{16} \url{https://www.health.ny.gov/health_care/medicaid/program/longterm/tbi.htm}: “to assist participants to live in community-based settings and achieve maximum \textit{independence}.” (italics added)
supported living of the caregiver/care receiver dyad would require other ways of looking at how to provide support.

Creative solutions recognizing that caregiving occurs at various times throughout peoples’ lives and that would provide tangible supports are needed to truly support informal family caregiving. For example, direct payments to caregivers for the management of the care they provide would furnish them with funds to pay those they choose to help in the provision of care to the care receiver, since control over the care situation was seen to increase caregiver’s positive experiences of providing care. If families were provided with an automatic caregiver allowance, as is currently provided in countries such as New Zealand\textsuperscript{17} and the UK\textsuperscript{18}, they would be able to pay for whatever they deem necessary, whether directly related to providing care or some other aspect of life, such as housing payments or leisure activities. This is an important point because caregivers express wanting to spend time doing things with the care receiver that they did prior to the injury. A caregiver allowance could be used for travel, museum or movie visits, physical activities or anything else the caregiver/care receiver dyad indicates as important in their lives. In addition, Social Security credits\textsuperscript{19}, which would increase caregiver’s retirement income, even if they necessarily ceased employment outside the home to provide care, would help prevent the creation of the next generation of impoverished elders. This would be particularly important for women, who make up

\textsuperscript{17} See \url{http://www.workandincome.govt.nz/individuals/a-z-benefits/supported-living-payment.html} for more information about New Zealand’s Supported Living Payment.

\textsuperscript{18} See \url{https://www.gov.uk/carers-allowance/overview} for more information on the UK’s Carer’s Allowance.

\textsuperscript{19} In August of 2015, Congresswoman Nita Lowey (NY) recently introduced a bill, the Social Security Caregiver Credit Act, that would provide SS credits to family caregivers who leave paid employment to provide care to family members.
60% of caregivers and give up an estimated $324,000 in wages and benefits over their lifetime (MetLife, 2011).

Truly attentive and responsive support might mean providing people with tangible assistance directly, so they do not necessarily need to interact with the formal long-term care system in their day-to-day lives in order to attempt to get help. As we have seen, these interactions are so difficult that a caring response might be to protect the caregivers from the system, in the ways they protect their loved ones from the same system, whenever possible. This leaves us with recognition that supports and services are potentially separate and instead of developing more services, we need to find out what support looks like to families enmeshed in relationships of care, and to respond accordingly.

**Informal and Formal Caregivers: The invisible link**

Where paid in-home services are in place, there needs to be an attempt to better understand the micro-relationships existing in the home and how these relationships relate to the provision of care and the needs of the caregiver, as well as the care receiver and paid caregivers. Taking the needs of the care triad seriously would require a valuing of care which is missing in popular discussions around caregiving. Respecting and nurturing ‘caregiver teams’ means fully assessing what is good for all involved, in relation to one another. This is very different from services provided using agency regulations as a basis as to what paid caregivers can and can’t do and to whom these services are directed.

The ideology of the individual needs to be examined as a problematic feature of the provision of caregiver and long-term care services in order to shift the discussion
towards the importance of autonomy through relational interdependence. This would reduce the artificial separation existing in current services between the caregiver/care receiver dyad as well as between the dyad and paid caregiver triad.

**Scale of the Household**

Support for caregivers must recognize the importance of the work that caregivers must do, both materially and socially, within the home in order to maintain the places where support services are ultimately delivered. As a result of household negotiations, live-in caregivers are required to tend to household chores as well as the social aspects and relational activities of daily living (RADLs), which are integral parts of peoples’ lives.

Based on the findings from this research, I propose that RADLs be included in measures of caregiver burden to better represent the extent to which the social and emotional activities related to managing the relationships surrounding the caregiver/care receiver dyad as well as the triad that exists when paid in-home services are present.

RADLs become more burdensome as service providers enter the homospace without acknowledging the shared nature of the household, and that the care receiver may no longer be able to contribute sufficiently. This shift in realizing the importance of helping the care receiver contribute to the household could provide tangible assistance to the family caregiver, who is overwhelmed by household level maintenance, at both the material and social levels.

The scale of the household is also where ideas about space and living together come together. We have seen caregivers creatively navigate what it means to live together with someone who requires significant care. Ideally, caregivers would not be
forced to live with or separately from care receivers if either of these situations infringed on the self-care of the caregiver. In some instances living together may be what the caregiver wants, in others they may have a desire for their own, separate space. Re-conceptualizing what “living together” means and how to facilitate various forms of living together while meeting the needs of the dyad must be explored.

With the desire for one’s own space being present, as well as caregivers creative, difficult and costly methods for creating space for themselves, we must recognize that many caregivers would not have the means to support two households. In addition, living together makes sense in many ways, but there needs to be some mechanism for people to move more dynamically through the care relationship and various aspects of living together in way that are currently unavailable, so they don’t get “stuck” in living situations that are not good for them. In addition, an emphasis on support at the household level is important in order to provide household supports to the family so that living together is not unbearable, with all of the aspects of household maintenance and management falling on the family caregiver. Without the benefits of living with others, including their contributions to the household, it may be more appealing for caregivers to live separately from the care recipient. However, many in this study, although they wanted some space for themselves, did not want to live separately. Here, we see the importance of a variety of ways to live with or near the care recipient in ways that are dynamic and alterable, if necessary throughout the life course and potentially long duration of care needs.

A comprehensive long-term care agenda will need to pay attention to and provide financial assistance for housing for care receivers as well as caregivers to support their
ability to live separately, but in very close proximity to the care receiver, if they wish to do so. This study indicates a place-based need to create new forms of dwelling which might better match the care needs and experiences of people in need of care and those who provide it. This should include working on things such as housing policy and collaborating with architects and urban planners to develop zoning initiatives supporting elder cottage-type residences\(^20\) or garage-to-apartment conversions. In cities, a similar arrangement in apartments could be a viable alternative, with apartments being paired for families with care needs who want to reside close, but not in the same apartment. Subsidized assisted living-type residences for care receivers and their family caregivers is an alternative which would recognize the importance of maintaining the relational ties so important to caregiver/care receiver dyads. In general, alternative living arrangements keeping caregivers and care receivers in very close proximity to each other must be explored and developed to address the issues surrounding living together.

The above recommendations must all be considered utilizing an *ethic of care* framework taking as its starting point the interconnectedness of all individuals as well as the relational aspects of providing care to each other. More sensitivity to the care needs of everyone, not only people with extreme care needs due to illness, disability, or advanced age, will provide a foundation upon which long-term care and support can rest. If we all acknowledge our interdependence from the beginning, needing or providing care will be less of a shock when our time inevitably comes.

To be truly caring requires attentiveness, responsiveness, responsibility and competence. This is my attempt to shed light on the uncaring and harmful processes that make life so unbearable for family caregivers enmeshed with the system, as we know it

today. It is also my attempt to re-imagine what a caring long-term care system might look like.

**Future Research**

There are many unanswered questions remaining at the completion of this study. Future research is needed specifically focusing on family caregiver/care receiver dyads in relation to the triads formed with the inclusion of in-home service providers to gain a more nuanced understanding of the micro-relationships between them. For example, when families are present, do professionals see them as helpers or hindrances to the care of and/or independence of the person with care needs? Do families feel included in the life of the person with the disability or as if they are being pushed away by well-intentioned service providers? In addition, research with service providers, including agencies, as well as paid, in-home caregivers is necessary to see if they are aware of how their presence may negatively impact family caregivers. Questions that problematize the presence of the long-term care system, in general and paid in-home caregivers, in particular will shed light on the structural problems inherent in the long-term care system, as well as the micro-relationships between dyads and triads in the homes where care is provided.

In relation to the difficulty I had in recruiting people through service provider agencies, future research should look at why families aren’t involved with people who receive in-home services. Is it that they opt out, for reasons pointed to in this research, or do families abandon their family members to be taken care of by service providers because they need help, but have difficult interactions with providers and chose to leave instead of stay and be traumatized by services? The current assumptions about why
Caregiver support services remain underutilized may be challenged with new information about the difficulties people experience when interfacing with service providers.

Lastly, but of utmost importance, all of the above research must include male caregivers as well as low-income and caregivers who are people of color.
References


Brandon, I.L. (2013). Easing the burden on family caregivers. *Nursing;* 43(8): 36-42. DOI: 10.1097/01.NURSE.0000432098.08196.8d


Higginson, I.J., Gao, W., Jackson, D. Murray, J and Harding, R. (2010). Short-form Zarit caregiver burden interviews were valid in advanced conditions. Journal of


Jennings, A. (1997). Community retraumitazition: Trauma survivors speak out about how they are re-traumatized within community mental health and substance abuse service systems. Maine Department of Behavioral and Developmental Services Office of Trauma Services.


National Alliance for Caregiving. (n.d. b) [http://www.caregiving.org/resources/caregiver-health/](http://www.caregiving.org/resources/caregiver-health/)


Pratt, M.G. (2009). From the editors: For the lack of a boilerplate: Tips on writing up (and reviewing) qualitative research; Academy of Management Journal; 52(5): 856-862.


