

City University of New York (CUNY)

CUNY Academic Works

Dissertations, Theses, and Capstone Projects

CUNY Graduate Center

9-2021

Health-Illness Transition Experiences Among Patients with Pancreatic Cancer

Jessica Goldberg

The Graduate Center, City University of New York

[How does access to this work benefit you? Let us know!](#)

More information about this work at: https://academicworks.cuny.edu/gc_etds/4506

Discover additional works at: <https://academicworks.cuny.edu>

This work is made publicly available by the City University of New York (CUNY).

Contact: AcademicWorks@cuny.edu

Health-Illness Transition Experiences Among Patients with Pancreatic Cancer

Jessica I. Goldberg

A dissertation submitted to the Graduate Faculty in Nursing in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York
2021

© 2021

JESSICA I. GOLDBERG

All Rights Reserved

Health-Illness Transition Experiences Among Patients with Pancreatic Cancer
By
Jessica I. Goldberg

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

Date

Elizabeth Capezuti

Chair of Examining Committee

Date

Juan Battle

Executive Officer

Supervisory Committee:

Steven Baumann

Elizabeth Cohn

Daniel Gardner

Dena Schulman-Green

Judith Nelson

Abstract

Health-Illness Transition Experiences Among Patients with Pancreatic Cancer

By

Jessica I. Goldberg

Advisor: Elizabeth Capezuti

Pancreatic cancer is one of the most commonly diagnosed cancers and is associated with a poor prognosis measured in terms of months and with significant palliative care needs, including psychological distress. Self-management describes a patient's ability to manage the sequelae of serious illness, which can have an impact on quality of life and psychological health. One of the fundamental self-management skills is the management of transitions. A transition is a change in life situation or status that causes a shift in a patient's identity, role, behavior, or interpersonal relationships. Patients with cancer experience multiple, often overlapping transitions that can influence their ability to self-manage.

The aim of this dissertation was to identify transitions experienced by patients with pancreatic cancer and to measure their management of these transitions. This study was guided by the Self- and Family Management Framework and Transitions Theory. In this prospective longitudinal multi-method correlational study, a convenience sample of 55 patients with pancreatic cancer from one medical oncology clinic at Memorial Sloan Kettering Cancer Center were asked to report on their health-illness transition experiences at two time-points with the Measurement of Transitions in Cancer Scale (MOT-CA) and the Distress Thermometer (DT).

Patients reported experiencing multiple health-illness transitions and managed these transitions moderately well. The patients experienced emotional distress, and

there was a correlation between unmanaged transitions and distress at both time points. Patients reported several new transition domains, including financial and caregiver transitions, and described the impact of COVID-19 on their experience. Transitions were found to influence the self-management practices of the patients. Barriers and facilitators to active self-management were identified. Future research is needed to better understand the transition experiences of patients with different tumor types and disease course, and of family caregivers.

Keywords: transition, self-management, distress, pancreatic cancer

Dedication

I would like to express my gratitude to my dissertation committee for their guidance through each step of this process. I am grateful to have had the opportunity to take classes with Dr. Steven Baumann and Dr. Elizabeth Cohn where they challenged me to think about nursing philosophy and theory in new and exciting ways. I have been so lucky to have known and learned from Dr. Dena Schulman-Green for almost the past decade. She has nurtured me as I develop as a nurse researcher and is the source of inspiration for this research. I am grateful to work with Dr. Judith Nelson, who motivates me every day to be a better palliative care clinician and researcher and pushes me to ask the hard questions. Dr. Elizabeth Capezuti has been my steady guide throughout this PhD program. I am grateful for her presence; she has celebrated my success and helped me to learn from the challenges that I have faced.

I am thankful to Dr. Margaret Barton-Burke and the entire staff of the Nursing Research Department at Memorial Sloan Kettering for providing practical support and funding with the Leslie B. Tyson Nursing Research Award. I would like to thank the Robert Wood Johnson Future of Nursing Scholars program which offered financial support for my PhD program and introduced me to an inspiring cohort of fellow nurse researchers.

I am grateful for the support of my friends and my work family in the Supportive Care Service; they provide encouragement when I am feeling defeated and were the reason I survived getting my PhD during COVID. I am forever indebted to the love and support from my siblings, my nieces, and my wonderful parents. My mother, in particular, is my forever cheerleader and I dedicate this work to her.

Table of Contents

Abstract	iv
Dedication	vi
Chapter 1: Background and Study Purpose	1
Background	1
Statement of the Problem.....	3
Significance of the Study.....	4
Purpose Statement and Research Questions	5
Conceptual Framework	5
Chapter 2: Literature Review.....	8
Pancreatic Cancer Treatment	8
Distress	9
Self-management	10
Transitions.....	11
Chapter 3: Methods.....	13
Design	13
Setting	13
Inclusion and Exclusion Criteria	13
Sample Size	14
Variables and Measures.....	14
Transitions.....	14
Distress.	16
Demographic and Clinical Characteristics.....	16
Human Subject Considerations	17
Study Procedures.....	17
Data Management.....	18
Data Analysis	18
Quantitative Assessment.....	18
Qualitative Assessment.....	20
Chapter 4: Results.....	22
Recruitment.....	22

Demographic and Clinical Characteristics	22
Primary Aim 1	22
Frequency of Transitions.....	22
Extent of Transitions.....	23
Management of Transitions.....	23
Need for Improvement in Managing Transitions.....	24
Exploratory Aim 1	24
Exploratory Aim 2	24
Qualitative Findings.....	25
Alternate transition domains.....	25
Characteristics of the transition.	26
Influence of transition on self-management.....	27
Facilitators and barriers to self-management.	28
Chapter 5: Discussion	31
Summary.....	31
Implications for Nursing.....	33
Limitations	34
Conclusion	35
Appendix	36
Appendix Figures	36
Appendix Tables.....	39
IRB Letters	47
References.....	51

List of Figures

Figure 1. Revised Self- and Family Management Framework..... 36
Figure 2. Transition Theory 37
Figure 3. Cohort Diagram..... 38

List of Tables

Table 1. Demographic and Clinical Characteristics.....	39
Table 2. Frequency of Transitions (N = 55).....	40
Table 3. Descriptive Statistics for Extent of Transitions	41
Table 4. Descriptive Statistics for Management of Transitions.....	42
Table 5. Descriptive Statistics for Proportional Need for Improvement (NFI) Composite Score (N= 55).....	43
Table 6. Distress Score by Time	44
Table 7. Correlation Between Proportional Need for Improvement (NFI) Composite Score and Distress (N = 55).....	45
Table 8. Transition Themes.....	46

Chapter 1: Background and Study Purpose

Background

Pancreatic cancer is one of the ten most commonly diagnosed cancers in both men and women and is associated with a poor prognosis (Siegel, Miller, & Jemal, 2019). By 2030, pancreatic cancer will be the second most common cause of cancer-related deaths (Rahib et al., 2014). The mortality rates for most cancer types have declined during the past several decades due to improved screening, detection, and treatment (Loud & Murphy, 2017); however, in pancreatic cancer, the death rate has increased and the five-year survival is currently nine percent (J. Ma & Jemal, 2013; Siegel et al., 2019). Patients with pancreatic cancer have significant palliative care needs (Beesley et al., 2016), including high psychological distress (Carlson et al., 2018; Clark, Loscalzo, Trask, Zabora, & Philip, 2010).

Psychological distress is a common experience for patients with cancer (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Twenty to 40% of all patients with cancer, regardless of diagnosis with solid or hematologic malignancy, will experience distress at some point during the disease trajectory (Mitchell et al., 2011). Psychological distress, as described by the National Comprehensive Cancer Network, is a multidimensional experience that can affect a patient's ability to cope with a cancer diagnosis and its consequences (2018). Several oncologic organizations have published guidelines that highlight the importance of screening, diagnosis, and management of distress in patients with cancer (Andersen et al., 2014; J. C. Holland et al., 2013; Pirl et al., 2014). Despite the national spotlight on cancer-related distress, many patients continue to experience unmet psychological needs, including untreated

distress (J. C. Holland, 2013; Krebber, Jansen, Cuijpers, Leemans, & Verdonck-de Leeuw, 2016; Zebrack et al., 2015).

Self-management is the process or series of tasks in which a patient participates to manage the sequelae of serious illness (McCorkle et al., 2011). The degree to which a patient engages in self-management may affect their quality of life and psychological health, including the experience of cancer-related distress (Richard & Shea, 2011). A key self-management skill is the management of transitions (McCorkle et al., 2011). A transition is a shift that a patient experiences in life situation or status that brings about a resultant change in their identity, role, behavior, or interpersonal relationships (Schumacher & Meleis, 1994). Self-management can influence a patient's ability to respond to transitions in physical and emotional symptoms, spiritual well-being, interpersonal relationships, functional ability and lifestyle (Richard & Shea, 2011).

Patients with cancer experience multiple, often simultaneous transitions, such as physical, emotional, social, and spiritual changes (Geary & Schumacher, 2012). Examples of transitions include changes in sleeping habits, anxiety, employment, relationship with a higher power, and goal of treatment. These transitions can trigger periods of increased distress (Schulman-Green, Bradley, et al., 2012) and can influence a patient's ability to self-manage (Schulman-Green et al., 2011). In patients with a poor prognosis and limited life expectancy, such as those with a pancreatic cancer diagnosis, the presence of multiple simultaneous transitions during a shortened period of time may make self-management particularly difficult, leading to unmanaged transitions.

Statement of the Problem

The aim of this dissertation was to identify transitions experienced by patients receiving tumor-directed therapy for pancreatic cancer and to measure their engagement with these transitions. This population, in whom survival is measured in terms of months, is particularly at risk for poor health outcomes due to experiencing multiple, simultaneous transitions that can cause distress over a brief period of time and this distress can influence their self-management. We aimed to add to the nascent health-illness transition literature and to describe the transition experiences of a different population of patients with a unique disease trajectory.

Significance of the Study

Patients with pancreatic cancer are at an especially high risk of developing psychological distress (Carlson et al., 2018). There is evidence that cancer-related distress has an adverse effect on quality of life (Zenger et al., 2010) and is associated with increased overall mortality (Brown, Levy, Rosberger, & Edgar, 2003; Hamer, Chida, & Molloy, 2009; Russ et al., 2012). Self-management can help to mitigate the emotional experience of cancer, including the development of distress (Howell, Harth, Brown, Bennett, & Boyko, 2017). Patients with a diagnosis of pancreatic cancer likely have limited emotional capacity due to high levels of distress and a short amount of time to learn and integrate self-management skills. Therefore, there is small window of opportunity to reach these patients. In previous work, patients with ovarian and breast cancer reported that simply acknowledging and discussing transitions was a validating experience and played an important role in helping them to identify the source of their distress (Goldberg, Hinchey, Feder, & Schulman-Green, 2016).

Management of transitions is an important self-management skill (Schulman-Green, Jaser, et al., 2012), and previous research has demonstrated that patients with breast (Schulman-Green et al., 2011) and ovarian cancer (Schulman-Green, Bradley, et al., 2012) experience increased distress during times of transition. This relationship has not yet been studied in other cancer populations; however, if it is shown to be more widely applicable, this work may provide a foundation for an intervention to improve the psychological health and quality of life for patients with cancer, including the particularly vulnerable population of patients with pancreatic cancer.

Purpose Statement and Research Questions

The specific aims of this study were:

Primary Aim 1: Identify the pattern(s) of transitions, the management of the transitions, and the need for improvement in managing the transitions in patients with pancreatic cancer who are receiving chemotherapy.

Hypothesis: Patients with pancreatic cancer will report multiple, overlapping health-illness transitions. They will report difficulty managing the personal and care transitions.

Exploratory Aim 1: Explore the relationship between demographic (gender, age, race) and clinical (tumor type, time since diagnosis, stage) factors and the need for improvement in managing transitions.

Hypothesis: In patients with pancreatic cancer, diagnosis with stage IV adenocarcinoma and recent diagnosis will be associated with unmet transition needs.

Exploratory Aim 2: Explore the relationship between distress and the need for improvement in managing transitions.

Hypothesis: Patients who report that they have unmanaged transitions will report distress.

Qualitative Assessment: Conduct thematic analysis of the responses to the question (“Is there anything else about your transition experience that you would like to add?”).

Conceptual Framework

The study of transitions is guided by the Self- and Family Management Framework (Grey, Knafl, & McCorkle, 2006; Grey, Schulman-Green, Knafl, & Reynolds, 2015) and the Theory of Transitions (Schumacher & Meleis, 1994). The Self- and

Family Management Framework describes how facilitators and barriers can influence the process of self-management, which in turn affects individual and health outcomes in patients with chronic illness (Grey et al., 2006; Grey et al., 2015) (Figure 1). Facilitators and barriers that affect self-management include personal and lifestyle qualities, health status, resources, environmental characteristics, and the health care system (Grey et al., 2015). The framework describes three main self-management processes, focusing on illness needs, activating resources, and living with the condition (Grey et al., 2015). Although the framework does not use the language of “transitions”, it does highlight the importance of acknowledging and managing change as a self-management task. Specifically, the transition experience is reflected in the self-management process of living with the condition, which in part describes a patient’s ability to adjust to and integrate the chronic illness in their life.

Transition theory is a middle-range theory that provides a comprehensive view of the transition experience and highlights the importance of the role of the nurse in this process (A. I. Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Schumacher & Meleis, 1994). The theory describes four fundamental components: the nature of the transition; facilitators and barriers to the transition; patterns of response; and nursing therapeutics (A. I. Meleis et al., 2000) (Figure 2). Each of these components affects the other bidirectionally. The nature of transitions encompasses the types, patterns, and properties of the changes. The transition conditions, explained as the facilitators and barriers, can be categorized as personal, community, and society. The patterns of response include process indicators and outcome indicators.

Transition theory demonstrates that transitions are complex experiences with several fundamental properties, including awareness, engagement, change and difference, time span, and critical points and events (A. I. Meleis et al., 2000). Awareness refers to the knowledge and recognition that one is experiencing a transition, which is one of the defining characteristic of a transition (Chick & Meleis, 1986). Engagement describes the degree of involvement in the processes of the transition, such as seeking out help and information from medical providers and making changes to one's lifestyle (A. I. Meleis et al., 2000). Change and difference are essential to the transition experience (A. I. Meleis & Trangenstein, 1994); all transitions are triggered by a change, and all transitions result in a change. Critical points and events are also important in the transition experience. Transitions are both triggered by a critical point and cause a series of events to occur (A. I. Meleis et al., 2000).

The characteristics of the Self- and Family Management Framework and the Theory of Transitions help to guide the aims of the study. Aim 1 tested fundamental tenets of the transition experience, including the awareness and engagement with the transition and the presence of changes and critical points. Additionally, Aim 1 acknowledged the importance of changes over time in the transition experience. Therefore, in the study, patients were asked to identify the transitions they have experienced and their engagement with the process at two different time points. The experimental aims explored the patterns of response to transitions, and specifically examined whether there is a relationship between the transition experience and the presence of psychological distress.

Chapter 2: Literature Review

In 2021, it is projected that almost two million new patients will be diagnosed with cancer in the United States and more than six hundred thousand will die from cancer (Siegel, Miller, Fuchs, & Jemal, 2021). Patients with cancer report a significant burden which may be related to the cancer itself or to the treatment (Stark, Tofthagen, Visovsky, & McMillan, 2012). The most commonly reported physical symptoms include pain, fatigue, nausea/vomiting, and gastrointestinal issues (Deshields, Penalba, Liu, & Avery, 2017; Wochna Loerzel, 2015). The most frequently reported psychological symptoms include worry, anxiety, and depression (Deshields, Potter, Olsen, Liu, & Dye, 2011; Jimenez et al., 2011). The physical and psychological symptom burden contributes to the prevalence of cancer-related distress in many patients (Mehnert et al., 2018; Thiagarajan et al., 2016).

Pancreatic Cancer Treatment

Few patients diagnosed with pancreatic cancer have localized disease that will allow for surgical resection (White & Lowy, 2017), and the majority will experience recurrence of their disease (Sahin, Elias, Chou, Capanu, & O'Reilly, 2018). Therefore, the NCCN guidelines recommend the use of adjuvant chemotherapy for all patients diagnosed with pancreatic cancer (Tempero et al., 2019). The two most common chemotherapy regimens for patients with pancreatic cancer are Gemcitabine/Abraxane (Von Hoff et al., 2013) and FOLFIRINOX (Conroy et al., 2011). In the Gemcitabine/Abraxane protocol, patients receive medication on days one, eight, and fifteen, and the cycles of treatment repeat every 28 days. In the FOLFIRINOX protocol,

patients receive Oxaliplatin, Irinotecan, and Leucovorin on day one, and Fluorouracil on days one and two. The FOLFIRINOX cycle repeats every 14 days. Regardless of the chemotherapy regimen, all patients undergo restaging scans every three months. These treatments are associated with varied side effects, including fatigue, peripheral neuropathy, neutropenia, thrombocytopenia, and anemia, which may be chronic and have a significant impact on quality of life (Hronek & Reed, 2015).

Distress

The National Comprehensive Cancer Network (NCCN) defines distress as “a multifactorial unpleasant experience... that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (2018). Distress exists along a continuum, and patients may develop feelings that range from sadness to anxiety and depression, leading to a psychological crisis (National Comprehensive Cancer Network, 2018). Over the past decade, there has been an increased focus on the importance of distress to the cancer experience. In 2009, the International Psycho-oncology Society designated distress as the sixth vital sign (J. Holland, Watson, & Dunn, 2011). In 2012, the American College of Surgeons Commission on Cancer published guidelines which mandated routine distress screening as a requirement for accreditation (Commission on Cancer, 2012).

Numerous systematic reviews and meta-analyses have addressed the potential benefit of various interventions to decrease the distress burden of patients with cancer. The results from many of these reviews are mixed (Chien, Liu, Chien, & Liu, 2014; Faller et al., 2013; Graves, 2003; Hersch, Juraskova, Price, & Mullan, 2009), making it

difficult to draw systematic conclusions. In addition, although the studies included patients with various tumor types at different stages, the majority focused on women with non-metastatic breast cancer (D'Egidio et al., 2017; Duijts, Faber, Oldenburg, van Beurden, & Aaronson, 2011; Huang, He, Wang, & Zhou, 2016). There emerges a need to better understand and to explore the distress experiences among a wider population of patients.

Self-management

Self-management refers to the tasks that patients complete to manage a chronic illness (Lorig & Holman, 2003) and improve overall quality of life (Schulman-Green, Brody, Gilbertson-White, Whittemore, & McCorkle, 2018). The goal of self-management is to maximize functioning and improve physical and psychological well-being (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Integral self-management skills include problem solving, goal setting, decision making, resource utilization, relationship-building with health care providers, development of a plan for action, and self-tailoring (Lorig & Holman, 2003). Self-management is a dynamic process that is relevant throughout the cancer trajectory, from diagnosis to survivorship or end of life (McCorkle et al., 2011; Schulman-Green et al., 2018). As the experience of living with cancer changes over time, the self-management processes that are valuable to and helpful for a patient may shift (Schulman-Green et al., 2018; Schulman-Green, Jaser, et al., 2012). There is a strong bi-directional relationship between self-management and distress; self-management skills can be used to decrease the experience of distress (Howell et al.,

2017), but distress, in turn, can interfere with a patient's ability to self-manage (Schulman-Green, Jaser, Park, & Whittemore, 2016).

Transitions

A transition is a life change that influences a patient's identity, relationships, and behaviors (Schumacher & Meleis, 1994) and represents a central concept in nursing practice (Im, 2011). The relationship between the nurse and the patient is often most important during a time of transition (Harrison, 2004; A.I. Meleis, 2010). Nurses need to be able to identify times of transition and to recognize how patients will react to transition in order to be effective in their role and to ultimately affect the outcome of the transition (Harrison, 2004; A.I. Meleis, 2010). The role of the nurse is to facilitate transitions in their patients, namely to prevent risks from unmanaged transition and changes due to the transitions, to promote good health, and to teach self-management skills (A.I. Meleis, 2010; Schumacher & Meleis, 1994).

Transitions are complex but can be characterized by several key processes: an inciting critical event such as a diagnosis of cancer and the subsequent awareness, engagement, and adjustment by the patient over time (A.I. Meleis, 2010). The patient engagement and adjustment over time are key steps in this process and are necessary to ensure mastery or management of the transition experience. Unmanaged transitions can result in worse health outcomes (A. I. Meleis et al., 2000). There are several conditions that influence the experience of transitions. These include the meaning individuals attach to a transition, their expectations for the transition, their level of

knowledge or skill related to the transition, the surrounding environment, their level of planning, and their emotional and physical well-being (Schumacher & Meleis, 1994). Schumacher and Meleis described four distinct categories of transitions: developmental; situational; organizational; and health-illness (1994). The experience of cancer patients can best be explained as health-illness transitions, which are changes that occur with a diagnosis of an illness (Schumacher & Meleis, 1994). The majority of the previous work on health-illness transitions has focused narrowly on care transitions, which include changes in cancer status, treatment type, or goals of care (Duggleby et al., 2010; Kantsiper et al., 2009; Miller et al., 2015; Schulman-Green et al., 2011; Vaartio, Kiviniemi, & Suominen, 2003); however, patients with cancer have reported that their experience is not limited to care transitions and also endorse the importance of personal health-illness transitions, which incorporate physical, emotional, social, and spiritual changes (Schulman-Green, Jeon, McCorkle, & Dixon, 2017).

The health-illness transition experience of cancer patients is varied and complex. While not a novel concept, cancer patients describe transitions as a new way of thinking about times of change (Goldberg et al., 2016). Patients with breast cancer have reported that transitions may be a positive, negative, or neutral experience (Schulman-Green et al., 2011). They also describe that times of transitions are associated with increased reliance on their support network (Schulman-Green et al., 2011).

Chapter 3: Methods

Design

In this prospective longitudinal multi-method correlational study, a convenience sample of patients with pancreatic cancer receiving tumor-directed therapy were asked to report on their health-illness transition experiences.

Setting

Patients were approached for their voluntary participation in one medical oncology clinic at Memorial Sloan Kettering Cancer Center (MSKCC). MSKCC is a National Comprehensive Cancer Institute that serves an international population of patients. The designated medical oncology clinic, led by a single attending oncologist, cares primarily for patients with hepatobiliary malignancies, including pancreatic cancer. This clinic was selected as it sees the highest volume of patients with pancreatic cancer at MSKCC and would allow for standardization of the research practices. In 2017, over 750 new patients with a diagnosis of pancreatic cancer were seen at MSKCC.

Inclusion and Exclusion Criteria

The inclusion criteria for this study were: 1) adult patients 21 years of age and older; 2) read and understand English; 3) biopsy-proven diagnosis of pancreatic cancer; and 4) within the first three months after initiating chemotherapy at the Rockefeller Outpatient Pavilion at MSKCC. The exclusion criterion was: 1) previous history of cancer.

Sample Size

For the study, we calculated sample size for our primary outcome, the Measurement of Transitions in Cancer Scale (MOT-CA) (Schulman-Green et al., 2017), using a two-tailed Wilcoxon signed-rank test and an alpha adjusted for multiple (7) comparisons ($\alpha = 0.008$) (Faul, Erdfelder, Lang, & Buchner, 2007). A sample size of 55 had 80% power to detect a change in MOT-CA between the two time points at a 5% significance level.

Variables and Measures

Transitions.

Transitions were measured with The Measurement of Transitions in Cancer Scale (MOT-CA) (Schulman-Green et al., 2017), a tool that was developed to identify cancer-related transitions that patients experience and to measure how well they believe they have managed each transition. There is a tool that measures exclusively the site of care transitions (Coleman et al., 2002); the MOT-CA is the only scale that exists to measure the complete health-illness transition experience. The MOT-CA measures seven transition domains (physical, emotional, social, spiritual, cancer status, treatment, approach to care) which correspond to seven health-illness transitions reported by patients with breast and ovarian cancer (Schulman-Green et al., 2011; Schulman-Green, Bradley, et al., 2012) and are guided by the Self- and Family Management Framework (Grey et al., 2015). The seven transition domains of the MOT-CA are categorized as either Personal (physical, emotional, social, spiritual) or Care (cancer status, treatment, approach to care) Transitions. Factor analysis has

demonstrated that Personal ($\alpha = 0.74$) and Care ($\alpha = 0.79$) are distinct and have an inter-factor correlation of 0.323 (Jeon, Schulman-Green, McCorkle, & Dixon, 2019). The only published use of this tool has been in population testing with breast cancer patients (Goldberg et al., 2016).

The MOT-CA has seven items, and each item has two parts. The first part of each item refers to the extent of the transition (part A) and the second part refers to the management of the transition (part B). Thus, patients are first asked to rate the amount of change they have experienced within the past month for each transition (from '0= no change' to '10= complete change') and next how well they have dealt with the transition (from '1= not well at all' to '10= very well'). Patients can designate 'no change' and 'N/A' if they have not experienced a particular transition. The scores on part A can be stratified; 1-3 means little transition, 4-6 means moderate transition, and 7-10 means much transition (Schulman-Green et al., 2017). On part B, lower scores mean that the transition was not managed well and higher scores mean that the transition was well managed. The MOT-CA has not been used in the pancreatic cancer population. In an effort to evaluate validity in this population, the author of the tool (DSG) agreed to allow the researcher to add a question to the end of the assessment asking for additional comments about the transition experience ('Is there anything else about your transition experience that you would like to add?'). After a review of the first several responses and identification of several common themes, the researcher added several additional questions including, "Did COVID affect your transition experience?", "Did you experience any financial transitions?", and "Did you experience any caregiver transitions?". The responses to these questions were transcribed verbatim.

Distress.

Distress was measured with the Distress Thermometer (DT), which was developed by the NCCN Distress Management Panel ("NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network," 1999; Roth et al., 1998). The DT is one of the most commonly used tools to measure distress in cancer patients (Donovan, Grassi, McGinty, & Jacobsen, 2014). The reliability and validity of the DT has been described in multiple cancer populations (Chambers, Zajdlewicz, Youlden, Holland, & Dunn, 2014; Gessler et al., 2008; X. Ma et al., 2014; Wiener, Battles, Zadeh, Widemann, & Pao, 2017), although never specifically in a pancreatic cancer population. All patients at Memorial Sloan Kettering receive the DT as part of their new visit documentation.

The DT is a one item, 11-point visual analog scale superimposed on a graphic of a thermometer. Patients are asked to rank how much distress they have experienced in the past week on a scale that ranges from 0 ('no distress') to 10 ('extreme distress'). Scores less than four are reflective of mild distress, and any score of four or above indicates clinically meaningful distress (J. C. Holland et al., 2013).

Demographic and Clinical Characteristics.

The following demographic and clinical data were collected from the electronic medical record (EMR) to describe the sample: age; gender; race; date of diagnosis; primary tumor histology; cancer stage; chemotherapy regimen; date of initiation of chemotherapy; and date of death.

Human Subject Considerations

Human subject approval was granted by the Institutional Review Board at MSKCC (IRB #20-028) and the Human Research Protection Program (HRPP) at CUNY/Hunter College (2020-0174).

Study Procedures

The researcher, as an employee of MSKCC and with the approval of the medical clinical administrator and the MSKCC IRB, identified potentially eligible patients by reviewing the medical oncology clinic list in the electronic medical record. A list of the patients who met the study inclusion criteria was emailed to the medical team (medical oncologist, nurse practitioner, and registered nurse) one business day before the clinic was held. On the day of the clinic, the researcher (JG) approached the eligible patients in the chemotherapy clinic suite for informed consent. Consented patients received a number (assigned sequentially), which was used for identification on all study documents, and they were asked to complete paper copies of the DT (Distress Thermometer; ("NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network," 1999; Roth et al., 1998) and the and MOT-CA (Measurement of Transitions in Cancer Scale; (Schulman-Green et al., 2017) (Time 1). The researcher also identified and documented demographic and clinical variables from the EMR. The researcher tracked the patients' subsequent medical oncology visits using the EMR. Four to six weeks after the baseline visit, the patients again completed the DT and MOT-CA at a chemotherapy treatment visit (Time

2). This time point was chosen to follow patients long enough so that all had completed at least one cycle of chemotherapy and had enough time to experience a transition, although short enough that the majority of the patients had not become severely debilitated. In the event that a patient did not complete assessments at both time points, due to drop-out or death, they were not included the final analysis.

Data Management

The original paper copies of the study documents (consent form, DT, MOT-CA) and the list linking the participants name to the participants study identification numbers were housed in a locked file cabinet in a locked office which can only be accessed by approved study personnel. Data collected for this study were entered by the researcher without any personal identifiers into the Research Electronic Data Capture Database (REDCap) (Harris et al., 2009). REDCap is an open-source platform that allows for the secure collection of data using a web-based interface. Data was housed in the MSKCC New Jersey data center. The MSKCC Information Systems group is responsible for applying all operating system patches and security updates to the REDCap servers. All connections to REDCap utilize encrypted (SSL-based) connections to ensure data is protected and the server is backed up nightly. Only the MSKCC members of the research personnel have access to this data.

Data Analysis

Quantitative Assessment.

The plan for data analysis was as follows:

Frequencies and descriptive statistics were used to summarize the demographic and clinical characteristics of the sample.

Primary Aim 1: Identify the pattern(s) of transitions, the management of transitions, and the need for improvement in managing the transitions in patients with pancreatic cancer who are receiving chemotherapy.

Frequencies and descriptive statistics were calculated for the transition variables (presence of change, extent of the change, management of the change, and need for improvement in management) at both time points. The proportional need for improvement (NFI) in management score measures unmanaged transitions and is the preferred method to analyze the correlation between extent of the transition and management of the transition (Jeon et al., 2019). The NFI is calculated as $[(10 - \text{management of transition})/10] \times \text{extent of transition}$. A score of zero reflects either successful management of the transition or a minor transition. The higher the NFI score, the greater the need for improved management. Differences between the transition variables at the two time points were calculated using a two-tailed Wilcoxon signed rank test.

Hypothesis: Patients with pancreatic cancer will report multiple, overlapping health-illness transitions. They will report difficulty managing the personal transitions.

Exploratory Aim 1: Explore the relationship between demographic (gender, age, race) and clinical (tumor type, time since diagnosis, stage) factors and the need for improvement in managing transitions.

The demographic and clinical factors were made into categorical (gender, race, tumor type) and continuous (age, time since diagnosis) variables. The relationship between the categorical factors (gender, race, tumor type) and the need for improvement in managing transitions (NFI) for each of the seven transition domains was calculated using a two-tailed Wilcoxon rank sum test. The relationship between the continuous factors (age, time since diagnosis) and the need for improvement in managing transitions (NFI) for each of the seven transition domains was calculated using Spearman's correlation.

Hypothesis: In patients with pancreatic cancer, diagnosis with stage IV adenocarcinoma and recent diagnosis will be associated with unmanaged transitions.

Exploratory Aim 2: Explore the relationship between distress and the need for improvement in managing transitions.

Frequencies and descriptive statistics were calculated for the distress score (on the DT) at both time points. Correlation between the distress score and the need for improvement in managing transitions were explored using Spearman's correlation.

Hypothesis: Patients who report that they have unmanaged transitions will report distress.

Qualitative Assessment.

The patient responses were synthesized using deductive thematic analysis; familiarizing yourself with the data, generating initial codes, searching for themes, and collapsing and redefining themes (Braun & Clarke, 2006). Two authors (EC and JG) independently coded the patient responses using inductive analysis. They then

compared and discussed their codes and resolved any discrepancies. Themes were identified and the corresponding codes were grouped together. The final code key consisted of five themes and nineteen codes and was applied to all of the patient responses.

Chapter 4: Results

Recruitment

154 patients were screened for eligibility, and 96 were deemed ineligible. Of the 58 eligible patients, 56 consented to participate in the study and completed the Time 1 data collection. One patient died before the Time 2 assessment and was not included in the final analysis. In total, 55 patients completed the questionnaires at the two time points (Figure 3).

Demographic and Clinical Characteristics

Approximately half of the sample was female (51%), and most were white (87%) and older (Median age= 70 years, range 48-82). Median time from diagnosis to consent was four months (range 0-50). Most of the participants had a diagnosis of stage IV (75%) pancreatic adenocarcinoma (98%), and few (22%) had undergone a Whipple procedure before study enrollment. The most common chemotherapy regimens were FOLFIRINOX (45%) or Gemcitabine/Abiraxane (31%) (Table 1).

Primary Aim 1

Frequency of Transitions.

The frequency of experiencing a transition ranged from 29 to 90% for all of the transition domains at Time 1, with 50% or more patients describing at least some physical, emotional, social, cancer status, and treatment transitions. At Time 2, the frequency of transitions ranged from nine to 96% for the seven transition domains, with proportions of 50% or more for physical, emotional, and social transitions only. The

frequency of care transitions (cancer status, treatment, approach to care) significantly decreased between Time 1 and Time 2 ($p < 0.05$) (Table 2).

Extent of Transitions.

Part A of the MOT-CA question asks about the extent of transition experienced. Among those patients who reported experiencing a transition, the mean extent of change ranged from 2.88 to 8.75 at Time 1 and from 2.42 to 8.38 at Time 2. At Time 1, patients described much transition in cancer status and treatment. By Time 2, only treatment transitions were frequently reported. Patients experienced moderate amounts of physical and emotional transitions and little spiritual transitions at both time points. Overall, the extent of each of the seven transition domains decreased between Time 1 and Time 2 (Table 3).

Management of Transitions.

Part B of the MOT-CA question asks about the management of the transition. Among the patients who experienced a transition, the mean management ranged from 4.46 to 7.58 at Time 1 and from 4.62 to 7.68 at Time 2. Overall, the patients reported that they managed all transitions at least moderately well. At both time points, patients described better management of the personal transitions (physical, emotional, social), in comparison to the care transitions (cancer status, treatment, approach to care) (Table 4).

Need for Improvement in Managing Transitions.

The proportional need for improvement (NFI) is a composite score that combines the extent and management of a transition (Jeon et al., 2019). The mean NFI score ranged from 0.29 to 2.35 at Time 1 and from 0.17 to 2.12 at Time 2. Overall, the patients reported successful management of the transitions at both time points. The need for improvement in management significantly decreased for the care transitions (cancer status, treatment, approach to care) between Time 1 and Time 2 (Table 5)

Exploratory Aim 1

At Time 1, women were more likely to have unmanaged emotional transitions (2.50 vs 0.60, $p = 0.002$), and patients with locally advanced disease reported more unmanaged social transitions (1.55 vs 0.40, $p = 0.030$). There were no statistically significant relationships between the need for improvement in management composite score and race, age, or time since diagnosis at either Time 1 or Time 2 ($p > 0.05$). Since the majority of the sample (98%) had pancreatic adenocarcinoma (in comparison to pancreatic neuroendocrine), tumor type was not included in the analysis.

Exploratory Aim 2

The level of distress reported by patients at all time points (first MSK visit, Time 1, Time 2) was unchanged ($M = 3.87, 4.07, 4.02$) (Table 6). At Time 1, patients with greater levels of unmanaged physical, emotional, and cancer status transitions reported more distress. At Time 2, patients with higher levels of unmanaged physical, emotional, social, spiritual, cancer status, and treatment transitions experienced greater distress.

The correlation between unmanaged emotional transitions and distress was moderate ($r_s = 0.60$) at Time 1 and high ($r_s = 0.82$) at Time 2 (Hinkle, Wiersma, & Jurs, 2002) (Table 7).

Qualitative Findings

Thirty-one of the patients provided 46 responses to the open-ended question about their transition experience. The statements were organized into four themes: alternate transition domains, characteristics of the transition, influence of the transition on self-management, and facilitators and barriers to self-management (Table 8).

Alternate transition domains.

Patients identified several alternate transition domains that were not reflected on the MOT; they included COVID transitions, financial transitions, and caregiver transitions. Many of the patients described the influence of COVID-19 on their cancer experience as a source of increased anxiety, social isolation, and in one patient who had a concurrent diagnosis of COVID, increased vigilance and awareness of physical symptoms. Several of the patients explained that the COVID-19 pandemic was the source of a transition that was unique from any triggered by their cancer diagnosis.

COVID changed everything for us. My wife and I are both doctors and we changed our practice to 100% telemedicine. I've totally isolated myself... we used to be really social and would be out to dinner every night. Now I basically never see friends in person. It's 100% from COVID, not the cancer.

Patients frequently mentioned the financial changes that they experienced. For many of these patients, the financial transitions included changes in job status or insurance coverage. Several of the patients described these financial changes as a distinct transition experience, which was associated with increased uncertainty and distress.

MSK doesn't take my insurance anymore so I'll be getting treatment at Yale.

Maybe this will be a good change... it's just been so expensive every time we come into the city, it's been a constant problem. This is all a lot to take. I'm sure it'll be fine in the end but it seems like a big deal now.

Many patients also reported their family caregivers experienced transitions as a result of the patient's cancer diagnosis.

My wife's life has changed a lot. She's definitely been praying more. She had to go back to work. I don't know that she loves going back to work. I'm now Mr. Mom around the house.

Characteristics of the transition.

Patient reported several characteristics of the transition, including that their experience shifted throughout the disease course and that they frequently used avoidance. Many patients described that the way that they engaged with and experienced a transition changed over time. For many of these patients, the cancer diagnosis acted as an inciting event which triggered multiple simultaneous changes or transitions. Over time, patients became acclimated to the ways that these transitions influenced their life.

I think I'm pretty used to the ebb and flow by now. If you'd asked me in the beginning it was a different story. My whole life had to change... cut back on work hours, stopped going out, prayed much more. Now this seems like the new normal.

Several patients described not wanting to acknowledge that they were experiencing a transition.

There might be a difference between actual change and what someone might acknowledge. I don't want to see changes in my body but if my wife was here she might tell you something different.

These patients may have used avoidance as a protective measure against the uncertainty and distress experienced during a transition.

I try not to think about all of it... I guess I'm the wrong person to ask. My wife jokes that I could look past a burning house. It's always been easier to not think too much about what's going on.

Influence of transition on self-management.

Patients described having difficulty engaging in self-management when they were experiencing a transition. Physical transitions, most notably, changes in pain level, affected patient's ability to participate in self-management.

This month hasn't been great... it feels like it's catching up with me. The pain is definitely worse now, that's really wearing me down. When I feel awful it's hard to face anything else.

The experience of emotional transitions, and the presence of uncertainty, also interfered with self-management practices.

I feel suspended, like I'm attached to a wire. I can't go forward or backward.

There's so much uncertainty... that's been the biggest change. I can't live my life.

I don't know what'll happen next. Makes it hard to know how to help myself.

Facilitators and barriers to self-management.

The patient reports several facilitators to participating in self-management, including gaining knowledge and receiving support. Patients described the importance of seeking out information about pancreatic cancer and its treatment and described having a sense of control as a result of this knowledge.

Now I'm in a good place. I had to understand the data and pay attention to the science to get past how scary the diagnosis is. Now I know the numbers and that's been helpful.

Many of the patients identified the importance of social support in their coping, particularly the support from their family caregivers.

My husband is my nurse. I used to do everything- cooking, cleaning. Now it's all him, he's a new man. I never asked him... expected him to do housework. Now he spoils me. All this doesn't seem so bad because I have support.

Patients also described the importance of the support they received from their primary oncology nurse. For many of these patients, the nursing support helped to alleviate uncertainty and distress.

I feel supported- that makes all the difference. The nurses here know what to expect, they're always checking in and have something to recommend. I'm not left to my own devices. I don't have to figure out how to cope when things change.

One patient even explained that their family was having a more difficult time coping with the changes because they did not have the same level of support from the nursing staff.

My kids have been having more difficulty with the day-to-day. Their lives have changed more, I think more than me. I get to come here, I have the nurses for support. My kids are more isolated- they're not the ones with cancer, they don't have the same support.

Several patients described feeling supported by their religious beliefs and identified prayer as an important self-management skill.

Prayer has been the most helpful. My faith gives me strength and when I'm feeling challenged, stuck, I turn to prayer.

One of the most commonly cited barriers to participating in self-management was financial difficulties. Many of the patients described feeling overwhelmed by the costs associated with the cancer experience and the resulting financial strain.

There've been a lot of out-of-pocket costs I never expected. It's not even the big things- the meds or treatment. It's been the small things that add up every month. For treatment we take the train to the city, stay in a hotel, and then take cabs. It really adds up. I think it's been the hardest part.

Although caregiver support was frequently cited as a positive influence for patients, many also described negative consequences as a result of their increased reliance on the caregivers. Patients reported feeling dependency guilt and identified sources of family stress.

My daughter's life absolutely changed in a heartbeat. I didn't expect her to rearrange things so much in her life but it's been really helpful. Of course I feel guilty, she should be living her own life, but instead she worries about me all the time. I know it puts a lot of emotional strain on her.

Chapter 5: Discussion

Summary

We found that patients with pancreatic cancer who were receiving chemotherapy experienced multiple overlapping health-illness transitions; the most commonly reported were physical, emotional, and social transitions. For most patients, the extent of the transitions decreased by Time 2, four to six weeks after study enrollment. Overall, patients reported that they managed these transitions moderately well, although the personal transitions were managed better than the care transitions. The patients experienced clinically significant levels of distress, which did not change over time. There was a correlation between unmanaged transitions and distress at both time points.

Patients' descriptions of their overall transition experience confirmed much of the previous understanding about health-illness transitions. The patients with pancreatic cancer in this study described experiencing uncertainty during a transition and also identified that their physical and emotional symptoms influenced the transition experience (Schumacher & Meleis, 1994). Additionally, the patterns of transitions reported by patients in this study were similar to those experienced by patients with breast cancer (Goldberg et al., 2016). In both studies, the personal transitions (physical, emotional, social, spiritual) were reported more frequently than the care transitions (cancer status, treatment, approach to care). However, in the previous work with breast cancer patients there was little difference in the management of the transitions; in the current study, patients reported greater difficulty with management of the care transitions. This finding may reflect the difference in prognosis between breast and

pancreatic cancer; perhaps the patients with pancreatic cancer found managing their transitions more difficult in the context of a poor prognosis.

The MOT-CA was designed to describe the broad categories of health-illness transitions (Schulman-Green et al., 2017). This tool has not been extensively used in previous research, though in this study, seemed to accurately reflect the overall transition domains experienced by patients with pancreatic cancer. However, the patients in this study did describe transitions that were not included in the MOT-CA. Many patients reported experiencing significant financial stress and associated financial transitions. This finding is consistent with a growing body of literature which highlights that patients with advanced cancer may experience financial toxicity related to transitions (Kayser, Smith, Washington, Harris, & Head, 2021) and often report that their out-of-pocket costs were higher than they expected (Chino et al., 2017). There is evidence that in patients with cancer, financial toxicity is associated with worse quality of life outcomes (Arastu et al., 2020).

Additionally, many patients in this study described that their family caregivers underwent their own transitions as a result of the cancer diagnosis. However, this is from the patient's perspective only; it is not yet clear whether the caregivers would confirm this observation. The health-illness transition experience of family caregivers is not well understood; much of the research focuses on the caregivers' response when their loved one undergoes a transition (Petrin, Bowen, Alfano, & Bennett, 2009; Wong, George, Godfrey, Le, & Pereira, 2019). Future iterations of the MOT-CA should incorporate these findings and evaluate for the presence of financial and caregiver transitions.

One unexpected finding from this study was that overall, the patients reported only moderate levels of transitions. The frequency of transitions was similar between the sample of patients with non-metastatic breast cancer in previous work (Goldberg et al., 2016) and in this sample of patients with advanced and metastatic pancreatic cancer. One possible explanation for this finding may be that patients are unaware or unwilling to acknowledge the presence of a transition. It is possible that there is a difference between unconscious and conscious transitions (Fringer, Hechinger, & Schnepf, 2018). For example, a patient in the early stages of a social transition may start to unconsciously demonstrate increased reliance on their family caregiver. This change could continue unconsciously until the patient and their caregiver are forced to be active in the process and make adjustments to their behavior and decisions. In the seminal work on transition theory, awareness of the transition was identified as a key property of the transition experience (Chick & Meleis, 1986). However, more recent scholarship has challenged this and suggested that a transition may exist regardless of the acknowledgement by the patient; these authors describe that the nurse's knowledge of the transition may be sufficient (A. I. Meleis et al., 2000). Perhaps the use of only patient self-report for the identification of transitions is not sufficient to accurately describe the transition experience.

Implications for Nursing

Nurses have an opportunity and a responsibility in shaping the health-illness transition experience of patients with cancer. The role of the nurse has always been an important component of the transition theory (Chick & Meleis, 1986) and nurses can

influence the preparation for and education and management of health-illness transitions (Schumacher & Meleis, 1994). Palliative care and hospice nurses in particular, are “transition specialists” (Ferrell, 2021) and are uniquely suited to guide patients through the transition experience.

Limitations

Our study has a few limitations, including that the sample of patients was largely homogenous in its racial background. In the United States, Black individuals are more likely to be diagnosed with and die from pancreatic cancer as compared to whites regardless of age (Zavala et al., 2021). As a result, it is unclear if the findings from this study would be generalizable to a larger, more diverse population. Additionally, the patients were eligible for enrollment if they were receiving chemotherapy, and therefore patients who were being treated with immunotherapy and other targeted treatments were excluded. As the second- and third-line treatment options for pancreatic cancer continue to evolve beyond the traditional chemotherapy regimens (Sohal et al., 2020), patients may have different transition experiences. The patient sample was also consented from a single oncology clinic in a dedicated cancer center, and therefore may not be generalizable to a different care setting. In addition, the results may have been influenced by the study time period. The timeframe may have been too short for some of the patients to experience a transition, or to acknowledge the presence of a transition.

The most significant limitation that may have influenced the data of this study was the presence of the COVID-19 pandemic. The patients in this study were all

enrolled several months after the appearance of COVID in the United States. Cancer care was influenced by COVID; many visits with the oncologist were switched from in-person to telemedicine, and patients were no longer allowed to have companions during office visits or while receiving treatment (Al-Shamsi et al., 2020). These changes may have influenced the transition experience by changing the relationship between the patient and the health-care providers or by impacting the involvement of the family caregivers. Several of the patients enrolled in this study had a previous or concurrent diagnosis of COVID and many described the COVID pandemic as a source of increased distress and uncertainty.

Conclusion

This study describes health-illness transition experiences of patients with pancreatic cancer and adds to the nascent literature about how the extent and management of transitions varies by tumor type. Future research should focus on the experience of patients with cancers that follow a different disease course, such as patients with hematologic malignancies who are treated with the expectation for cure, minority patients, and those who are uninsured. In addition, more research is needed to identify and describe transition domains particular to family caregivers.

Appendix

Appendix Figures

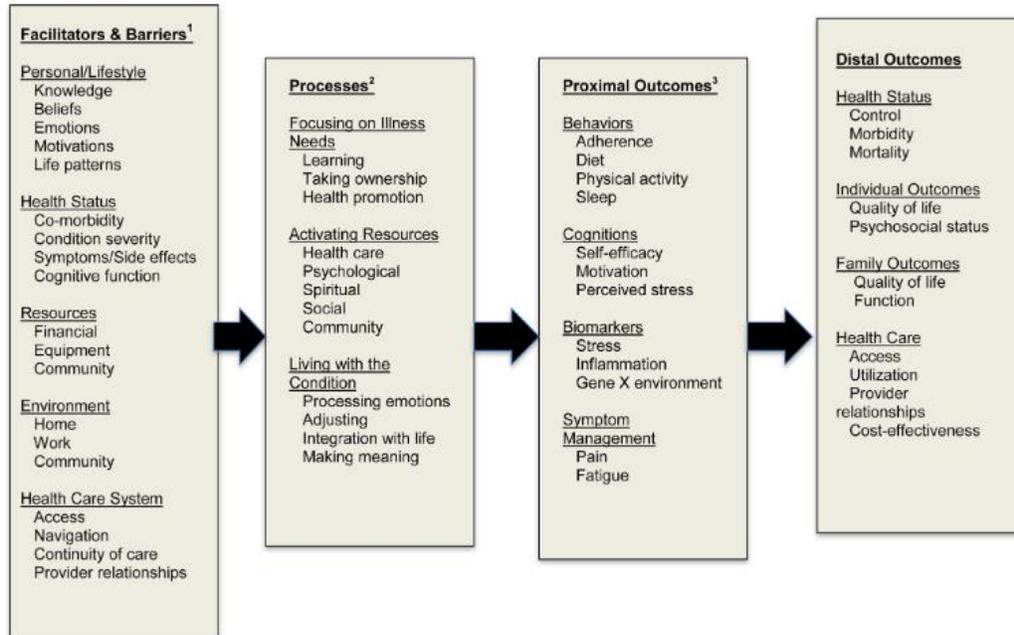


Figure 1. Revised Self- and Family Management Framework

Grey, M., Schulman-Green, D., Knaf, K., & Reynolds, N. R. (2015). A revised Self- and Family Management Framework. *Nurs Outlook*, 63(2), 162-170. doi:10.1016/j.outlook.2014.10.003

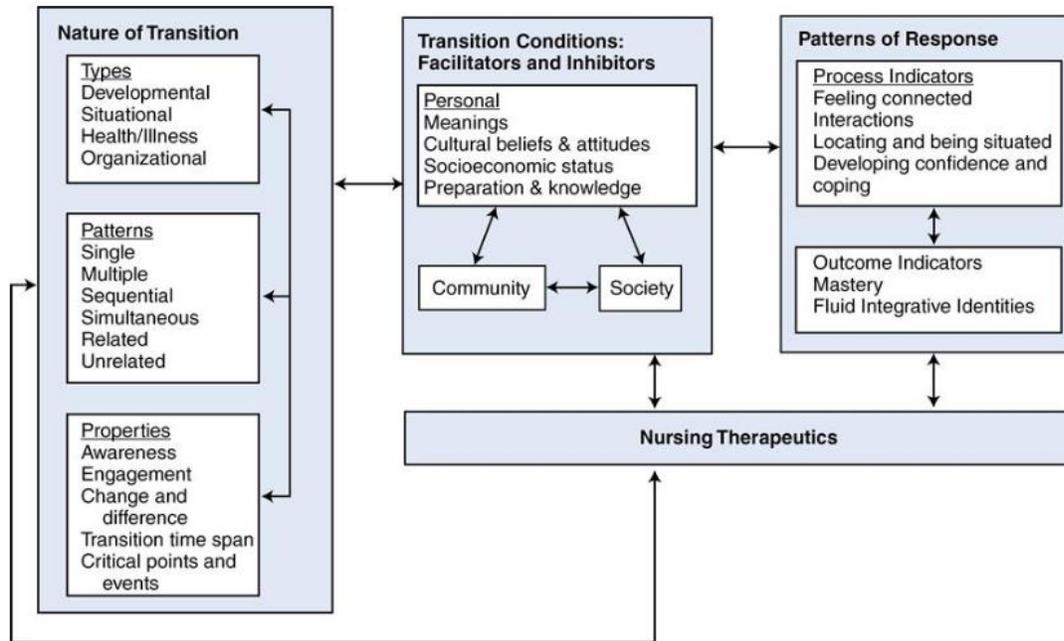


Figure 2. Transition Theory

Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *ANS Adv Nurs Sci*, 23(1), 12-28.

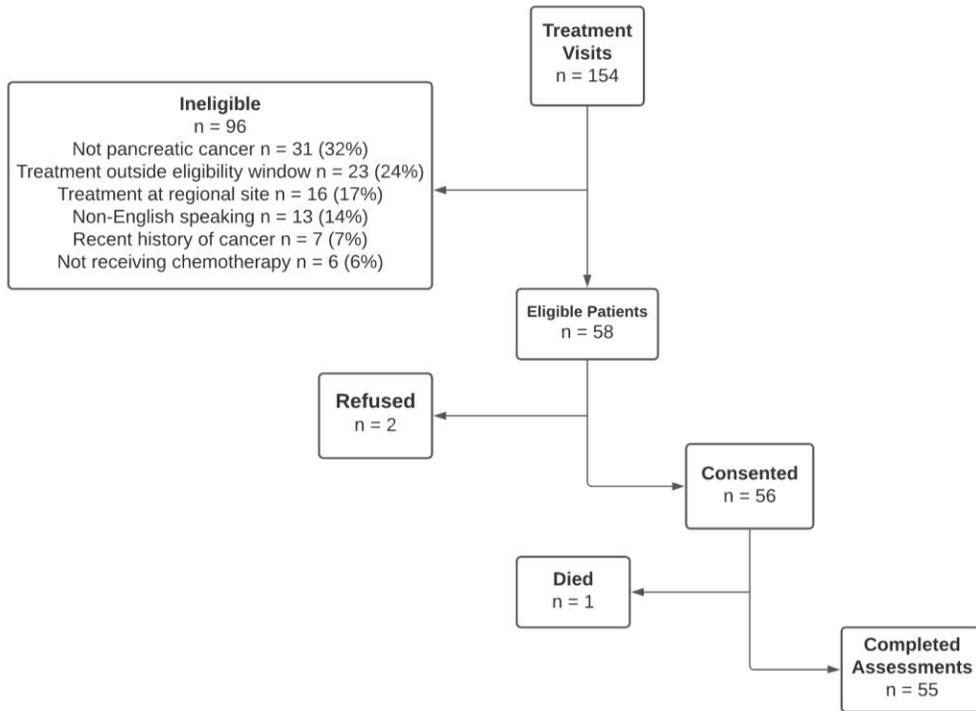


Figure 3. Cohort Diagram

Appendix Tables

Table 1. *Demographic and Clinical Characteristics*

Characteristic	n (%)	Median (Range)
Age		
At diagnosis		70 (46-82)
At consent		70 (48-82)
Sex		
Female	28 (50.9)	
Male	27 (49.1)	
Race		
Asian	6 (10.9)	
Black	1 (1.8)	
White	48 (87.3)	
Time from diagnosis to consent (month)		4 (0-50)
Tumor type		
Adenocarcinoma	54 (98.2)	
Neuroendocrine	1 (1.8)	
Stage		
II	10 (18.2)	
III	4 (7.3)	
IV	41 (74.5)	
Surgery		
No	43 (78.2)	
Yes	12 (21.8)	
Chemotherapy		
FOLFIRINOX	25 (45.5)	
Gemcitabine/Abiraxane	17 (30.9)	
FOLFIRI	7 (12.7)	
FOLFOX	4 (7.3)	
Gemcitabine/Capecitabine	1 (1.8)	
Gemcitabine/Cisplatin/Abiraxane	1 (1.8)	

Note. FOLFIRINOX = folinic acid, fluorouracil, irinotecan, and oxaliplatin; FOLFIRI = folinic acid, fluorouracil, irinotecan; FOLFOX = folinic acid, fluorouracil, oxaliplatin

Table 2. *Frequency of Transitions (N = 55)*

Transition Item	Time 1 n (%)	Time 2 n (%)	p value*
Physical	52 (95)	53 (96)	>0.9
Emotional	51 (93)	53 (96)	0.7
Social	44 (80)	39 (71)	0.3
Spiritual	24 (44)	19 (35)	0.4
Cancer status	28 (51)	16 (29)	0.025
Treatment	32 (58)	8 (15)	<0.001
Approach to care	16 (29)	5 (9)	0.010

* McNemar's Test

Table 3. *Descriptive Statistics for Extent of Transitions*

Transition Item	Time 1				Time 2			
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>Mdn</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>Mdn</i>
Physical	52	5.00	2.14	5.00	53	4.70	1.85	5.00
Emotional	51	4.73	2.50	5.00	53	4.43	2.37	4.00
Social	44	4.14	3.15	3.00	39	2.72	2.05	2.00
Spiritual	24	2.88	2.05	2.00	19	2.42	1.64	2.00
Cancer status	28	7.00	3.20	8.00	16	4.44	2.53	3.50
Treatment	32	8.75	2.14	10.00	8	8.38	2.83	10.00
Approach to care	16	5.25	3.36	5.00	5	3.20	2.17	2.00

Note. Data are based on the number of participants who reported experiencing a transition for each transition domain. Higher scores indicate more change. *M* = mean; *SD* = standard deviation, *Mdn* = median

Table 4. *Descriptive Statistics for Management of Transitions*

Transition Item	Time 1				Time 2			
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>Mdn</i>	<i>n</i>	<i>M</i>	<i>SD</i>	<i>Mdn</i>
Physical	52	6.04	1.98	6.00	53	6.02	1.90	6.00
Emotional	51	5.94	2.10	6.00	53	5.98	2.15	6.00
Social	44	6.91	1.91	7.00	39	6.77	1.95	7.00
Spiritual	24	7.58	1.35	8.00	19	7.68	1.25	8.00
Cancer status	28	4.46	1.93	4.50	16	6.19	2.23	6.00
Treatment	32	5.59	1.98	5.00	8	4.62	2.00	4.50
Approach to care	16	5.94	1.69	5.00	5	4.80	1.79	6.00

Note. Data are based on the number of participants who reported experiencing a transition for each transition domain. Higher scores indicate better management. *M* = mean; *SD* = standard deviation, *Mdn* = median

Table 5. *Descriptive Statistics for Proportional Need for Improvement (NFI) Composite Score (N= 55)*

Transition Item	Time 1			Time 2			p value*
	M	SD	Mdn	M	SD	Mdn	
Physical	2.15	1.77	1.60	2.07	1.67	1.60	0.6
Emotional	2.08	2.01	1.60	2.12	2.03	1.40	0.8
Social	1.18	1.70	0.50	0.83	1.34	0.30	0.10
Spiritual	0.29	0.56	0.00	0.21	0.50	0.00	0.4
Cancer status	2.12	2.68	0.00	0.56	1.37	0.00	<0.001
Treatment	2.35	2.52	1.50	0.67	1.88	0.00	0.002
Approach to care	0.66	1.39	0.00	0.17	0.73	0.00	0.028

Note. The Proportional Need For Improvement (NFI) is a measure of unmanaged burden of transition. Proportional NFI scores of zero could represent either fully successful management or absence of the transition. Higher scores indicate a greater extent of unmanaged transition. *M* = mean; *SD* = standard deviation, *Mdn* = median

* Wilcoxon signed rank test

Table 6. *Distress Score by Time*

Time Point	<i>n</i>	<i>Mean</i>	<i>SD</i>	<i>Median</i>
First MSK visit	51	3.87	2.92	4.00
Time 1	55	4.07	2.15	4.00
Time 2	55	4.02	2.04	3.00

Note. *SD* = standard deviation

Table 7. *Correlation Between Proportional Need for Improvement (NFI) Composite Score and Distress (N = 55)*

Transition Item	Time 1 <i>r_s</i>	Time 2 <i>r_s</i>
Physical	0.40**	0.59**
Emotional	0.60**	0.82**
Social	0.19	0.71**
Spiritual	0.09	0.49**
Cancer status	0.28*	0.48**
Treatment	0.06	0.33*
Approach to care	0.21	0.21

Note. r_s = Spearman's rank correlation coefficient

* $p < .05$. ** $p < .01$.

Table 8. *Transition Themes*

Themes	Codes
Alternate transition domains	Financial transition Caregiver transition COVID transition
Characteristics of the transition	Change over time Avoidance
Influence of transition on self-management	Overwhelmed by physical symptoms Overwhelmed by emotional symptoms Overwhelmed by prognosis
Facilitators and barriers to self-management	In control with knowledge Feels supported by family caregiver Feels supported by nurse Feels supported by religion/prayer Self-support Financial difficulties Lack of support Conflicting demands Dependency guilt Role change Family stress

IRB Letters



TO: Jessica Goldberg
Department of Nursing

FROM: John H Healey, MD
Associate Chair, Institutional Review Board/Privacy Board-B

DATE: 01/28/2020

RE: IRB Approval: Protocol and Consent Form # 20-038

Your protocol and consent form entitled "Health-Illness Transition Experiences Among Patients with Pancreatic Cancer", were reviewed by the expedited review process as per 45 CFR 46.110 and/or 21 CFR 56.110 on 01/27/2020 by the Institutional Review Board/Privacy Board-B. The IRB determined that the protocol meets the requirements as set forth in the regulatory criteria for research approval (45 CFR 46.111 and/or 21 CFR 56.111) and has been granted approval for 12 months.

The IRB/PB has determined that the investigation, presented for approval, is at a low protocol risk level.

The Board determined that the research does not require ongoing Continuing Review Reports in accordance with 45 CFR 46.109(f)(1). For future reviews, an HRPP Progress Report will be required on an annual basis.

The request for a Limited Waiver of Authorization for the recruitment activities outlined in your above protocol is granted based on a finding that the criteria in 45 CFR 164.512(i)(2) are met. The limited access to, handling and maintenance of the potential subjects' protected health information (PHI) that will occur during the recruitment and enrollment process involves no more than minimal risk to the privacy of the patients whose information will be used and disclosed for these purposes. It would be impracticable to seek individual authorization from those potential subjects. The limited use and disclosure of PHI described in the protocol is necessary to enable you, the principal investigator and research team to identify potential research subjects and to approach those subjects about the research study. If the subject agrees to participate, informed consent and a research authorization will be obtained.

The IRB correspondence for sites that are engaged in human subjects research and not reliant on the MSK IRB must be submitted to the Multicenter Office before the site commences any research activities. Please see participating site submission instructions within the Multicenter Toolkit on the Clinical Research Portal.
Note: For protocols under an MSK IND, FDA approval is required prior to distributing protocol documents to the sites.

The IRB Reviewed the Following:

*Memorial Sloan-Kettering Cancer Center
1275 York Avenue, New York, New York 10065
Telephone 212.639.7592*

NCI-designated Comprehensive Cancer Center

Jessica Goldberg

1/28/2020

Page 2

- NUR19-007_Appendix_Measurements of Transitions Scale
- NUR19-007_Biostats_Resp
- NUR19-007_Biostats_Resp2
- NUR19-007_Biostats_Resp_3
- NUR19-007_Consent
- NUR19-007_Distress Thermometer
- NUR19-007_MED_Resp
- NUR19-007_NUR_Resp
- NUR19-007_Protocol
- NUR19-007_RC Resp
- NUR19-007_RPSF_Locked

If you have any questions, please contact the IRB Office.

IRB-B Determination of Risk

Protocol: Low

Children: N/A

Device: N/A



University Integrated Institutional Review Board
 205 East 42nd Street
 New York, NY 10017
<http://www.cuny.edu/research/compliance.html>

**Approval Notice
 Initial Application**

05/21/2020

Jessica Goldberg, PhD
 The Graduate School & University Center

RE: IRB File #2020-0174
 Health-Illness Transition Experiences Among Patients with Pancreatic Cancer

Dear Jessica Goldberg,

Your Initial Application was reviewed and approved on 05/21/2020. You may begin this research.

Please note the following information about your approved research protocol:

Protocol Approval Period: 05/21/2020
 Protocol Risk Determination: Minimal
 Expedited Categor(ies): (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b) (2) and (b)(3). This listing refers only to research that is not exempt.)
 Funding Source: Robert Wood Johnson Foundation
 Grant/Contract Title: Robert Wood Johnson Future of Nursing Scholars Program
 Grant/Contract Number: n/a

Documents / Materials:

Type	Description	Version #	Date
Survey(s)	Distress Thermometer.docx	1	10/09/2019
Survey(s)	Measurement of Transition in Cancer Scale.docx	1	10/09/2019
Site Letter of Compliance	MSK letter of support	1	02/19/2020
Site Letter of Compliance	MSK CITI certificates	1	02/19/2020



University Integrated Institutional Review Board
 205 East 42nd Street
 New York, NY 10017
<http://www.cuny.edu/research/compliance.html>

Site Letter of Compliance	MSK IRB documentation	1	02/19/2020
Site Letter of Compliance	MSK protocol	1	02/19/2020
Site Letter of Compliance	MSK eligibility	1	02/19/2020
Recruitment Script	Consent script.doc	1	02/19/2020
Site Letter of Compliance	MSK consent	1	04/22/2020
Site Letter of Compliance	MSK IRB approval letter	1	05/04/2020

Please remember to:

- Use the IRB file number 2020-0174 on all documents or correspondence with the IRB concerning your research protocol.
- Review and comply with CUNY Human Research Protection Program [policies and procedures](#).
- The IRB has the authority to ask additional questions, request further information, require additional revisions, and monitor the conduct of your research and the consent process.
- Any modifications to currently approved research must be submitted to and approved by the CUNY-UI IRB before implementation.

If you have any questions, please contact:

Alan Teller
at4599@hunter.cuny.edu

References

- Al-Shamsi, H. O., Alhazzani, W., Alhuraiji, A., Coomes, E. A., Chemaly, R. F., Almuhanna, M., . . . Xie, C. (2020). A Practical Approach to the Management of Cancer Patients During the Novel Coronavirus Disease 2019 (COVID-19) Pandemic: An International Collaborative Group. *Oncologist*, *25*(6), e936-e945. doi:10.1634/theoncologist.2020-0213
- Andersen, B. L., DeRubeis, R. J., Berman, B. S., Gruman, J., Champion, V. L., Massie, M. J., . . . Rowland, J. H. (2014). Screening, assessment, and care of anxiety and depressive symptoms in adults with cancer: an American Society of Clinical Oncology guideline adaptation. *Journal of Clinical Oncology*, *32*(15), 1605-1619. doi:10.1200/jco.2013.52.4611
- Arastu, A., Patel, A., Mohile, S. G., Ciminelli, J., Kaushik, R., Wells, M., . . . Loh, K. P. (2020). Assessment of Financial Toxicity Among Older Adults With Advanced Cancer. *JAMA Network Open*, *3*(12), e2025810. doi:10.1001/jamanetworkopen.2020.25810
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, *48*(2), 177-187.
- Beesley, V. L., Janda, M., Goldstein, D., Gooden, H., Merrett, N. D., O'Connell, D. L., . . . Neale, R. E. (2016). A tsunami of unmet needs: pancreatic and ampullary cancer patients' supportive care needs and use of community and allied health services. *Psychooncology*, *25*(2), 150-157. doi:10.1002/pon.3887

- Braun, V. & Clarke, V (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brown, K. W., Levy, A. R., Rosberger, Z., & Edgar, L. (2003). Psychological distress and cancer survival: a follow-up 10 years after diagnosis. *Psychosomatic Medicine*, 65(4), 636-643.
- Carlson, L. E., Zelinski, E. L., Toivonen, K. I., Sundstrom, L., Jobin, C. T., Damaskos, P., & Zebrack, B. (2018). Prevalence of psychosocial distress in cancer patients across 55 North American cancer centers. *Journal of Psychosocial Oncology*, 1-17. doi:10.1080/07347332.2018.1521490
- Chambers, S. K., Zajdlewicz, L., Youlden, D. R., Holland, J. C., & Dunn, J. (2014). The validity of the distress thermometer in prostate cancer populations. *Psychooncology*, 23(2), 195-203. doi:10.1002/pon.3391
- Chick, N., & Meleis, A. L. (1986). *Transitions: A nursing concern*. Gaithersburg, MD.
- Chien, C. H., Liu, K. L., Chien, H. T., & Liu, H. E. (2014). The effects of psychosocial strategies on anxiety and depression of patients diagnosed with prostate cancer: a systematic review. *International Journal of Nursing Studies*, 51(1), 28-38. doi:10.1016/j.ijnurstu.2012.12.019
- Chino, F., Peppercorn, J. M., Rushing, C., Kamal, A. H., Altomare, I., Samsa, G., & Zafar, S. Y. (2017). Out-of-Pocket Costs, Financial Distress, and Underinsurance in Cancer Care. *JAMA Oncology*, 3(11), 1582-1584. doi:10.1001/jamaoncol.2017.2148

Clark, K. L., Loscalzo, M., Trask, P. C., Zabora, J., & Philip, E. J. (2010). Psychological distress in patients with pancreatic cancer--an understudied group.

Psychooncology, 19(12), 1313-1320. doi:10.1002/pon.1697

Coleman, E. A., Smith, J. D., Frank, J. C., Eilertsen, T. B., Thiare, J. N., & Kramer, A. M. (2002). Development and testing of a measure designed to assess the quality of care transitions. *International Journal of Integrated Care*, 2, e02.

Conroy, T., Desseigne, F., Ychou, M., Bouche, O., Guimbaud, R., Becouarn, Y., . . .

Ducreux, M. (2011). FOLFIRINOX versus gemcitabine for metastatic pancreatic cancer. *New England Journal of Medicine*, 364(19), 1817-1825.

doi:10.1056/NEJMoa1011923

D'Egidio, V., Sestili, C., Mancino, M., Sciarra, I., Cocchiara, R., Backhaus, I., . . . La

Torre, G. (2017). Counseling interventions delivered in women with breast cancer to improve health-related quality of life: a systematic review. *Quality of Life Research*, 26(10), 2573-2592. doi:10.1007/s11136-017-1613-6

Deshields, T. L., Penalba, V., Liu, J., & Avery, J. (2017). Comparing the symptom experience of cancer patients and non-cancer patients. *Supportive Care in Cancer*, 25(4), 1103-1109. doi:10.1007/s00520-016-3498-2

Deshields, T. L., Potter, P., Olsen, S., Liu, J., & Dye, L. (2011). Documenting the symptom experience of cancer patients. *Journal of Supportive Oncology*, 9(6), 216-223. doi:10.1016/j.suponc.2011.06.003

Donovan, K. A., Grassi, L., McGinty, H. L., & Jacobsen, P. B. (2014). Validation of the distress thermometer worldwide: state of the science. *Psychooncology*, 23(3), 241-250. doi:10.1002/pon.3430

- Duggleby, W. D., Penz, K. L., Goodridge, D. M., Wilson, D. M., Leipert, B. D., Berry, P. H., . . . Justice, C. J. (2010). The transition experience of rural older persons with advanced cancer and their families: a grounded theory study. *BMC Palliative Care, 9*, 5. doi:10.1186/1472-684x-9-5
- Duijts, S. F., Faber, M. M., Oldenburg, H. S., van Beurden, M., & Aaronson, N. K. (2011). Effectiveness of behavioral techniques and physical exercise on psychosocial functioning and health-related quality of life in breast cancer patients and survivors--a meta-analysis. *Psychooncology, 20*(2), 115-126. doi:10.1002/pon.1728
- Faller, H., Schuler, M., Richard, M., Heckl, U., Weis, J., & Kuffner, R. (2013). Effects of psycho-oncologic interventions on emotional distress and quality of life in adult patients with cancer: systematic review and meta-analysis. *Journal of Clinical Oncology, 31*(6), 782-793. doi:10.1200/jco.2011.40.8922
- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavioral Research Methods, 39*(2), 175-191.
- Ferrell, B. R. (2021). TRANSITIONS. *Journal of Hospice and Palliative Nursing, 23*(2), 109-110. doi:10.1097/njh.0000000000000740
- Fringer, A., Hechinger, M., & Schnepf, W. (2018). Transitions as experienced by persons in palliative care circumstances and their families - a qualitative meta-synthesis. *BMC Palliative Care, 17*(1), 22. doi:10.1186/s12904-018-0275-7

- Geary, C. R., & Schumacher, K. L. (2012). Care transitions: integrating transition theory and complexity science concepts. *ANS Advancing Nursing Science, 35*(3), 236-248. doi:10.1097/ANS.0b013e31826260a5
- Gessler, S., Low, J., Daniells, E., Williams, R., Brough, V., Tookman, A., & Jones, L. (2008). Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psychooncology, 17*(6), 538-547. doi:10.1002/pon.1273
- Goldberg, J., Hinchey, J., Feder, S., & Schulman-Green, D. (2016). Developing and Evaluating a Self-Management Intervention for Women With Breast Cancer. *Western Journal of Nursing Research, 38*(10), 1243-1263. doi:10.1177/0193945916650675
- Graves, K. D. (2003). Social cognitive theory and cancer patients' quality of life: a meta-analysis of psychosocial intervention components. *Health Psychology, 22*(2), 210-219.
- Grey, M., Knafl, K., & McCorkle, R. (2006). A framework for the study of self- and family management of chronic conditions. *Nursing Outlook, 54*(5), 278-286. doi:10.1016/j.outlook.2006.06.004
- Grey, M., Schulman-Green, D., Knafl, K., & Reynolds, N. R. (2015). A revised Self- and Family Management Framework. *Nursing Outlook, 63*(2), 162-170. doi:10.1016/j.outlook.2014.10.003
- Hamer, M., Chida, Y., & Molloy, G. J. (2009). Psychological distress and cancer mortality. *Journal of Psychosomatic Research, 66*(3), 255-258. doi:10.1016/j.jpsychores.2008.11.002

- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics, 42*(2), 377-381. doi:10.1016/j.jbi.2008.08.010
- Harrison, M. B. (2004). Transitions, continuity, and nursing practice. *Canadian Journal of Nursing Research, 36*(2), 3-6.
- Hersch, J., Juraskova, I., Price, M., & Mullan, B. (2009). Psychosocial interventions and quality of life in gynaecological cancer patients: a systematic review. *Psychooncology, 18*(8), 795-810. doi:10.1002/pon.1443
- Hinkle, D. E., Wiersma, W., & Jurs, S. G. (2002). *Applied Statistics for the Behavioral Sciences* (5th edition ed.): Houghton Mifflin.
- Holland, J., Watson, M., & Dunn, J. (2011). The IPOS new International Standard of Quality Cancer Care: integrating the psychosocial domain into routine care. *Psychooncology, 20*(7), 677-680. doi:10.1002/pon.1978
- Holland, J. C. (2013). Distress screening and the integration of psychosocial care into routine oncologic care. *Journal of the National Comprehensive Cancer Network, 11*(5 Suppl), 687-689.
- Holland, J. C., Andersen, B., Breitbart, W. S., Buchmann, L. O., Compas, B., Deshields, T. L., . . . Freedman-Cass, D. A. (2013). Distress management. *Journal of the National Comprehensive Cancer Network, 11*(2), 190-209.
- Howell, D., Harth, T., Brown, J., Bennett, C., & Boyko, S. (2017). Self-management education interventions for patients with cancer: a systematic review. *Supportive Care in Cancer, 25*(4), 1323-1355. doi:10.1007/s00520-016-3500-z

- Hronek, J. W., & Reed, M. (2015). Nursing Implications of Chemotherapy Agents and Their Associated Side Effects in Patients With Pancreatic Cancer. *Clinical Journal of Oncology Nursing*, 19(6), 751-757. doi:10.1188/15.cjon.751-757
- Huang, H. P., He, M., Wang, H. Y., & Zhou, M. (2016). A meta-analysis of the benefits of mindfulness-based stress reduction (MBSR) on psychological function among breast cancer (BC) survivors. *Breast Cancer*, 23(4), 568-576. doi:10.1007/s12282-015-0604-0
- Im, E. O. (2011). Transitions theory: a trajectory of theoretical development in nursing. *Nursing Outlook*, 59(5), 278-285.e272. doi:10.1016/j.outlook.2011.03.008
- Jeon, S., Schulman-Green, D., McCorkle, R., & Dixon, J. K. (2019). Four Approaches for Determining Composite Scores for the Measurement of Transition in Cancer Scale. *Nursing Research*, 68(1), 57-64. doi:10.1097/nnr.0000000000000318
- Jimenez, A., Madero, R., Alonso, A., Martinez-Marin, V., Vilches, Y., Martinez, B., . . . Feliu, J. (2011). Symptom clusters in advanced cancer. *Journal of Pain and Symptom Management*, 42(1), 24-31. doi:10.1016/j.jpainsymman.2010.10.266
- Kantsiper, M., McDonald, E. L., Geller, G., Shockney, L., Snyder, C., & Wolff, A. C. (2009). Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers. *Journal of General Internal Medicine*, 24 Suppl 2, S459-466. doi:10.1007/s11606-009-1000-2
- Kayser, K., Smith, L., Washington, A., Harris, L. M., & Head, B. (2021). Living with the financial consequences of cancer: A life course perspective. *Journal of Psychosocial Oncology*, 39(1), 17-34. doi:10.1080/07347332.2020.1814933

- Krebber, A. M., Jansen, F., Cuijpers, P., Leemans, C. R., & Verdonck-de Leeuw, I. M. (2016). Screening for psychological distress in follow-up care to identify head and neck cancer patients with untreated distress. *Supportive Care in Cancer, 24*(6), 2541-2548. doi:10.1007/s00520-015-3053-6
- Lorig, K. R., & Holman, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7. doi:10.1207/s15324796abm2601_01
- Loud, J. T., & Murphy, J. (2017). Cancer Screening and Early Detection in the 21(st) Century. *Semin Oncol Nurs, 33*(2), 121-128. doi:10.1016/j.soncn.2017.02.002
- Ma, J., & Jemal, A. (2013). The rise and fall of cancer mortality in the USA: why does pancreatic cancer not follow the trend? *Future of Oncology, 9*(7), 917-919. doi:10.2217/fon.13.76
- Ma, X., Zhang, J., Zhong, W., Shu, C., Wang, F., Wen, J., . . . Liu, L. (2014). The diagnostic role of a short screening tool--the distress thermometer: a meta-analysis. *Supportive Care in Cancer, 22*(7), 1741-1755. doi:10.1007/s00520-014-2143-1
- McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K., & Wagner, E. H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer Journal of Clinicians, 61*(1), 50-62. doi:10.3322/caac.20093
- Mehnert, A., Hartung, T. J., Friedrich, M., Vehling, S., Brahler, E., Harter, M., . . . Faller, H. (2018). One in two cancer patients is significantly distressed: Prevalence and indicators of distress. *Psychooncology, 27*(1), 75-82. doi:10.1002/pon.4464

- Meleis, A. I. (Ed.) (2010). *Transitions theory: Middle-range and situation specific theories in nursing research and practice*. New York, NY: Springer Publisher.
- Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *ANS Advancing Nursing Science*, 23(1), 12-28.
- Meleis, A. I., & Trangenstein, P. A. (1994). Facilitating transitions: redefinition of the nursing mission. *Nursing Outlook*, 42(6), 255-259.
- Miller, S. J., Desai, N., Pattison, N., Droney, J. M., King, A., Farquhar-Smith, P., & Gruber, P. C. (2015). Quality of transition to end-of-life care for cancer patients in the intensive care unit. *Annals of Intensive Care*, 5(1), 59. doi:10.1186/s13613-015-0059-7
- Mitchell, A. J., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C., & Meader, N. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncology*, 12(2), 160-174. doi:10.1016/s1470-2045(11)70002-x
- NCCN practice guidelines for the management of psychosocial distress. National Comprehensive Cancer Network. (1999). *Oncology (Williston Park)*, 13(5a), 113-147.
- Petrin, K., Bowen, D. J., Alfano, C. M., & Bennett, R. (2009). Adjusting to pancreatic cancer: perspectives from first-degree relatives. *Palliative and Supportive Care*, 7(3), 281-288. doi:10.1017/s1478951509990204

- Pirl, W. F., Fann, J. R., Greer, J. A., Braun, I., Deshields, T., Fulcher, C., . . . Bardwell, W. A. (2014). Recommendations for the implementation of distress screening programs in cancer centers: report from the American Psychosocial Oncology Society (APOS), Association of Oncology Social Work (AOSW), and Oncology Nursing Society (ONS) joint task force. *Cancer, 120*(19), 2946-2954.
doi:10.1002/cncr.28750
- Rahib, L., Smith, B. D., Aizenberg, R., Rosenzweig, A. B., Fleshman, J. M., & Matrisian, L. M. (2014). Projecting cancer incidence and deaths to 2030: the unexpected burden of thyroid, liver, and pancreas cancers in the United States. *Cancer Research, 74*(11), 2913-2921. doi:10.1158/0008-5472.can-14-0155
- Richard, A. A., & Shea, K. (2011). Delineation of self-care and associated concepts. *J Nursing Scholarship, 43*(3), 255-264. doi:10.1111/j.1547-5069.2011.01404.x
- Roth, A. J., Kornblith, A. B., Batel-Copel, L., Peabody, E., Scher, H. I., & Holland, J. C. (1998). Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer, 82*(10), 1904-1908.
- Russ, T. C., Stamatakis, E., Hamer, M., Starr, J. M., Kivimaki, M., & Batty, G. D. (2012). Association between psychological distress and mortality: individual participant pooled analysis of 10 prospective cohort studies. *British Medical Journal, 345*, e4933. doi:10.1136/bmj.e4933
- Sahin, I. H., Elias, H., Chou, J. F., Capanu, M., & O'Reilly, E. M. (2018). Pancreatic adenocarcinoma: insights into patterns of recurrence and disease behavior. *BMC Cancer, 18*(1), 769. doi:10.1186/s12885-018-4679-9

- Schulman-Green, D., Bradley, E. H., Knobf, M. T., Prigerson, H., DiGiovanna, M. P., & McCorkle, R. (2011). Self-management and transitions in women with advanced breast cancer. *Journal of Pain and Symptom Management, 42*(4), 517-525.
doi:10.1016/j.jpainsymman.2010.12.007
- Schulman-Green, D., Bradley, E. H., Nicholson, N. R., Jr., George, E., Indeck, A., & McCorkle, R. (2012). One step at a time: self-management and transitions among women with ovarian cancer. *Oncology Nursing Forum, 39*(4), 354-360.
doi:10.1188/12.onf.354-360
- Schulman-Green, D., Brody, A., Gilbertson-White, S., Whittemore, R., & McCorkle, R. (2018). Supporting self-management in palliative care throughout the cancer care trajectory. *Current Opinions in Supportive and Palliative Care, 12*(3), 299-307.
doi:10.1097/spc.0000000000000373
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., . . . Whittemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship, 44*(2), 136-144. doi:10.1111/j.1547-5069.2012.01444.x
- Schulman-Green, D., Jaser, S. S., Park, C., & Whittemore, R. (2016). A metasynthesis of factors affecting self-management of chronic illness. *Journal of Advanced Nursing, 72*(7), 1469-1489. doi:10.1111/jan.12902
- Schulman-Green, D., Jeon, S., McCorkle, R., & Dixon, J. (2017). The Measurement of Transitions in Cancer Scale. *Journal of Nursing Measurement, 25*(1), 103-120.
doi:10.1891/1061-3749.25.1.103
- Schumacher, K. L., & Meleis, A. I. (1994). Transitions: a central concept in nursing. *Image Journal of Nursing Scholarship, 26*(2), 119-127.

- Siegel, R. L., Miller, K. D., Fuchs, H. E., & Jemal, A. (2021). Cancer Statistics, 2021. *CA Cancer Journal for Clinicians*, 71(1), 7-33. doi:10.3322/caac.21654
- Siegel, R. L., Miller, K. D., & Jemal, A. (2019). Cancer statistics, 2019. *CA Cancer Journal for Clinicians*, 69(1), 7-34. doi:10.3322/caac.21551
- Sohal, D. P. S., Kennedy, E. B., Cinar, P., Conroy, T., Copur, M. S., Crane, C. H., . . . Laheru, D. (2020). Metastatic Pancreatic Cancer: ASCO Guideline Update. *Journal of Clinical Oncology*, Jco2001364. doi:10.1200/jco.20.01364
- Stark, L., Tofthagen, C., Visovsky, C., & McMillan, S. C. (2012). The Symptom Experience of Patients with Cancer. *Journal of Hospice and Palliative Nursing*, 14(1), 61-70. doi:10.1097/NJH.0b013e318236de5c
- Tempero, M. A., Malafa, M. P., Chiorean, E. G., Czito, B., Scaife, C., Narang, A. K., . . . Zuccarino-Catania, G. (2019). Pancreatic Adenocarcinoma, Version 1.2019. *Journal of the National Comprehensive Cancer Network*, 17(3), 202-210. doi:10.6004/jnccn.2019.0014
- Thiagarajan, M., Chan, C. M., Fuang, H. G., Beng, T. S., Atiliyana, M. A., & Yahaya, N. A. (2016). Symptom Prevalence and Related Distress in Cancer Patients Undergoing Chemotherapy. *Asian Pacific Journal of Cancer Prevention*, 17(1), 171-176.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 45. doi:10.1186/1471-2288-8-45

- Vaartio, H., Kiviniemi, K., & Suominen, T. (2003). Men's experiences and their resources from cancer diagnosis to recovery. *European Journal of Oncology Nursing, 7*(3), 182-190.
- Von Hoff, D. D., Ervin, T., Arena, F. P., Chiorean, E. G., Infante, J., Moore, M., . . . Renschler, M. F. (2013). Increased survival in pancreatic cancer with nab-paclitaxel plus gemcitabine. *New England Journal of Medicine, 369*(18), 1691-1703. doi:10.1056/NEJMoa1304369
- White, R. R., & Lowy, A. M. (2017). Clinical Management: Resectable Disease. *Cancer Journal, 23*(6), 343-349. doi:10.1097/ppo.0000000000000291
- Wiener, L., Battles, H., Zadeh, S., Widemann, B. C., & Pao, M. (2017). Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics. *Psychooncology, 26*(4), 461-468. doi:10.1002/pon.4038
- Wochna Loerzel, V. (2015). Symptom Experience in Older Adults Undergoing Treatment for Cancer. *Oncology Nursing Forum, 42*(3), E269-278. doi:10.1188/15.onf.e269-e278
- Wong, S. S., George, T. J., Jr., Godfrey, M., Le, J., & Pereira, D. B. (2019). Using photography to explore psychological distress in patients with pancreatic cancer and their caregivers: a qualitative study. *Supportive Care in Cancer, 27*(1), 321-328. doi:10.1007/s00520-018-4330-y
- Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psychooncology, 10*(1), 19-28.

- Zavala, V. A., Bracci, P. M., Carethers, J. M., Carvajal-Carmona, L., Coggins, N. B., Cruz-Correa, M. R., . . . Fejerman, L. (2021). Cancer health disparities in racial/ethnic minorities in the United States. *British Journal of Cancer*, *124*(2), 315-332. doi:10.1038/s41416-020-01038-6
- Zebrack, B., Kayser, K., Sundstrom, L., Savas, S. A., Henrickson, C., Acquati, C., & Tamas, R. L. (2015). Psychosocial distress screening implementation in cancer care: an analysis of adherence, responsiveness, and acceptability. *Journal of Clinical Oncology*, *33*(10), 1165-1170. doi:10.1200/jco.2014.57.4020
- Zenger, M., Lehmann-Laue, A., Stolzenburg, J. U., Schwalenberg, T., Ried, A., & Hinz, A. (2010). The relationship of quality of life and distress in prostate cancer patients compared to the general population. *Psychosocial Medicine*, *7*, Doc02. doi:10.3205/psm000064