

**Symptom representations and meaning-making in mothers with recurrent ovarian cancer:
A mixed-methods investigation**

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Background: Mothers with advanced cancer face numerous challenges as they strive to meet the demands of parenting while facing the physical, emotional, and psychological tasks of navigating life with a potentially life-threatening illness. It remains unclear how parenting affects the cancer experience and how having cancer impacts one's role as a mother.

Purpose: The purpose of this study was to deepen our understanding of the experiences and coping efforts of mothers with recurrent ovarian cancer and to explore the ways in which these might be influenced by the parenting role.

Methods: Using a phenomenologically-informed thematic analysis combined with the quantitative method of group-based trajectory modeling, this mixed-methods ancillary study was conducted using data from mothers with advanced ovarian cancer who participated in an online symptom management intervention. Themes were identified through iterative coding of all participant data, and then revisited through the lenses of both parenting status and symptom burden trajectory.

Results: Data from a total of 174 participants was analyzed for the primary aim of characterizing the experience of mothers with advanced cancer. Through written message board exchanges with nurse interventionists and responses to open-ended questions, as well as journal entries, women described ways in which being

diagnosed and living with advanced ovarian cancer had altered their experiences of themselves, their ability to meet the demands of mothering and other life roles, and their sense of their future and concerns about their families. The changes described reflect both terrifying but also clarifying aspects of a diagnosis of advanced cancer as well as the challenges inherent in juggling multiple life roles and responsibilities during advanced illness. Further analysis of themes expressed by participants revealed no meaningful differences by parenting status or by symptom severity patterns in themes expressed.

Conclusion: These findings suggest that mothers perceive their advanced cancer diagnoses as highly intertwined with their experiences of themselves as parents, and offer enhanced insight into the lives and needs of mothers with recurrent ovarian cancer that can serve as a foundation for the development of tailored interventions to meet their needs during the trajectory of advanced illness.

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Preface

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1.0 Proposal Introduction

Recent studies estimate that between 14 and 18% of cancer patients are actively parenting dependent children while facing symptoms and other demands related to cancer diagnosis and treatment in addition to the potential for a foreshortened lifespan (J. Ernst et al., 2013; Weaver, Rowland, Alfano, & McNeel, 2010). Approximately 1.5 million adults and 2.7 million children in the U.S. are affected by parental cancer, and these figures may be underestimates since parenting status is not reliably recorded or reported in many studies (Muriel et al., 2012; Weaver et al., 2010). Despite the substantial number of parents with cancer, there is little information available regarding the challenges faced by parents with advanced and recurrent cancers who are parenting while also living with and managing advanced, potentially life-threatening disease (Nilsson et al., 2009; E. M. Park, Deal, et al., 2015). Cancer diagnosis and treatment for all cancer patients are associated with distress, and evidence suggests that this may be particularly compounded for parents (especially parents of minor children), who are already at increased risk for psychological distress, including anxiety and depression. (Helseth & Ulfsaet, 2005; Kuswanto, Stafford, Sharp, & Schofield, 2018; Loiselle & Santerre-Theil, 2017; Muriel et al., 2012; Nilsson et al., 2009; E. M. Park, Deal, et al., 2015; Semple & McCance, 2010; Tavares, Brandão, & Matos, 2018).

Recurrent ovarian cancer can serve as an exemplar population for understanding the experience of mothers parenting with advanced cancer since women diagnosed with recurrent disease have a median survival of 12-28 months after recurrence (Vidal et al., 2016), are faced with the challenge of managing symptoms which often persist even after active treatment, and are often diagnosed while dependent children are still living in the home (Weaver et al., 2010).

Although the five-year survival rates for ovarian cancer have increased in recent years, overall mortality rates continue to be high, particularly for patients who experience recurrence within 12 months of initial treatment (Coleman et al., 2019; Vidal et al., 2016). Women with ovarian cancer often live the remainder of their lives with advanced or recurrent disease, including some degree of symptom burden due to illness or treatment. Many women with recurrent ovarian cancer are faced with the difficult task of balancing the potential life-extending benefits of palliative chemotherapy with the often-severe side effects of these treatments. *These patients face unique challenges in both their role as mothers and their role as patients navigating a life-limiting or life-threatening illness, yet few studies have been conducted to adequately characterize the exact nature of these challenges* (Elmberger, Bolund, Magnusson, Lützén, & Andershed, 2008; Helseth & Ulfsaet, 2005; Houldin & Lewis, 2006; Kuswanto et al., 2018; Muriel et al., 2012; Nilsson et al., 2009; E. M. Park, Deal, et al., 2015; Rauch & Muriel, 2004; Semple & McCance, 2010).

Some issues common among women who are actively parenting minor children while facing cancer diagnosis, treatment, survivorship and, in some cases, end-of-life issues have been documented (Aamotsmo & Bugge, 2014; J. C. Ernst et al., 2013; Houldin & Lewis, 2006; Kuswanto et al., 2018; Lebel et al., 2013; Muriel et al., 2012; Nilsson et al., 2009; E. M. Park, Deal, et al., 2015; E. M. Park, Stephenson, Moore, Deal, & Muriel, 2019; Turner et al., 2007; Vos, 2014); these include the need to manage burdensome symptoms of illness and treatment while also managing concerns such as:

- a) how to meet the daily physical and emotional demands of parenting,
- b) how to talk with their children about their cancer,

- c) how to protect their children from the impact of their disease in the short- and long-term while also respecting their children's needs for developmentally appropriate information, and
- d) how to obtain needed psychosocial support for themselves and their family members.

Other authors have noted that fear of recurrence and other concerns are increased among parents regardless of their child(ren)'s age or objective measures of disease severity (Arès, Lebel, & Bielajew, 2014; Lebel et al., 2013).

Although the literature has documented the fact that the manner in which individuals manage cancer diagnoses is impacted by parenting status (whether or not they have children as well as the ages and stages of the children), it remains unclear exactly how parenting status and parenting-related concerns influence:

- a) the meaning patients ascribe to their symptoms, and
- b) their symptom management behaviors and coping efforts,
- c) their information, communication and support needs, and decision-making during illness, treatment and at end-of-life.

Understanding the ways in which parenting might influence symptom perceptions and management attempts can provide a foundation for enhanced understanding of the needs of this population and for future exploration of the ways in which parenting may influence other aspects of the illness experience in women with advanced cancers.

1.1 Purpose

The purpose of this proposed dissertation study is to understand the coping efforts and symptom management behaviors of mothers with recurrent ovarian cancer and to explore the ways in which these behaviors, and other aspects of the cancer experience, might be influenced by the parenting role. This will be accomplished through a mixed methods approach combining thematic analysis of narrative qualitative data with parenting status and symptom severity data from the WRITE Symptoms parent study, a large three-arm randomized controlled trial of a web-delivered symptom management intervention for women with recurrent ovarian cancer.

1.2 Specific Aims

The proposed study will achieve the following specific aims:

AIM 1: *To identify and explore themes related to experiencing and managing symptoms described by mothers with recurrent ovarian cancer, including any explicit references made by mothers regarding ways in which their experience of having children or being a mother might influence their cancer or symptom management experience.*

Approach: Thematic analysis will be conducted by two raters using NVivo qualitative data analysis software to identify themes in the concerns and the symptom management behaviors described by women parenting with recurrent ovarian cancer, and to explore relationships between themes identified so as to better characterize the

experiences of symptom perception and management, social support, and quality of life in mothers with advanced cancer.

AIM 2: *To explore and characterize potential differences between the themes identified by women parenting minor children in the home as those compared with those whose children are outside the home.*

Approach: Themes related to parenting with advanced and recurrent cancer from mothers parenting dependent children will be compared with those whose children have left home to identify and explore any differences that may exist.

AIM 3: *To explore potential differences in themes between women with differing trajectories on a composite measure of symptom burden.*

Approach: Following the initial qualitative analysis described in Aims 1 and 2, group-based trajectory modeling (GBTM) will be used to classify participants into distinctive subgroups based on patterns of changes in symptom burden data across three data collection time points (baseline, 4 weeks, 8 weeks), and qualitative data will be further explored through the lens of symptom burden trajectory to explore its influence on the themes expressed. Participants will be stratified into groups based on patterns in composite scores of symptom burden on the Symptom Representation Questionnaire over the 8-week period during which they received the intervention. Themes will be explored within each subgroup to detect and characterize any differences related to symptom burden trajectory and to consider the ways in which symptom burden may play a role in these differences.

This mixed-methods study will provide a novel view of the illness perceptions and symptom management experiences of women with recurrent ovarian who are parenting children

inside or out of the home and will consider those perceptions and experiences through the lens of their attempts to make meaning of their experience as mothers with cancer. The mixed-methods approach incorporating GBTM will allow for rich and detailed exploration of the qualitative findings while also garnering the benefits offered by quantitative data that has already been collected from this sample. Using this approach can help detect and illuminate differences that may exist based on distinct symptom burden trajectories. By further elucidating and describing the unique needs of women parenting with recurrent ovarian cancer, and considering these needs through the lens of symptom burden and distress, the findings of this study will serve as a foundation for future work to develop interventions aimed at identifying and addressing the needs of this vulnerable population of women and their families. Additionally, the findings will provide a body of knowledge that can inform the development of innovative teaching strategies to familiarize and sensitize nursing students and professional nurses to the unique needs of women with advanced cancers and their families, thereby improving the clinical care they receive.

This study will directly address the National Institute of Nursing Research's initiative to enhance palliative care and end-of-life communication and decision-making through a focus on symptom management during advanced illness and identification of decision-making and end-of-life treatment planning domains that may be unique to women mothering during advanced cancer.

1.3 Background

As early as 2009, Nilsson and colleagues (Nilsson et al., 2009) described the presence of significant, poorly-met psychosocial needs of parents with advanced cancers, including increased rates of anxiety, less advanced-care planning, higher rates of aggressive rather than palliative care, and poorer quality of life during their final week of life as compared with their non-parenting counterparts. They noted the paucity of research focused on characterizing and attending to the unique distress of this population. Six years later, the work of Park et al. (E. M. Park, Deal, et al., 2015) contributed additional insights regarding patients parenting with cancer, demonstrating that patients parenting dependent children scored higher on measures of parenting concerns, anxiety, and depression and lower on measures of quality of life. In the intervening time between and since these two important studies, however, there have been only a limited number of additional investigations to further identify and characterize the needs of this vulnerable population of cancer survivors or to develop effective interventions to address them. (Harper et al., 2016; Kuswanto et al., 2018; Loiselle & Santerre-Theil, 2017; E. M. Park et al., 2019; Tavares et al., 2018)

1.3.1 Illness as a life-course disruption and existential challenge

The literature on chronic, serious, and/or life-limiting illness is consistent in describing the challenges of advanced illness as a life-course, or biographical, disruption (Bury, 1982; Hannum & Rubinstein, 2016; Jowsey, Yen, Bagheri, & McRae, 2014; Larsson & Grassman, 2012; Williams, 2000; Wilson, 2007). Bury's classic treatment of biographical disruption notes the shattering effects of serious or chronic illness on the individual's underlying meaning structures and expectations for a future characterized by good health, longevity, and freedom from

suffering.(Bury, 1982) The possibilities of disability or even death can no longer be held at arms' length and treated as if they will always only be the afflictions of unknown others, and they instead become immediately salient and distressing following a diagnosis that threatens the life course one had imagined for oneself. This "shattering of the assumptive world" (Janoff-Bulman, 1992) represents an existential challenge and often initiates a search for meaning aimed at reconstructing global meaning in a way that allows for integration of the crisis of illness while providing a path for moving forward constructively. Although this search for meaning is, by definition, highly personal since it is rooted in underlying values and beliefs (Fegg et al., 2010; Ferrell, Smith, Juarez, & Melancon, 2003; Fjelland, Barron, & Foxall, 2008; Karlsson, Friberg, Wallengren, & Ohlén, 2014; la Cour, Johannessen, & Josephsson, 2009; Romanoff & Thompson, 2006), individuals often require guidance in these endeavors, and developing sensitive, effective, and tailored interventions to support patients during periods of crisis and meaning reconstruction is therefore a critical task of health care professionals. Supportive approaches must be both evidence-based and founded on a deep understanding of the unique needs of seriously ill parents, and much work is still needed in these arenas.

1.3.2 Balancing parenting with the challenges of coping with serious illness

In addition to the life course disruptions posed by serious illness (i.e. prospect of physical pain and emotional distress; uncertainty on multiple fronts; information deficits combined with the need for making critical treatment-related decisions; and the potential for a foreshortened lifespan, to mention a few), seriously ill patients who are also parents face additional assaults to their well-being and life trajectories (Bugge, Helseth, & Darbyshire, 2009; J. C. Ernst et al., 2013; Helseth

& Ulfsaet, 2005; Muriel et al., 2012; Nilsson et al., 2009; E. M. Park, Deal, et al., 2015; Turner et al., 2007). Parents, especially those of young children, typically hold the taken-for-granted assumptions of being able to raise their children to adulthood, to protect them from undue distress, to provide for them physically and emotionally, and to benefit from the joys of watching them emerge successfully into adulthood. Many of these expectations are assaulted by diagnosis of a serious illness such as advanced cancer, which often thrusts parents into the difficult circumstances of reconciling the already-demanding nature of life as a parent with the distressing and unexpected demands of being a patient with a serious and potentially life-limiting illness. Accustomed to being guides and protectors, parents may instead become dependent on others in the short-term and, in some cases, for the remainder of their lives. Little investigation has been done regarding the nature of the challenges faced by these parents, nor have interventions been developed to adequately address the needs that arise among parents with advanced cancer.

1.3.3 Meaning-making as a response to serious and/or life-limiting illness

In addition to the well-established need for addressing the physical symptoms of cancer and treatment, there is a substantial and growing body of literature supporting the importance of helping patients attain psychosocial adjustment during cancer survivorship, be it short-term survivorship with a focus on end-of-life issues, or long-term survivorship in which the individual's response to cancer resembles that of coping with a chronic illness (Adelstein, Anderson, & Taylor, 2014; Alfano & Rowland, 2006; Camacho, Garland, Martopullo, & Pelletier, 2013; Lee, 2008; Lee, Robin Cohen, Edgar, Laizner, & Gagnon, 2006; Mok, Lau, Lai, & Ching, 2012; C. L. Park, Edmondson, Fenster, & Blank, 2008; Romanoff & Thompson, 2006). Much of this literature endorses the value of meaning in influencing psychological adjustment to cancer diagnosis, and a

number of authors have described and provided data to support the use of meaning-making approaches in coping with serious illness such as advanced cancer and optimizing psychological outcomes (Casellas-Grau, Font, & Vives, 2014; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006; Lee, Robin Cohen, et al., 2006; Mok et al., 2012; Romanoff & Thompson, 2006). Keall and colleagues (Keall, RM, Butow, PN, Steinhauser, KE, Clayton, 2013) note that patients with advanced cancers are more likely than their earlier-stage counterparts to engage in meaning-making activities, either as a result of their own spontaneous actions or through increased receptiveness to meaning-making interventions, possibly due to existential distress related to heightened awareness of the chronic, relapsing and/or life-limiting nature of their illness and the potential for foreshortened lifespan/premature death.

Attempting to further understand the construct of meaning-making and its role in response to the crisis of serious illness led this investigator to conduct a concept analysis of meaning-making in cancer. Using the guidelines provided by Rodgers (Rodgers, 1989; Tofthagen & Fagerstrøm, 2010), existing definitions of meaning-making, specifically as it pertains to advanced cancer, were identified and synthesized to arrive at a working definition that could provide a foundation for future investigation.

After surveying a range of definitions in the theoretical and empirical literature (Boals, 2012; Collie & Long, 2005; Duran, 2013; Egnew, 2005; Ferrell et al., 2003; Janoff-Bulman, 1992; Joseph, Murphy, & Regel, 2012; Morris & Shakespeare-Finch, 2011; C. L. Park et al., 2008; N. Park, Park, & Peterson, 2010; Romanoff & Thompson, 2006; Skaggs & Barron, 2006), the following areas of consensus in *definition* were identified:

- Meaning-making efforts arise when the worldview that has shaped an individual's sense of order, purpose and meaning is violated by a traumatic event, such as cancer diagnosis (Collie & Long, 2005; Janoff-Bulman, 1992; Joseph et al., 2012; C. L. Park et al., 2008; Skaggs & Barron, 2006; van der Spek et al., 2013b). In most cases the worldview which is violated [the "shattered assumptive world" (Janoff-Bulman, 1992)] had remained unconscious prior to the onset of the traumatic event.
- A large component of meaning-making is a cognitive process. This process comprises the individual's appraisal of the initiating event (e.g., cancer diagnosis) as a threat as well as his/her assessment of the degree to which existing or accessible internal or external resources will be adequate to meet the challenge represented by the event (Boals, 2012; Collie & Long, 2005; Janoff-Bulman, 1992; Joseph et al., 2012; Morris & Shakespeare-Finch, 2011; C. L. Park et al., 2008).
- Meaning-making efforts arise as a result of the individual's need to reconcile perceived incompatibility between previously-held worldviews and the threat posed by the cancer diagnosis, a phenomenon described by Janoff-Bulman in the Theory of Shattered Assumptions (Collie & Long, 2005; Janoff-Bulman, 1992; Joseph et al., 2012).
- Both the form and the ultimate outcome of meaning-making are highly idiosyncratic and vary widely from one person to another. The degree to which successful resolution of the search for meaning is attained depends largely on personal values and beliefs as to what is an acceptable quality of life and level of functioning, and the degree to which the gap between these beliefs and expectations and the reality imposed by the trauma of diagnosis can be closed (Collie & Long, 2005; Janoff-Bulman, 1992; C. L. Park et al., 2008).

- Appraised meanings are not only individually but also culturally determined, and, as such, may contain shared elements within particular social groups (Collie & Long, 2005; Skaggs & Barron, 2006).
- Meaning-making efforts are almost inevitably initiated by experiences that are perceived as traumatic and are often associated with short-term distress. Furthermore, meaning-making attempts do not uniformly lead to successful reduction or resolution of existential distress (C. L. Park et al., 2008).

The *core attributes* of meaning-making involve cognitive processes that are initiated by a traumatic event and are deliberately deployed by the individual in the hope and belief that they will successfully resolve the mismatch between the expectations arising from the previously-held worldview and the assault represented by the trauma (i.e., diagnosis). Meaning-making efforts that are *reflective* rather than *ruminative* and *intentional* rather than *obsessional* have been associated with the most favorable outcomes (Janoff-Bulman, 1992; Morris & Shakespeare-Finch, 2011; Muriel et al., 2012; C. L. Park et al., 2008).

Sub-dimensions of meaning-making identified by the concept analysis include *global meaning* and *situational meaning*, the former being the individual's beliefs and expectations regarding the meaningfulness, justice, predictability and safety of the world, and one's place and efficacy within it, and the latter referring to the individual's appraisal of the situation at hand and the adequacy of his/her resources to respond effectively (Janoff-Bulman, 1992; N. Park et al., 2010; Skaggs & Barron, 2006; van der Spek et al., 2013a). Events that are sufficiently traumatic as to be incompatible with the individual's global meaning structure lead to a shattering of

previously-held (but often unrecognized) assumptions, an event which often serves as a catalyst for meaning-making attempts.

The *antecedent* to meaning-making is confrontation with a crisis that ruptures the individual's assumptive world and creates the need for reconstruction of global meaning (Collie & Long, 2005; Janoff-Bulman, 1992; C. L. Park et al., 2008; N. Park et al., 2010). Successful meaning-making attempts lead to the *consequence* of restoration of the individual's sense of global meaning, which has been described in the literature using a variety of terms, including "post-traumatic growth," "meaning-made," and "benefit-finding" (Aldwin & Levenson, 2004; Collie & Long, 2005; Janoff-Bulman, 1992; Joseph et al., 2012; McMillen, 2004; Morris & Shakespeare-Finch, 2011; Sears, Stanton, & Danoff-Burg, 2003).

This investigator arrived at the following definition of meaning-making as a result of the concept analysis:

- Meaning-making efforts are elicited by a traumatic event that exceeds the individual's coping capacity and shatters the previously-held global meaning structure.
- Meaning-making is a deliberate cognitive process which optimally is both reflective and intentional.
- Meaning-making, by its very nature, is highly individual since the goal is re-configuration of the individual's worldview in a manner that allows for integration of the traumatic events and provides a foundation for future growth. Meaning-making efforts are guided by the individual's values and belief system and, as such, meanings are not inherent to the precipitating event but rather are influenced by the individual's global

worldview, which influences meaning structures, values, and expectations, and the appraisal that they have been violated. Attributes such as disease characteristics, perceived social support, emotional resources, and coping skills, among others also influence meaning-making attempts (Arida, 2014).

This concept analysis provided the investigator with an enriched understanding of the elements of meaning-making and the role and value of meaning-making in helping patients realign life narratives that have been derailed by a crisis such as diagnosis with cancer. Although some ambiguity remains regarding the precise definitions of “meaning” and “meaning-making” across studies, there is general consensus about the benefit of exploring patient’s underlying meaning structures to support their effective coping with serious illness. A currently-unpublished integrative review by this investigator of studies of interventions that specifically employed meaning-making approaches for patients with advanced cancer (Arida, 2015) revealed that their use led to significant improvements in outcomes including quality of life, self-efficacy, self-esteem, optimism and psychological and spiritual well-being, as well as reductions in symptom burden, anxiety, depression, and hopelessness.

1.3.4 Illness and symptom representations as forms of meaning-making

The Common Sense Model (CSM) is a theory that has been widely applied to multi-disciplinary research on coping with health threats (Diefenbach & Leventhal, 1996). As described by Donovan and colleagues, one of the basic tenets of the CSM is that an individual’s cognitive representations of health problems—their “illness representations”—influence coping and health-

related outcomes, and therefore must be understood prior to providing novel information such as education or a psychosocial or behavioral intervention (Heidi Scharf Donovan et al., 2007). Illness representations comprise networks of related information (including prior experience, memories, attitudes, and beliefs) that an individual has created to understand and explain the illness and its role in his/her life. Numerous researchers have described both the content and the structure of illness representations and the role they play in influencing health-related behaviors (Leventhal, Diefenbach, & Leventhal, 1992; Schiaffino, Shawaryn, & Blum, 1998), and their findings have demonstrated that illness representations consist of a *cognitive component* (ideas about the identity, cause, timeline, consequences, and controllability of an illness) as well as a parallel *emotional component* (burden and distress related to the illness) in response to a given health problem. Illness representations are influenced by a wide range of factors including traditional, information-based learning as well as everyday experiences and stories from influential others and, as a result, they often lack scientific foundation and medical accuracy. Nonetheless, these representations play a critical role in influencing the health-related coping behaviors in which people choose to engage and consequently, the CSM recognizes the importance of eliciting and exploring an individual's everyday, or "common sense" representations of his/her illness as a necessary first step in planning or delivering an intervention. Adequately exploring these representations is essential to effective intervention since underlying representations form the cognitive and emotional scaffolding through and into which all new information is perceived, understood, and integrated (Diefenbach & Leventhal, 1996).

Arising as they do from the interactions between, on the one hand, previous experiences, understandings, and beliefs and, on the other, confrontation with the crisis of illness which leads

to the need to reconcile discrepancies in beliefs, experiences and future expectations, illness representations can be conceived as a form of meaning-making. In other words, illness representations are the result of the individual's search for integration of the illness event into previously held conceptions of their life-course trajectory and coping resources.

By their very nature, illness representations arise within the context of, and are intimately connected to, an individual's everyday life, a large part of which, for parents of minor children, is affected by the individual's parenting role. These meaning-making efforts will both influence and be influenced by the individual's identification of and ability to manage the demands of parenting while also meeting the challenge of a serious illness such as cancer and its treatment. The WRITE Symptoms parent study, in which mothers with recurrent ovarian cancer responded to open-ended questions and prompts and engaged in back-and-forth dialogue with nurses about their perceptions of their illness and symptoms, generated a wealth of qualitative data that will offer a new window into the experience of mothering with advanced cancer that may offer direction for continued exploration aimed at targeting interventions for this vulnerable population. Learning more about the ways that women reference or discuss their roles as mothers while responding to prompts in a symptom management intervention will help to illuminate more about the interaction between parenting and symptom representations.

1.4 Significance and Innovation

1.4.1 Significance

This investigation will augment the limited body of literature about the support and information needs of mothers with advanced cancer who are facing serious, life-limiting or life-threatening illness while also being challenged to meet the everyday demands of parenting their children and helping them cope with a significant family event. Although there are a substantial number of advanced cancer patients who are actively parenting (Weaver et al., 2010), until recently their needs for support and education have been poorly understood and largely overlooked (Burns & Russell, 2012; Elmberger et al., 2008; Muriel et al., 2012; Nilsson et al., 2009; E. M. Park, Check, et al., 2015; E. M. Park, Deal, et al., 2015), and this study will provide insight into the ways in which motherhood may influence symptom perception and management, perceived need for support and information, and decision-making related to treatment- and end-of-life .

The aims of this study directly support the NINR's mission of improving symptom management as well as enhancing palliative/end-of-life care (*National Institute of Nursing Research: Bringing Science to Life: NINR Strategic Plan*, 2011). They also address the Institute of Medicine's initiative to increase patient-centeredness of care for patients with cancer (Spinks et al., 2011).

1.4.2 Innovation

This study will offer a much-needed, multi-faceted description of the relationship between mothering and various aspects of the cancer experience, including symptom perception and management and quality of life, in addition to identifying and characterizing concerns that are unique to the women who are mothering while facing advanced cancer. Its mixed-methods design will include an initial qualitative thematic analysis of data from a sample for whom secondary quantitative analysis has already been conducted by this investigator followed by applying group-based trajectory modeling (GBTM) to composite scores from the Symptom Representation Questionnaire (SRQ) over three measurement points to stratify participants by symptom burden trajectory, allowing for further exploration of concepts that emerged from the thematic analysis. These findings will contribute to our understanding of the support and information needs of a population of cancer survivors and their families that are currently inadequately understood and therefore ineffectively served (Bugge et al., 2009; J. C. Ernst et al., 2013; Schroevers, Helgeson, Sanderman, & Ranchor, 2010).

1.5 Preliminary Work

1.5.1 Concept analysis of meaning-making in cancer

A description of findings was presented in Background section above. See draft form of Manuscript in Appendix A.

1.5.2 Palliative care triggers in gynecologic oncology

This investigator conducted interviews with 19 gynecologic oncology providers (physicians, physician assistants, nurse practitioners, and chemo nurses) and 29 patients in the gynecologic oncology service at UPMC Magee-Women's Hospital in addition to serving as a coder and data analyst for the resulting qualitative data (interview transcripts). The purpose of the study was to explore provider and patient understandings of palliative care and the facilitators and barriers to making and accepting referrals to palliative care. During the course of the patient interviews, many patients spontaneously described concerns and challenges related to their role as mothers facing advanced gynecologic cancer. This work demonstrates this researcher's ability work with a research team to interact with a body of qualitative data to identify emergent themes, achieve consensus on code development and theme identification, and derive meaningful synthesis of concepts revealed. Several podium presentations, including a secondary analysis of patient engagement and preferences for prognosis communication by this investigator, arose from this project.

1.5.3 Exploring perceptions of clients of a community food bank-based health center: A focus group study

In collaboration with a DNP student, this researcher developed a focus group guide designed to characterize the experiences of clients using a volunteer-staffed Health Connections

Center located in a community-based food bank. Two focus groups were conducted by this investigator, who also coded the resulting transcripts and produced a report of findings to inform the co-investigator's capstone study. This demonstrates the investigator's ability to design, conduct, analyze, and report focus group findings.

1.5.4 Secondary qualitative analysis of data related to motherhood from focus groups on self-advocacy in cancer

This researcher was the primary investigator in a secondary analysis of focus group data gathered as part of a study on self-advocacy among women with advanced cancer. A subset of women in the self-advocacy study who were parenting made reference to their role as mothers and the influence of that role on their cancer experience. These excerpts were coded by six raters (this investigator, two PhD-prepared nurses, and three research assistants) to identify themes specific to women parenting while facing the diagnosis and treatment of cancer. Themes identified suggested a process that reflected the changing self-identity of women as they transitioned from healthy mothers to cancer patients to mothers living with gynecologic cancer. This project led to the publication of a manuscript in *Cancer Nursing* of which this investigator was the primary author. See Appendix B for permission to reprint and Appendix C for a link to the published article (Data-Based Manuscript #2) entitled *Mothering with advanced cancer: 'You've got to find that little thing that's going to make you strong,'* published in *Cancer Nursing*.

1.5.5 Examining the influence of children in the home on symptom representations, social support, and quality of life among mothers with recurrent ovarian cancer: a quantitative secondary analysis

1.5.5.1 Design

- a. Exploratory, correlational, descriptive study examining relationships between parenting status and symptom representations, social support, and quality of life among women with recurrent ovarian cancer through a secondary quantitative analysis. This study used baseline data from the Written Representational Intervention to Ease Symptoms (WRITE Symptoms) parent study, a three-arm randomized, controlled trial of a web-delivered symptom management intervention for women with advanced ovarian cancer. Three aims were addressed:

- **Aim 1:** Investigate the relationship between the primary, three-level Independent Variable (IV) of Parenting Status (No children, Children outside the home, Children in the home) and the Dependent Variables (DV) of Symptom Representations (proximal DV; potential mediator) and Quality of Life (distal DV).

Aim 2: Explore the potential mediation by Symptom Representations of the relationship between Parenting Status and Quality of Life (QOL). **Aim 3:** Evaluate the potential moderating effect of Social Support on the relationships between Parenting Status and each QOL domain, Parenting Status and each domain of Symptom Representations, and between the domains of

Symptom Representations and QOL. (See proposed model in *Figure 1* below).

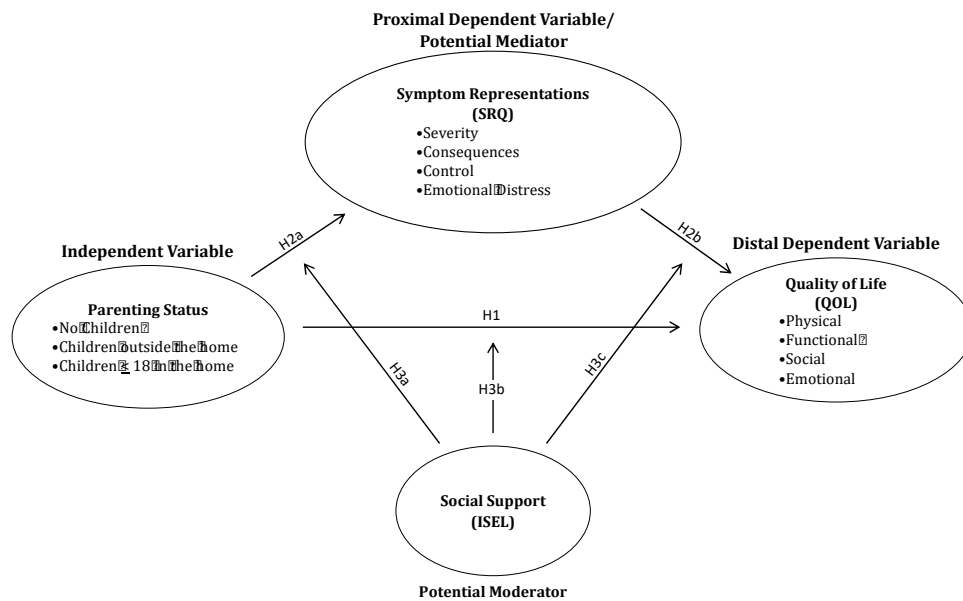


Figure 1. Proposed model of the relationships between parenting status, social support, symptom representations, and quality of life

1.5.5.2 Sample

496 participants were recruited from Gynecologic Oncology Group (GOG) clinics nationwide and enrolled in the WRITE Symptoms parent study. Of those taking part in the parent study, 474 participants met criteria for inclusion in this secondary analysis.

1.5.5.3 Inclusion criteria

- Inclusion criteria for WRITE Symptoms (parent study) were as follows:
 1. ≥ 18 years of age
 2. history of ovarian, fallopian tube, or primary peritoneal cancer that recurred or persisted following primary therapy
 3. GOG performance scale score <3
 4. ability to read and write in English
 5. access to computer and internet (or able to receive study-supported computer with 3G/4G internet access)

Additional inclusion criteria for secondary analysis were that participant data was available for all variables of interest. This resulted in the elimination of 22 participants for whom parenting status data was missing.

1.5.5.4 Procedures

Baseline data on the measures (indicated in Section E below) from the parent study were obtained and evaluated, and participants who were missing data on the primary IV (Parenting Status) (N=22) were eliminated from the sample. Data screening and data analysis were conducted by this researcher as specified in Section 1.5.5.6 below.

1.5.5.5 Measures

- **Parenting Status:** This three-level variable was created by the investigator using data from a center-developed sociodemographic form. Responses to the questions of whether the participant had children and how many children under 18 lived in the home were combined to yield

three Parenting Statuses: *0=Women without children, 1= Women whose children live outside the home, and 2=Women whose minor children live in the home.*

- **Social Support:** Social Support was measured using the Interpersonal Support Evaluation List-Revised (ISEL-R),(Cohen, S, Hoberman, 1983; Cohen, Mermelstein, Kamarck, & Hoberman, 1985; Merz et al., 2014) which is a 12-item scale assessing three types of perceived social support: *appraisal, belonging, and tangible support.*
- **Symptom Representations:** The Symptom Representation Questionnaire (SRQ) was used to measure symptom representations. Developed by Donovan et al. from the Illness Perception Questionnaire, the SRQ contains a symptom inventory of the 28 most commonly experienced symptoms by women with ovarian cancer as well as three subscales (consequences of symptoms, symptom-related distress, and symptom controllability) for each of three symptoms they identify as targets for intervention. The subscales demonstrated excellent internal consistency ($\alpha > .80$ for all subscales) and construct validity (supported by exploratory factor analysis) and concurrent validity evaluations were satisfactory.(H. Donovan, 2003)
- **Quality of Life:** The Functional Assessment of Cancer Therapy-General (FACT-G) was used to assess quality of life. This is a 28-item scale consisting of four subscales: Physical, Social, Functional and Emotional quality of life. In reliability and validity testing, internal

consistency for each of the subscales ranges from $\alpha=.69-.82$, and convergent validity with the Functional Living Index-Cancer (FLIC) was .79. Divergent validity with the Marlowe-Crowne Social Desirability Scale (M-CSDS) was supported by a Pearson correlation of .22. The FACT-G has been demonstrated to discriminate between patients at different stages of disease and across treatment location (inpatient vs. outpatient). Test-retest correlation coefficients were high, ranging from .82-.88.(Cella et al., 1993)

- **Age:** Age was measured by self-report at time of study enrollment.

1.5.5.6 Analysis

- **Data Screening:** Exploratory data analysis was conducted to identify missing data and any data irregularities that might affect the quality and validity of the analysis. Collateral sources of information were used to obtain missing data whenever possible. Participants for whom data for the Parenting Status variable (primary IV) could not be obtained were eliminated from the sample. However, the cases eliminated were not statistically different on any demographic characteristics from those that were retained. Before proceeding with the analysis, the data were screened to ensure that they met underlying assumptions of the multivariate General Linear Model, including normality, linearity, homogeneity of variance, and independence of observations. Each variable and all bivariate relationships between variables were examined

to identify outliers. The Winsorization procedure was employed for variables with outliers; this strategy involves substituting outliers with the highest (or lowest) score in the normal distribution.(Reifman & Keyton, 2010) In this case, high outlier scores were replaced with the 95% score and low outlier scores with the 5% score for four variables. Winsorization allows for the values to be retained in the sample without exerting undue influence on measures of central tendency. Irregularities in the Social Support variable could not be remedied, and this variable was therefore trichomotized into Low, Medium, and High Social Support.

- **Data Analysis:**

1. **To accomplish Aim 1:** Multivariate analysis of covariance (MANCOVA) was used to investigate the relationships between the primary IV of Parenting Status and the dependent variable of Quality of Life (physical, emotional, social, and functional) with age as a covariate.
2. **To accomplish Aim 2:** MANCOVA as well as multivariate regression were used to analyze the potential mediation of Symptom Representations in the relationship between Parenting Status and QOL. Mediation was examined with the influence of age as a covariate.

3. To accomplish Aim 3: Multivariate linear regression was used to evaluate the moderating role of Social Support on Symptom Representations and QOL, with age as a covariate.

1.5.5.7 Results

- **Sample descriptives:** The sample had an age range of 24 – 90 years of age; mean age was 59.1 (SD = 9.6). 72.4% of the sample was married or living with a partner. Only 5.3 % of the sample identified as non-white, 2.7% did not specify race, and the remaining 92.0% was non-Hispanic white. 36.2% of women had a high school education or less; 37.8% had some college; and 25.9% of women had post-graduate education. 32.7% of the sample was employed full- or part-time, while 35.5% was retired, 20% was disabled, laid off, or unable to work, and 11.6% identified as full-time homemakers, students, or other. 48.9% of the sample had a gross annual household income of <\$60,000, while 45.1% had incomes \geq \$60,000.
- **Disease and treatment characteristics:** All participants had a diagnosis of recurrent ovarian cancer. At baseline, 84.2% of the women were receiving chemotherapy. 58.8% of participants had received \geq 3 treatment regimens; the median number of previous chemotherapy cycles was 14.
- **Findings**
 1. **Findings for Aim 1 (Influence of Parenting Status on QOL):**
Findings from the multivariate analysis of covariance

(MANCOVA) and follow-up ANOVA and Pairwise Comparisons supported the hypothesis that Parenting Status had a significant effect on both Social and Emotional QOL in women with cancer. Furthermore, for both Social and Emotional QOL there were significant differences between mothers with children in the home, mothers with children outside the home, and women with no children, with mothers parenting children in the home having the lowest Social and Emotional QOL.

2. **Findings for Aim 2 (Partial mediation by Symptom**

Representations of the relationship between Parenting Status

and QOL): There were no significant findings to support partial mediation by Symptom Representations between Parenting Status and QOL; however, results of the multivariate linear regression suggested that Symptom Representations served as an independent predictor of QOL.

3. **Findings for Aim 3: (Moderation by Social Support):** There

was no evidence to support an interaction between Social Support and Parenting Status on Symptom Representations; however, there was an interaction between Symptom Representations and Social Support on Emotional QOL. In addition, Social Support exerted independent effects on Social and Functional QOL, and Social Support also serves as an independent predictor of Symptom Representations.

1.5.5.8 Updated Model

The proposed model seen above in *Figure 1*. was modified to reflect the findings of this quantitative analysis.

1.5.5.9 Relevance and transition to proposed dissertation study

This quantitative analysis has advanced our understanding of the associations between parenting status and quality of life, symptom representations and social support. However, as with most phenomenon involving complex interactions between individuals, disease processes, social roles, and personal experiences, there is much to be understood, and data arising from response-controlled instruments is limited in its capacity to illuminate some of the more nuanced or idiosyncratic aspects of the experiences of women parenting with cancer. Additionally, secondary analyses are inherently limited by the fact that measures designed to answer the question of interest were often not included in the parent study. These limitations may be among the reasons that symptom representations did not appear to serve a mediating role between parenting status and quality of life. Using a mixed-methods approach can mitigate some of these issues by combining the strengths of both quantitative and qualitative approaches to provide multiple vantage points of the phenomenon of interest. It is the hope and expectation of this researcher that the proposed mixed-methods study can explore the relationships between parenting status, symptom representations, and quality of life in a more complex and textured fashion and, in so doing, contribute to a fuller understanding of the lived experience of mothers with advanced cancer that will serve as a foundation for future work in developing both clinical interventions to meet the needs of this population as well as innovative approaches to educating healthcare providers and trainees about the unique burdens and needs of these women.

The complete findings of the quantitative analysis are presented in Data-Based Manuscript #3, Examining the influence of parenting on symptom representations, social support, and quality of life among women with recurrent ovarian cancer, found in Appendix F of this document.

2.0 Summary of proposed dissertation study

2.1 Research design

2.1.1 Theoretical approaches

Insofar as it represents an attempt to understand and characterize the lived experiences of women parenting while living with advanced ovarian cancer., this proposed mixed-methods dissertation study will be guided by the theoretical lens of phenomenology and the statistical technique of group-based trajectory modeling (Giacomi, 2010; Nagin, 2005). Phenomenology has roots in idealist, constructivist approaches, which arise from the underlying perspective that realities are inherently subjective and co-created through the interactions of individuals with their circumstances. Implicit in phenomenological approaches is a commitment to understanding these experiences from the perspectives of those living in the phenomenon, who are recognized as legitimate knowers as well as constructors of experiences (Creswell, 2007, 2009). Phenomenology as a mode of philosophical inquiry arose in the late 1800s from the work of Edmund Husserl and represented a departure from the prevailing Cartesian view of mind-body duality and the separation of consciousness (mental processes) and matter (physical objects) (Giacomi, 2010; Groenewald, 2013; McWilliam, 2010). In keeping with the inductive nature of most qualitative approaches, phenomenology emphasizes the importance of designs that allow for meanings to emerge through openness to participants, interaction with the data, and thoughtful, reflexive interpretation. This is in contrast to methods in which a preconceived structure is imposed upon participants and/or data by theoretical presuppositions or the biases of the researcher. Although

researchers in the phenomenological tradition recognize the importance of proficiency and familiarity with the body of literature related to their phenomenon of interest, they avoid using categories derived from the literature as pre-defined ways of viewing the data that could prematurely foreclose on meanings that might otherwise emerge. In other words, researchers make an effort to set their theoretical and conceptual knowledge aside during early encounters with participants and the data that is generated during qualitative inquiries, preferring instead to cultivate a stance of genuine curiosity that allows for the emergence and interpretation of themes from within the data itself; these can in turn be seated within theoretical and conceptual contexts during later phases of analysis. Another way in which investigators can achieve a stance of openness to the data is through the process of identifying, exploring, and maintaining awareness of one's own interest and investment in the topic at hand that arise from personal history, background, academic exposure, etc., prior to beginning work, and then intentionally "bracketing," or setting aside, these attachments in the service of maintaining openness to the participants' experiences of the phenomenon under investigation (Brink & Wood, 1998; Creswell, 2007; McWilliam, 2010; Melia, 2010; Sandelowski, 1989, 2000). In the phenomenological tradition, "data" includes the words of participants, and observations of interactions among participants (e.g., in focus group settings) as well as interactions between participants and researchers, and may also include other sources such as journals, artifacts, and other elements relevant to the topic of inquiry (Brink & Wood, 1998; Creswell, 2007, 2009; Sandelowski, 1989).

2.1.1.1 Approach for Aims 1 and 2

This proposed dissertation study will employ a phenomenologically-informed secondary analysis of qualitative data from the WRITE Symptoms parent study to accomplish Aims 1 and 2. Specifically, this will entail using 1) an iterative approach to data analysis, 2) development of

codes derived from interaction with data and achieved through consensus. and 3) memo-writing to allow for ongoing reflection and meaning construction. Numerous authors have discussed the critical importance of safeguards to assure high quality and rigor in qualitative methods (Creswell, 2007; Giacomi, 2010; Melia, 2010; Tracy, 2013). In this study, quality and rigor will be addressed through implementation of the following mechanisms:

- ***Selection of a worthy topic:*** As demonstrated in the Background section above, there is relatively little known about the unique challenges faced by mothers with advanced cancer, nor have adequate clinical interventions or innovative teaching methods for health professionals been developed to address them.
- ***Maintaining transparency:*** Detailed memo-writing throughout the preparation, coding, and analysis phases will create an “audit trail” of analytic activities.
- ***Establishing credibility:*** This will be accomplished through thick description (Geertz, 1973), in which rich detail describing the participants’ experience of their reality is collected and analyzed to provide a complex, multi-faceted view of the topic at hand.
- ***Self-Reflexivity:*** Identification of personal interest and investment in the topic of mothering with cancer and maintaining awareness of the ways in which this might influence perception and interpretation as a researcher.

2.1.1.2 Approach for Aim 3

Group-based trajectory modeling (GBTM) will be used to accomplish Aim 3 of this study. GBTM acknowledges that distinctive trajectories over time may exist within a data set, and provides a statistical method that allows patterns of change over

time, rather than *a priori*, theoretically based assumptions, to reveal these trajectories (Nagin, 2005). In this study, trajectories of change in symptom burden will be identified across three time points following the initial qualitative analysis, and participants' qualitative data will be re-examined through the lens of symptom burden trajectory to explore whether symptom experience influences mothers' meaning-making during their cancer experience.

2.1.2 Setting

As this is a secondary analysis of data from the WRITE Symptoms parent study, this mixed-methods study will occur on computers by two raters using NVivo qualitative data analysis software for the thematic analysis. and SAS to conduct group-based trajectory modeling.

2.1.3 Population and sample

The WRITE Symptoms parent study is a three-arm (nurse-delivered vs. self-directed vs. care-as-usual), internet-delivered symptom management RCT for women with recurrent ovarian cancer. The parent study had a total sample of 496 participants. Of these 496, 318 participants were randomized to conditions in which there was a possibility of qualitative data being elicited (Nurse-delivered or Self-Directed) and 373 were parents of children either inside or out of the home. The 253 participants at the intersection of these groups (those who were mothers and those who had the potential for qualitative data) are the participants for whom qualitative data will be included and analyzed in this secondary analysis. Of these, it is expected that approximately 180

will have participated in a way that will have yielded qualitative data for analysis in this study (i.e., based on a rate of 71.3% of participants in the parent study completing the intervention for at least one symptom). De-identified qualitative data from all participants with children will be imported into NVivo qualitative data analysis software package. Unlike the relatively straightforward calculations for establishing adequacy of sample size in quantitative methods, approaches to identifying an appropriate and adequate sample in a qualitative inquiry are more nuanced (though, of course, equally necessary). Numerous researchers in the qualitative tradition have addressed the guidelines for establishing sample adequacy; these include the need for investigator to consider the research question and the desired outcome of the inquiry when deciding on sampling methods, including sample size and appropriateness of participants as well as considering the density of information contained in each participant's data (Guest, Bunce, & Johnson, 2006; Malterud, Siersma, & Guassora, 2015; Sandelowski, 1995). In this sample, given the large number of participants for whom there is qualitative data, there should be ample data for conducting the proposed analyses.

2.1.4 Inclusion criteria

- As discussed above, inclusion criteria for the secondary analysis are as follows:
 - i. being a participant in the parent study
 - ii. having been assigned to a group for which qualitative data was potentially elicited
 - iii. being a parent of child(ren) living inside or out of the home (i.e., dependent minor children or those who are no longer dependent).

- iv. having participated in message board exchanges (Nurse-Delivered arm) or online modules (Self-Directed arm) to a degree that resulted in qualitative data.

2.1.5 Data sources

The WRITE Symptoms study is based on the Representational Approach (H S Donovan & Ward, 2001), which in turn is grounded in Leventhal's Common Sense Model (CSM) (Leventhal et al., 1997, 1992)(Diefenbach & Leventhal, 1996; Leventhal et al., 1997, 1992). The CSM of illness representations, and its framing of the parent study, provides a rationale for the value of examining everyday experiences as well as lifestyle characteristics such as parenting status, and their relationship to symptom burden, social support, and, ultimately, quality of life, as all of these constructs are seated within the framework of the individual's illness representations. In addition to collecting quantitative data using standardized measures administered at 13 time points, the WRITE Symptoms study elicited richly-textured qualitative data from participants regarding their symptom perceptions, including the meaning(s) they ascribed to the symptoms and their level of distress in response to the symptoms, along with details of the participants' coping efforts. 496 women with advanced and/or recurrent ovarian cancer were randomized to one of three treatment arms. Nurse-delivered participants were assigned to a nurse interventionist by whom they were guided via asynchronous message board exchanges through the Representational Approach to identifying, describing, and developing a symptom care plan to target three symptoms of their choice over which they hoped to gain more control. Participants randomized to the Self-Directed condition worked through the Representational Approach independently by responding to structured queries about their symptom representations and being presented with possible

management strategies from which to choose. Additionally, Self-Directed participants were given access to an online journal for their personal use in recording their reflections and experiences during the intervention. Online message-board interactions between nurse interventionists and participants, as well as participants' responses to questions regarding their most bothersome symptoms in a self-directed module, including online journal entries, will be read, coded, and analyzed by two independent raters to identify themes regarding the impact of parenting on women's experiences of their illness, symptom management efforts, treatment decision-making, and quality of life. The WRITE Symptoms parent study was not designed to evaluate the influence of parenting on the cancer experience, nor did the exchanges between nurses and participants explicitly probe for content related to mothering. However, each participant/nurse intervention began with the nurse introducing herself and inviting the patient to speak broadly about her own experience, both through open-ended questions as well as through modeling. As part of both the Nurse-delivered and Self-Directed arms of the parent study, patients each identified three symptoms over which they would most like to gain control and were asked to write about them. The first in a series of questions from the Nurse-delivered arm is as follows: "I would like you to tell me about (*the symptom selected by the patient*). Don't worry about writing too much—tell me in as much detail as possible. Often it is helpful if you describe a typical day or tell me how (*the symptom*) is affecting your life. Just tell me the story of your experience." Through this and other open-ended questions, patients were given opportunities to share their perceptions, including their understanding of the meaning of their symptoms, their beliefs about the cause of their symptoms, how the symptoms affect their lives, what they had done to try to manage them, the effectiveness of their efforts, and any barriers or facilitators to successful management they may have encountered. Many patients spontaneously mentioned their children/grandchildren and their

family lives and unique priorities during the introductory exchanges and throughout the course of describing the impact of cancer and symptoms on their lives as women and mothers. Similarly, participants in the Self-Directed arm were guided through a series of prompts to write about the identified symptom from the perspective of its impact on their lives, including its effect of their daily activity, changes it may have caused them to make, and strategies they had used in attempt to seek relief. Women working directly with nurse interventionists as well as those using the self-directed modules were given opportunities to respond with detailed descriptions of their lives and the ways in which their illness and symptoms had affected them. These open-ended prompts and queries yielded a rich source of data about meaning in the form of women's symptoms representations (attributes about cause, ability to control, and degree of severity and distress). It is anticipated that this qualitative analysis will extend and refine the findings of the preliminary quantitative analysis to illuminate the meaning-making experiences of women managing their cancer symptoms while navigating life as mothers.

2.1.6 Planned data collection procedures

De-identified data will be obtained for participants who participated in the WRITE Symptoms parent study and whose participation resulted in qualitative data. The number of participants for whom there is the potential for qualitative data is 253; however, as noted above, it is expected that the actual number will be lower since not every participant elected to participate fully in all of the Nurse-delivered or Self-Directed study activities.

2.1.7 Planned data analysis procedures

- Prior to initiating coding, the full body of qualitative data will be read by two independent raters to generate preliminary thoughts and impressions.
- Data reduction will be conducted as necessary by 1) reading all data and selecting sections relevant to the question of parenting and 2) using the strategy of key word analysis to rapidly select segments of text warranting close and careful analysis. However, this will be done with extreme care since it cannot be automatically assumed that passages in which parenting is not explicitly mentioned are not relevant to the analysis (e.g., additional exploration may be warranted if there are women who are known to be mothers but who do not mention parenting-related concerns).
- Primary coding (Saldana, 2013; Tracy, 2013) will be done in an iterative fashion using constant comparative methods by two raters who will code passages independently, meet regularly to discuss and achieve consensus on codes, revisit data to apply codes as applicable, and use established as well as emerging codes going forward.
- A codebook will be developed and modified through expanding, condensing, refining, or eliminating codes as appropriate. Clear guidelines and conditions for the use of each code as well as exemplar quotes will be included.
- Raters will proceed to secondary (analytic/interpretive) coding (Tracy, 2013) to identify associations between themes reflected by codes and to propose relationships and overarching themes.

- Procedural as well as conceptual/theoretical memos will be written before and during the process to track initial impressions, decisions, thoughts about coding and analysis, and other salient ideas that may arise.
- Following the qualitative analysis to address Aims 1 and 2, GBTM will be initiated to identify distinct symptom burden trajectories. The timing of this step after the initial qualitative analysis will prevent the investigator from being biased by symptom burden information during early encounters with the data.

Themes will be considered by sub-groups identified through trajectory modeling to identify and explore differences by symptom burden and distress trajectories. Re-examining previously coded data through the lens of symptom burden trajectory will allow for a more granular exploration of the possible relationships between burden, parenting status, and meaning-making.

2.1.8 Planned data interpretation

- Means, standard deviation, frequencies, and percentages will be provided for the subset of WRITE Symptoms participants included in this secondary analysis to describe and characterize the sample on the basis of mean age, race, marital status, education and income levels, and employment status.
- Themes and interpretations developed during analysis will be synthesized and integrated with exemplar quotes to describe the phenomenon of symptom representations as a form of making meaning as an element of the experience of facing cancer while mothering.

2.1.9 Anticipated study limitations

Since parenting was not an explicit focus of the WRITE Symptoms study, it is possible that not all of the qualitative data will contain references to parenting status or parenting concerns. However, it can reasonably be assumed that, for those participants who spontaneously offered statements related to parenting and its relationship on symptom perceptions, symptom management, treatment decision-making, or any other aspects of life with cancer, parenting influenced their experience of being a cancer patient. The hope and expectation is that the ways in which this occurred will be made more clear by this inquiry.

2.1.10 Potential benefits of proposed research

There are no direct benefits expected as a result of this secondary analysis since there will be no direct contact with research participants.

2.1.11 Importance of knowledge to be gained

The findings from this study will add to the existing but small body of knowledge about the experience of meaning-making among mothers with cancer. They will provide a foundation for, and directly inform the design of, future investigation of the experience of mothers with cancer that can lead to evidence-based interventions and teaching strategies to address the needs of this population.

2.1.12 Protection of human subjects and reduction of risks

As this is a secondary analysis with no direct contact with participants, there is no direct risk associated with this proposed study. Breach of confidentiality is a potential risk in any research study; however, data are identified using only a study ID from the parent study that does not reveal the identity of the participant. Information linking the participant's identity with her study ID in the parent study is maintained by the data manager in a password-protected computer file. De-identified data for this secondary analysis will be maintained by this investigator on a password-protected computer.

3.0 Summary of completed dissertation study

3.1 Methods

3.1.1 Data collection procedures

De-identified qualitative and quantitative data were obtained for participants who were mothers, who participated in the WRITE Symptoms parent study, and whose study assignment and level of participation resulted in qualitative data. This resulted in a sample of 174 participants for Aims 1 and 2. Data from participant responses to Master Message Board prompts and Open-Ended Questions as well as Journal entries were uploaded to NVivo Plus Version 12 computer-assisted qualitative analysis software (“NVivo qualitative data analysis software,” 2018).

3.1.2 Data analysis procedures for Aim 1

3.1.2.1 Preparation for analysis

Prior to initiating coding, the full body of qualitative data was read to generate preliminary thoughts and impressions.

3.1.2.2 Approach to data reduction

Although there was quite a large body of qualitative data, data reduction was not initially used. Strategies such as searching by keywords were considered but rejected so as not to run the risk of eliminating data that did not explicitly mention parenting, grandparenting, or children but

which would still be relevant to this analysis (e.g., additional exploration might be warranted if women known to be mothers did not mention parenting-related concerns, as this in itself may represent a significant finding).

3.1.2.3 Primary coding

A preliminary codebook was developed based on concepts identified in the literature related to parenting with cancer. Additional codes were added following initial engagement with the data; these included codes regarding participants' attitudes, aspects of their cancer diagnosis and treatment, and various elements of symptom experience and symptom management. Primary coding (Saldana, 2013; Tracy, 2013) of a total of 10% of the participants was done in an iterative fashion using four phases of coding by two raters who coded passages independently, met regularly to discuss and achieve consensus on codes, revisited data to apply codes as applicable, and used established as well as emerging codes going forward into each successive phase of coding. As the first three phases of coding proceeded, the need for several additional codes emerged, and refinements were made to several existing codes as well. A codebook was developed through adding, expanding, and refining codes. The codebook included clear definitions for all codes and sub-codes. Comparisons of coding between the two raters demonstrated satisfactory levels of concordance. None of the codes from the initial codebook were eliminated, although some were used less frequently than others as coding proceeded. Because the focus of the parent study was symptom management, many of the exchanges focused largely on symptoms; as a result, talk of symptoms became a sort of backdrop against which all other topics were addressed. Therefore, as coding progressed, the decision was made to be less vigilant about coding passages that referred only to symptom management in the absence of reference to parenting-related concerns since doing so did not add to understanding of the question at hand.

3.1.2.4 Establishment of the codebook

Discussion and consensus between the raters resulted in finalizing the codebook, after which coding and analysis of the remainder of the data were completed by the primary investigator only.

3.1.2.5 Secondary (analytic/interpretive) coding and analysis

Following initial coding, this investigator proceeded to secondary (analytic/interpretive) coding (Tracy, 2013) to identify associations between themes reflected by codes and to propose relationships and overarching themes.

3.1.2.6 Establishing an audit trail

Procedural as well as conceptual/theoretical memos were written throughout the process to track initial impressions, decisions, thoughts about coding and analysis, and other salient ideas as they arose.

3.1.3 Data analysis procedures for Aim 2

3.1.3.1 Classifying participants by Parenting Status

After coding the qualitative data from all 174 participants without regard to Parenting Status, demographic data specifying Parenting Status was added to the data set. Two sets were created within each of the three data sources to distinguish mothers parenting minor children in the home from those parenting children outside the home, and participants were added to the set that described their Parenting Status. This allowed the investigator to run matrix coding queries within NVivo using Parenting Status as a grouping variable.

3.1.3.2 Using matrix coding queries to compare groups by Parenting Status

Themes identified during Aim 1 were revisited using parenting status to allow for preliminary visualization of differences based on whether women were raising minor children in the home while facing advanced cancer or whether their children were out of the home. Similar to crosstabs, matrix coding queries allow for visualization of data by columns and rows to illuminate potential differences in the nature and distribution of coding by grouping variables—in this case, parenting status. This strategy was used to examine the prevalence of themes in each group to begin to investigate whether differences existed.

3.1.4 Data analysis procedures for Aim 3

Following the completion of Aims 1 and 2, the statistical technique of group-based trajectory modeling (GBTM) was initiated to identify distinct symptom burden trajectories to accomplish Aim 3. The timing of this step after the qualitative analysis prevented the investigator from being biased by symptom severity and burden information (beyond that contained in the participants' own words and descriptions) during early encounters with the data.

3.1.4.1 Establishing sub-sample for group-based trajectory modeling (GBTM)

Only participants with symptom severity data for at least two of the three timepoints during the 8-week active intervention period of the WRITE Symptoms parent study were retained in the sample for the GBTM analysis since a single data point cannot reflect a trajectory of symptom severity over time. This resulted in a sample of 120 participants for Aim 3.

3.1.4.2 Conducting GBTM

Symptom severity data for all participants for all available timepoints (≥ 2) were entered into SAS and the PROC TRAJ procedure was conducted iteratively to fit a model of symptom severity trajectories that accounted for all participants across the three time points that occurred during the 8-week intervention period. The most parsimonious and best-fitting model based on Bayesian Information Criteria (BIC) scores and non-overlapping confidence intervals yielded three distinct trajectories and is represented in *Figure 2* below. The trajectories were 1-Low (n=23), 2-Moderate/Declining (n=74), and 3-Sustained High (n=23).

Symptom Severity Trajectories

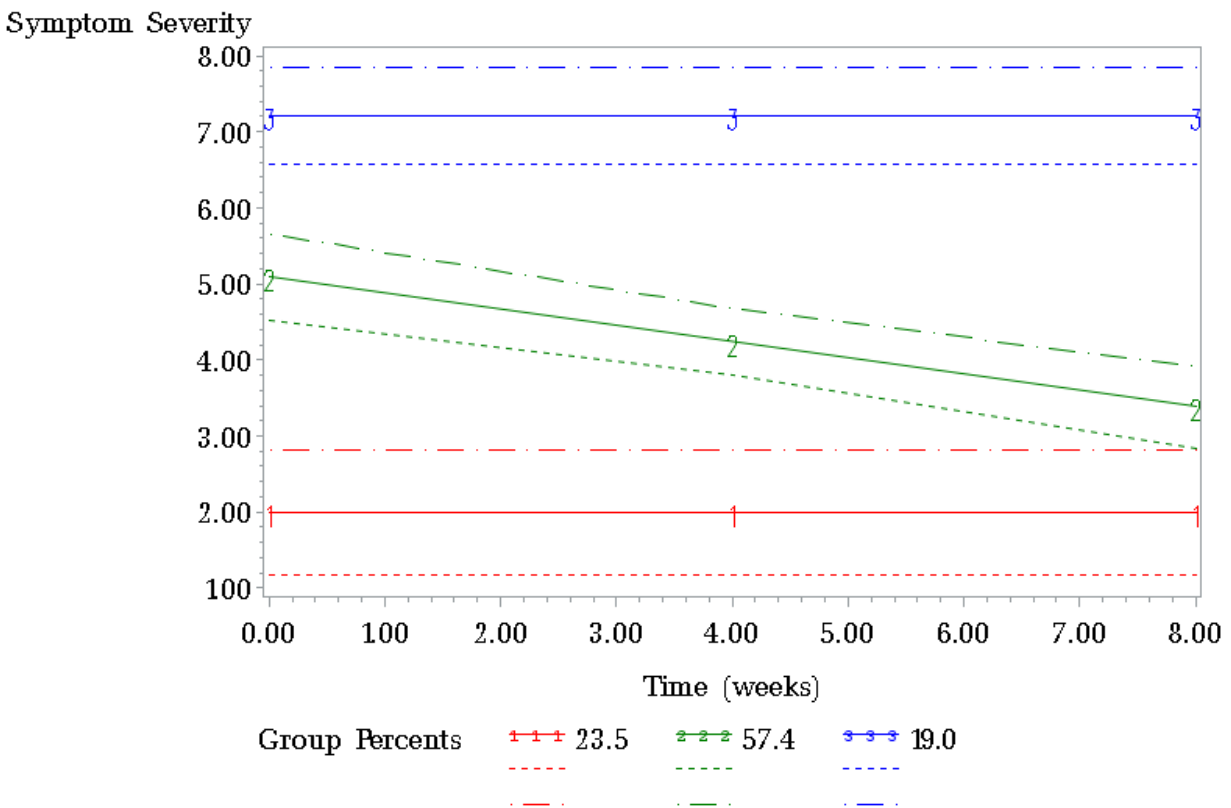


Figure 2 Symptom severity trajectories revealed by GBTM

3.1.4.3 Identifying participants in each trajectory

Based on probability of group membership, participants were assigned to one of three symptom severity trajectories, and three corresponding sets were created in NVivo to allow qualitative data from each of the three symptom trajectory groups to be evaluated separately.

3.1.4.4 Using matrix coding queries to compare groups by Symptom Severity Trajectory

Themes and sub-themes were considered through the lens of the symptom severity trajectories identified through group trajectory modeling to explore differences based on symptom severity and burden. Matrix coding queries were used to visualize the prevalence of themes within each respective group to generate a preliminary assessment of whether differences existed.

3.2 Summary of findings

3.2.1 Aim 1

Background, purpose, methods, and findings for the primary qualitative aim of this dissertation study are presented in Data-Based Manuscript #4 in Appendix G.

3.2.2 Aim 2

Comparing the percentage of coded references by parenting status did not reveal significant differences between women raising minor children and those whose children lived outside the home. Figure 3 below shows the percentage of coded references by theme and parenting status:

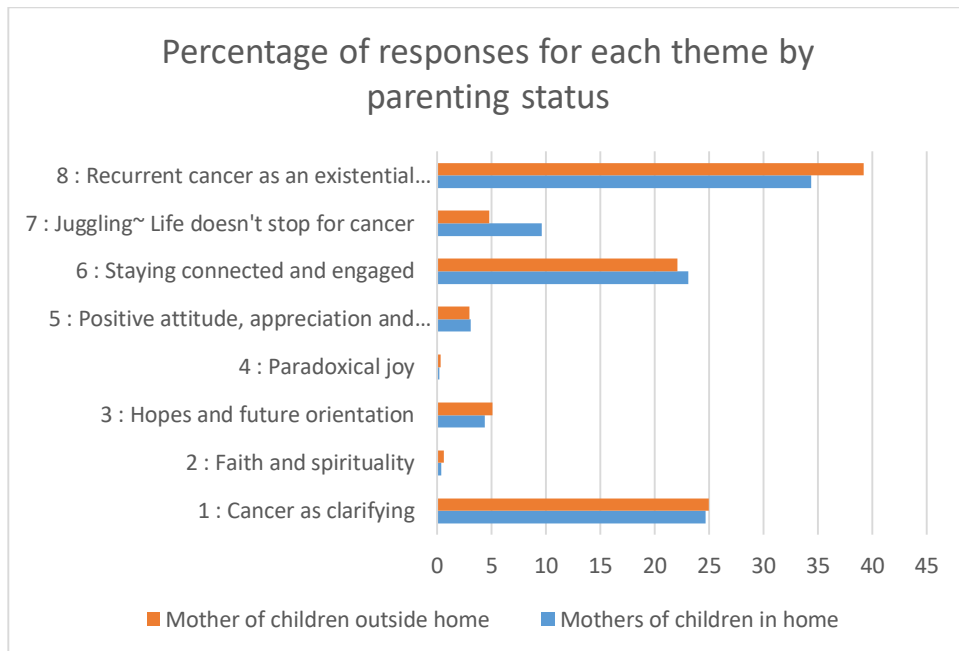


Figure 3 Percentage of coded references by theme and parenting status

3.2.3 Aim 3

As with the thematic analysis by parenting status in Aim 2, comparing number of coded references by symptom trajectory group did not suggest differences in themes described by women experiencing low, moderate/declining or sustained high symptom severity patterns. See Figure 4. below for details.

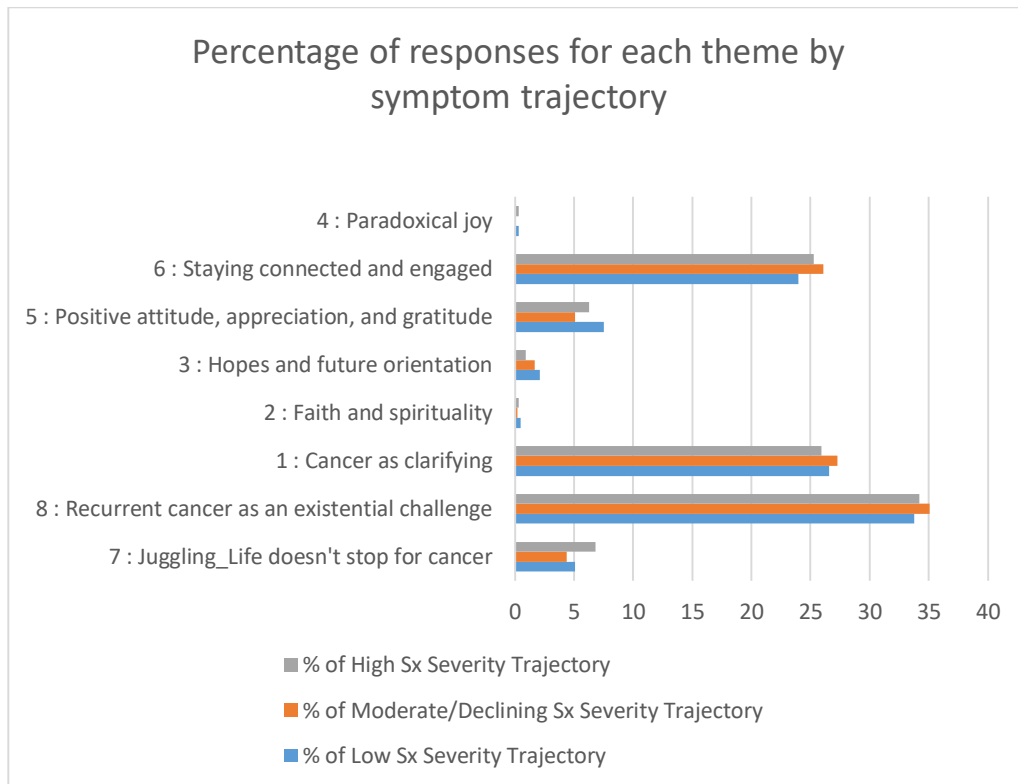


Figure 4 Percentage of coded responses for themes by symptom severity trajectory

Complete results of the mixed-methods portion of this study (Aims 2 and 3) will be reported in a separate manuscript.

3.3 Discussion

Discussion and implications of Aim 1 findings are included in Data-Based Manuscript #4 in Appendix G of this document.

The findings of Aims 2 and 3 suggest that, for women parenting with recurrent ovarian cancer, neither the age and stage of their children nor the degree of symptom burden they are experiencing outweighs the impact of the reality of their diagnosis as mothers with advanced

cancer. As revealed by the themes identified by Aim 1, women of all ages and parenting statuses spoke of their illness as both a challenge to their health and longevity and their ability to parent. They spoke of the difficulties inherent in balancing the demands of caring for others in their roles as mothers, partners, workers and friends even as they attempted to care for their own needs as patients with a serious, life-limiting illness. Finally, they spoke, movingly and with conviction, of the clarifying aspects of life with advanced cancer, and again they did so regardless of their parenting status or level of symptom severity. Most notably, they shared their sense of cancer as refining their priorities and, to some degree, their understanding of the world and their place in it while at the same time acknowledging the painful realities of living with a life-threatening illness. The findings from Aims 2 and 3 underscore the fact that, for mothers with cancer, their experience as mothers and the relationship of their mothering role to their cancer are far more significant than any differences based on age and stage of their children or severity of their symptoms.

3.4 Conclusion

Through the words of the women who participated in the WRITE Symptoms parent study, this work offers a granular and personal view into the experiences of women parenting with advanced cancer. However, there is much that remains to be understood about the needs of this population, including potential changes in needs for information and support along the continuum from diagnosis through treatment, recurrence, survivorship, and death. Supporting women and their families as they face serious illness can improve their quality of life, invite deeper and more meaningful conversation and connection, and provide opportunities for intentional legacy work

that may allow for healthy anticipatory grieving while decreasing the likelihood of complicated grieving for families when death does occur.

Taken together, the findings of the preliminary quantitative analysis as well as the qualitative and mixed methods analyses demonstrate the substantial impact of being a mother on the experience of having cancer as well as the influence of having advanced cancer on a woman's role as a mother in the physical, emotional, social, and functional domains. Although a relationship between parenting status and symptom experience (in the form of symptom representations) could not be reliably established, it is possible that the limitations of conducting secondary analyses may have been a factor. What was elucidated, however, is the important roles of parenting, symptoms, and social support on quality of life in mothers with advanced cancer. Additional qualitative work is needed to deepen our understanding of the exact nature of these relationships and to identify the information and support needs experienced by women parenting while facing cancer. Further, it is likely that these needs change throughout the course of illness from diagnosis through recurrence, survivorship, and death, and characterizing these changing needs would be an important contribution to our understanding of how to best support mothers with cancer and their families.

3.5 Implications for future work

Further investigation is needed to more fully understand and describe the experience of parents with serious, life-limiting illness. Mixed-methods approaches offer the benefits of both quantitative and qualitative methodologies, allowing for deeper, more nuanced understandings that can serve to ground and orient the development and implementation of tailored interventions and

provide a framework for educating healthcare and support professionals to better meet the needs of this vulnerable population. Ideally, future work would involve recruiting a novel sample of mothers (or parents) with cancer to address some or all of the following questions:

1. What are the differences between parents and non-parents with cancer?
2. What might drive these differences?
3. What are the differences between the experiences and needs of parents with cancer from diagnosis through treatment, survivorship, recurrence, and death?
4. Are there differences in the experiences of mothers and fathers with cancer based on gender and parenting role?
5. Based on the findings of these investigations, what interventions might be effective at addressing the needs identified?
6. Given that the experience of cancer appears to be embedded in maternal identity, how can interventions be provided in the context of the family unit?

**Appendix A Manuscript #1: An unpublished concept analysis of meaning-making in
advanced cancer**

Meaning-making in advanced cancer: A concept analysis

Janet Arida, PhD(c), RN

Heidi Donovan, PhD, RN

Catherine Bender, PhD, RN

Introduction

The urge to create a meaningful life, and to make meaning of adversity, is a centuries-old part of the human experience. Evidence of this search for meaning has been observed among humans since before the beginning of recorded history (Bliss, 2007; Gordon, 1949; Kleinman, 1998). Previously regarded as falling exclusively within the philosophical, metaphysical, or spiritual domains, the phenomenon described as meaning-making has become an increasing focus of inquiry in health care circles during recent decades; however, the exact nature of the concept has not been fully explored or clearly defined. (Romanoff & Thompson, 2006). A 2006 concept analysis by Skaggs and Barron examined articles published prior to 2004 to begin the process of developing a more comprehensive and consistent definition of meaning-making, but further investigation of the concept has been done on this topic since that time and warrants consideration. The purpose of this current work is to extend and refine the previous concept analysis on the search for meaning in negative events by examining more recent literature on meaning-making and specifically focusing on the work that pertains to meaning-making in patients with advanced cancer. We use the approach suggested by Rodgers (1989) to explore and clarify the existing definitions of meaning-making with the aim of arriving at a synthesis that can serve as a foundation for future investigation in this area.

Background

As treatment improves for a variety of cancers, survival times for patients with these life-threatening illnesses have lengthened correspondingly. This has led to increasing numbers of survivors who are faced with the challenge of negotiating life for months or years following a

diagnosis with a potentially life-limiting illness. As Lee and Loiselle (2012) note, the belief that cancer represents a death sentence is a commonly-held perception; therefore, a diagnosis of cancer often leads to a heightened awareness of one's own mortality, and this awareness alone can impose an ongoing burden on survivors. Surprisingly, however, this recognition does not necessarily elicit existential distress. Here I will explore some of the factors that influence whether existential distress arises, the response it elicits, and whether and how it is ultimately resolved through the process of meaning-making.

Uses and definitions of “meaning-making”

Both the theoretical and the empirical literature contain numerous definitions of meaning-making (Arpawong, et al., 2012; Boals, 2012; Collie & Long, 2005; Duran, 2013; Egnew, 2005; Ferrell, et al., 2003; Janoff-Bulman, 1992; Lee & Loiselle, 2012; Park, 2010; Park, et al., 2008; Romanoff & Thompson, 2006; Skaggs & Barron, 2006). Although these definitions differ to some degree, there is considerable consensus as well. The following aspects of meaning-making in patients following a cancer diagnosis were described by most or all of the authors cited above:

- Meaning-making efforts arise when the worldview which has shaped an individual's sense of order, purpose, and meaning is violated by a traumatic event such as a diagnosis of cancer (Arpawong, et al., 2012; Collie & Long, 2005; Janoff-Bulman, 1992; Joseph, Murphy & Regal, 2012; Lee & Loiselle, 2012; Park, et al., 2008; Skaggs & Barron, 2006). Although an individual's worldview plays a substantial role in shaping and organizing goals, values, beliefs, experiences and perceptions, it is often largely unconscious until threatened by a traumatic event.
- Meaning-making consists largely of cognitive processes: the degree to which the diagnosis is appraised as a threat, the resources the individual believes s/he has available

to respond, and the coping processes s/he deploys in response are largely mediated by the underlying construct of his or her worldview, or cognitive schema (Arpawong, et al., 2012; Boals, 2012; Collie & Long, 2005; Janoff-Bulman, 1992; Joseph, Murphy & Regal, 2012; Lee & Loiselle, 2012; Morris & Shakespeare-Finch, 2011; Park, et al., 2008; Skaggs & Barron, 2006)

- Meaning-making arises from an individual's efforts to reconcile incompatibility between previously-held worldviews and the disruption to those worldviews represented by the cancer diagnosis (Arpawong, et al., 2012; Collie & Long, 2005; Janoff-Bulman, 1992; Joseph, Murphy & Regal, 2012; Park, et al., 2008). This is described in Janoff-Bulman's Theory of Shattered Assumptions (1992).
- The process of meaning-making, both the form it takes and its ultimate outcome, is highly individualized and dependent on unique and personal determinations of what constitutes a satisfactory resolution of the dilemma introduced by the diagnosis and associated awareness of threat (Arpawong, et al., 2012; Collie & Long, 2005; Janoff-Bulman, 1992; Park et al., 2008)
- In addition to being influenced by an individual's values, beliefs, etc. and therefore unique, appraised meanings and meaning-making activities are also seated in social and cultural contexts, and therefore contain aspects that are shared among members of social and cultural groups (Collie & Long, 2005; Lee & Loiselle, 2012; Skaggs & Barron, 2006).
- Meaning-making efforts are often associated with distress in the short-term and, in some cases, do not lead to successful long-term resolution of the existential crisis (Arpawong et al., 2013; Park, et al., 2008).

The term meaning-making has been used at various times to describe both a process (“meaning-making,” “benefit finding,” and “searching for meaning” are some of the terms used to describe the phenomenon as a process) and an outcome (“meaning made,” “personal growth,” transformation,” “reconstruction of assumptive world” and “thriving” are among the phrases used to describe meaning-making as an outcome). This lack of precision has resulted in some ambiguity regarding the phenomenon of meaning-making. This concept analysis focuses predominantly on meaning-making as a process.

Core attributes of meaning-making

As previously noted, meaning making processes contain both personal and universal elements. Meaning-making efforts arise in response to perceived threats to one’s worldview, which until then had comprised a sense of safety, order, justice and meaning (Janoff-Bulman, 1992). Meaning-making involves the deliberate rallying of cognitive processes in a manner that the individual believes will be most likely to yield a resolution of the threat of existential distress (Janoff-Bulman, 1992; Park, et al. 2008; Skagg & Barron, 2006). Meaning-making efforts which have been demonstrated to be most effective in helping the individual incorporate the reality of the diagnosis, while reconstructing the shattered assumptive world, are reflective rather than ruminative, and intentional rather than obsessional (Janoff-Bulman, 1992; Morris & Shakespeare, 2011; Park, 2010; Park, et al., 2008).

Sub-dimensions of meaning-making

Two primary sub-dimensions of meaning-making have been described. These are global meaning and situational meaning. Global meaning corresponds to the foundational, orienting worldview each individual carries, often unconsciously. Formed through complex interactions

between sociocultural, familial, and individual factors in combination with life experiences, it provides a foundation on which to build one's life and a lens through which to view and interpret one's experience. Individuals are largely unaware of these global meaning structures until they fail to serve their customary organizing or meaning-generating roles in the face of unexpected tragedy, trauma, or loss. (Janoff-Bulman, 1992; Lee & Loiselle, 2012; Park, 2010; Skaggs & Barron, 2006). Situational meaning refers to the individual's process of appraising a given situation to assess the degree to which it poses a threat to which s/he is unprepared to respond, either because s/he lacks the necessary coping resources to manage the event, or because his or her worldview offers no way to understand or incorporate the event while remaining intact. If severe enough, this mismatch between global and situational meanings leads to a shattering of the global meaning structure and is often the initiating factor in the search for meaning (Janoff-Bulman, 1992). The task of the individual is to find a way to continue to go on. One strategy for achieving this is to reconfigure his or her global meaning (described by Janoff-Bulman and the individual's "assumptive world") so as to neutralize the traumatic event and incorporate it into a new worldview that is suitable for going forward. Another approach is to successively reappraise the stressor as being less threatening or one's own coping repertoire as being adequate to meet the challenge; this often occurs through downward ("I'm not as bad off as the patient in the next bed") or upward ("I can achieve that same longevity as my friend with cancer") comparisons (Arpawong, et al., 2013; Reb, 2007; Park, et al. 2008).

Antecedents and consequences of meaning-making

The antecedent to meaning-making activities is being presented with a crisis event that ruptures the individual's assumptive world and necessitates a reconstruction of global meaning (Arpawong, et al., 2012; Collie & Long, 2005; Janoff-Bulman, 1992; Park, 2010; Park et al., 2008).

When meaning-making efforts are successful, the consequence is repair of the individual's assumptive world, often (but not always) leading to increased resilience and a higher level of functioning than was present prior to the trauma of diagnosis (Arpawong, et al., 2012; Collie & Long, 2005; Janoff-Bulman, 1992; Lee & Loiselle, 2012; Park, 2010). This consequence is often described as "post-traumatic growth" (Collie & Long, 2005; Janoff-Bulman, 1992; Lee & Loiselle, 2012; Morris & Shakespeare-Finch, 2011; Park, 2010)

Refined definition of meaning-making in advanced cancer

The current concept analysis suggests a definition of meaning-making that includes the following aspects:

- Meaning-making efforts are elicited by a traumatic event which exceeds the individual's coping capacity and shatters the previously-held global meaning structure.
- Meaning-making is a deliberate cognitive process which, optimally, is reflective and intentional.
- Meaning-making by its nature is highly individual as its goal is the re-configuration of the individual's worldview in a way that allows for integration of the trauma of diagnosis and creates a foundation for future growth. Meaning-making efforts are oriented by the individual's values and belief system and, as a result, meanings are not inherent to the precipitating event (e.g., cancer diagnosis) but rather are influenced by factors such as the individual's global meaning, values, goals, and beliefs as well as disease characteristics, social support, and emotional resources, among other things.

Exemplar case illustrating meaning-making

Reb's 2007 grounded theory investigation of hope in women with advanced cancer used a guided interview to elicit the following accounts of meaning-making, which were collected from women at various points along the disease trajectory:

Immediately following the diagnosis: "The first thing I did was to ask God to give me the strength so I could help my family when I tell them, and it wasn't as hard telling my husband, but it was very hard telling my daughters. And I couldn't tell my sons at all."

During the early adjustment process: "You have to deal even [though] you know on some level, it's sort of like there's two people operating. You have to deal with it, but then sometimes it feels like somebody else is actually going through it."

In the rebuilding phase: "You always want to be proactive and now you're in the wait-and-see mode....But there's nothing you can do...It's mostly trying to figure out how you go on with your life without dwelling on the fact that three months from now you are going to have an exam...or the blood work...You can't—you just can't think that far in advance."

Shifting expectations and re-establishing a new sense of meaning: "I don't take anything for granted. I try to stop and enjoy, take things at a slower pace, and really enjoy and not just rush through everything. Enjoy watching the girls grow up, not just going through the motions every day but actually being there."

Conclusion

As survival times for advanced-stage cancers continue to lengthen, it will become increasingly important to understand the factors that lead to enhanced quality of life in addition to improved longevity. Investigating the ways in which individuals' ability to create meaning leads to repair of life narratives that have been ruptured by an unexpected traumatic event will be a fruitful area for further research.

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Appendix B Request and Permission Granted to Reprint Journal Article

Dear Sir or Madame:

I am completing a doctoral dissertation at the University of Pittsburgh School of Nursing entitled "Symptom representations and meaning-making in mothers with advanced cancer: A mixed methods investigation."

I am writing to obtain a non-Rights-Link permission to use an article originally published in the *Cancer Nursing*, July/August 2019, v. 42 (4), pp. E54-60, entitled, "Mothering with advanced ovarian cancer: You've got to find that little thing that's going to make you strong." I am the first author of this article.

This article will be included in my PhD dissertation.

Please note that I have already submitted a permission request through RightsLink, and received a message that permission to include this publication in print was not required and that it could be included electronically once the embargo period of 12 months had elapsed. (Please see attached file). However, I am contacting you to confirm your awareness of that the requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages, to the electronic publication of my dissertation by the University of Pittsburgh, and to the prospective publication of my dissertation by ProQuest. ProQuest may supply copies of my dissertation on demand. These rights will in no way restrict republication of the material in any other form by you, or by others authorized by you. Your response will also confirm that you own [or your company owns] the copyright to the above-described material.

If these arrangements meet with your approval, please return this e-mail with affirmation.

Thank you very much.

Please contact me at the phone number or email address below if you have any questions.

Thank you in advance for your response.

Sincerely,

Janet Arida, RN, BSN, MA, PhD(c)

University of Pittsburgh, School of Nursing

Mothering With Advanced Ovarian Cancer: “You've Got to Find That Little Thing That's Going to Make You Strong”

Author:

Janet Arida, Toby Bressler, Samantha Moran, et al

Publication: Cancer Nursing

Publisher: Wolters Kluwer Health, Inc.

Date: Jul 1, 2019

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Appendix C Data-base manuscript #2: Journal Article published in *Cancer Nursing*

- **Arida, J.A., Bressler, T., Moran, S., D'Arpino, S., Carr, A. & Hagan, T.L. (2019). Mothering with advanced ovarian: “You’ve got to find that little thing that’s going to make you strong.” *Cancer Nursing*, 42(4): E54-E60. DOI: [10.1097/NCC.0000000000000550](https://doi.org/10.1097/NCC.0000000000000550)**

<https://pubmed.ncbi.nlm.nih.gov/29489476/>

Appendix D IRB Approval for dissertation study

University of Pittsburgh
Institutional Review Board

Human Research Protection Office
3500 Fifth Avenue, Suite 106
Pittsburgh, PA 15213
Tel (412) 383-1480
www.hrpo.pitt.edu

APPROVAL OF SUBMISSION (Expedited)

Date:	October 7, 2019
IRB:	STUDY19070121
PI:	Janet Arida
Title:	Symptom Representations and Meaning-Making in Mothers with Recurrent Ovarian Cancer: A Mixed Methods Investigation
Funding:	None
Grant Title:	<Indicate "None" if there is none.>

The Institutional Review Board reviewed and approved the above referenced study. The study may begin as outlined in the University of Pittsburgh approved application and documents.

Approval Documentation

Review type:	Initial Study
Approval Date:	10/7/2019
Approved Documents:	<ul style="list-style-type: none"> • Arida_Dissertation proposal.IRB.08.11.2019.docx, Category: IRB Protocol; • Magee_Consent_WRITE_Symptoms_Study_OSIRIS_Appl_092512 (1).pdf, Category: Consent Form; • Protocol for WRITE Symptoms (parent) study, Category: Other; • WRITE Symptoms (Parent Study) consent form, Category: Other;

As the Principal Investigator, you are responsible for the conduct of the research and to ensure accurate documentation, protocol compliance, reporting of possibly study-related adverse events and unanticipated problems involving risk to participants or others. The HRPO Reportable Events policy, Chapter 17, is available at <http://www.hrpo.pitt.edu>.

Clinical research being conducted in an UPMC facility cannot begin until fiscal approval is received from the UPMC Office of Sponsored Programs and Research Support (OSPARS).

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, [Larry Ivancic](#).

Please take a moment to complete our [Satisfaction Survey](#) as we appreciate your feedback.

Appendix E Supplemental materials from WRITE Symptoms parent study

Study protocol, informed consent, and measures from WRITE Symptoms parent study are included in a Zip file here:

<https://d-scholarship.pitt.edu/39112/1/WRITE%20Symptoms%20PDFs.zip>

Appendix F Data-based manuscript #3

Link to manuscript with findings from quantitative pilot study:

<https://d->

[scholarship.pitt.edu/39112/4/Examining%20the%20Influence%20of%20Children%20in%20the](https://d-scholarship.pitt.edu/39112/4/Examining%20the%20Influence%20of%20Children%20in%20the)

[%20Home.Cancer_Final.05.28%20.docx](https://d-scholarship.pitt.edu/39112/4/Examining%20the%20Influence%20of%20Children%20in%20the%20Home.Cancer_Final.05.28%20.docx)

Appendix G Data-based manuscript #4

Link to manuscript with qualitative findings from mixed-methods investigation.

<https://d-scholarship.pitt.edu/39112/5/Thematic%20Analysis.JPSO.05.28.2020%20.docx>

Appendix H Codebook for qualitative aims of current dissertation study

Name	Description
Mothering and cancer are inextricably linked	Participants' descriptions of the experience of parenting or grandparenting while meeting the challenges of facing a cancer diagnosis, treatment, and symptom management.
Cancer as clarifying	Participants' descriptions of finding joy and beauty in their circumstances, persevering in the face of limitations, experiencing unexpected contentment and gratitude, trying to "find the silver lining," and making meaning of their cancer experience.
Faith and spirituality	Participants' discussion or description of their faith and spiritual lives and/or reliance on God/Higher Power, especially where their illness is concerned.
Hopes and future orientation	Participants' mentions of their hopes, desires, and thoughts about the future.
Paradoxical joy	Participants' descriptions of feeling joyful, present, peaceful, contented even as they are describing difficulties, sadness, fear, challenge, uncertainty.
Positive attitude, appreciation and gratitude	Participants' discussion of positive attitudes or practices such as appreciation or gratitude,
Staying connected and engaged	Participants' descriptions of being supported, remaining engaged, and staying connected with partners, family, friends, workplaces, providers, and activities.
Juggling~ Life doesn't stop for cancer	Participants' discussion of trying to meet the often-competing demands of motherhood, work, family, and friends as they negotiate the challenges of life with cancer.
Recurrent cancer as an existential challenge	Participants' discussion of the impact of recurrent cancer on their lives, including diagnosis, treatment, symptom experience, and symptom management. This includes descriptions of shock, fear,

Name	Description
	isolation, uncertainty, and loss of control, among other feelings and experiences.

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