

It's All About the Relationship: A Qualitative Exploration into Non-Cognitively Impaired  
Mother-Daughter Care Dyads in Hospice at Home

By

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A Dissertation


Presented to  
Oregon Health & Science University  
School of Nursing  
in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy


June 22, 2016

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### **Financial Support**

I gratefully acknowledge dissertation support from the Hartford Center of Gerontological Nursing Excellence, OHSU School of Nursing (Hartford Award for Research and Practice, 2015) and the OHSU School of Nursing Dean's Dissertation Award (2014).

## Acknowledgments

To my loving parents and three older brothers, who created a warm nest of love, chaos, and ever steadfastness for family relationships to prosper and grow. You nurtured all my eggs and passion for human relationships ever after: thank you.

To my committee, I am humbled by and grateful for the dedicated stewardship of each: Lissi Hansen, Karen Lyons, and Judith Baggs—all whom supported me through this process in individual, strength-based ways, displaying wonderful forbearance as well as mentorship. Each of you, especially Lissi, have seen me through trials and triumphs—both academic and personal. And Susan Rosenkranz: your insight and assistance helped the pieces all fall into place. This dissertation would not be what it is without any of you.

To qualitative mentors, Dena Hassouneh-Phillips and Kristin Lutz, who fired and fostered my passion for wisdom and scholarship inherent in both philosophy and stories—and taught me ever greater humility and reverence for those who tell them.

To participants who shared deepest thoughts and feelings with a virtual stranger: You revealed one of the most primal and yet complicated relationships a life is privileged to have—that between a mother and daughter—just as it was poignantly ending. I am honored and humbled by you.

To colleagues and cohort-mates who inspired me with brilliance and commitment throughout: Ashley Franklin, Kari Firestone and, especially, Lyndsey Miller—a bi-directional lifeline of (hopefully reciprocal!) support when no one else could possibly want or even attempt to understand.

To my children, Havah, Rivkah, Adi, and Edin, who urge me daily into better personhood by virtue of how they love and who they are—and are becoming. You

motivate and bless me each day: thank you. Troy, beloved: no one could truly know all this life involved, but you rise to each rhythm and beat with poise, humor, and more love than I knew existed: thank you, ever and always. And to my stepmother Elaine: you are so wonderful in your own right, and on top of that, you make Dad so happy I never have to worry about him—thank you!

Ultimately, this work is dedicated to the loving memory of my mother, Elene Solomon, who inspired with stunning grace, sophistication, love, human frailty and strength, and most of all, dignity—through living and dying. I was so lucky to be your only girl. I miss and hold you with me each day. Thank you.

## Abstract

**Background:** As women age, the majority outlive spouses and rely on daughters as care partners at end of life. In many family care dyads, relationship quality is known to be protective. Yet most of what is known of relationship quality in caregiving is taken from studies of spousal caregivers, and/or of patients with dementia. Additionally, this literature predominantly focuses on care providers rather than patients, and on factors related to burden rather than protection. Finally, it overlooks the end-of-life context, particularly dying at home with hospice, in line with patient and care partner preferences. Understanding relationship quality in mother-daughter dyads at end of life—and how these relationships may or may not influence the hospice context—is a critical first step to meeting any unique needs this most prevalent care dyad may have.

**Methods:** This dissertation manuscript commences with a systematic review focused on relationship quality in mother-daughter care dyads. Nineteen peer-reviewed articles were discovered and synthesized as to the nature of relationship quality, and as to bi-directional influences of relationship quality on the caregiving course. The second manuscript comprises a methods paper outlining a qualitative dyadic approach developed for the dissertation research. The third and final paper is an interpretive descriptive work, using the qualitative dyadic approach to address the transactional nature of relationship quality within mother-daughter dyads in the home hospice context. This final manuscript privileges the voices of both women in the dyad, using exemplars to distill and contextualize several relationship quality styles along a spectrum.

**Findings:** From the literature review, gaps in knowledge surrounding relationship quality in mother-daughter care partners were identified. Although researchers have suggested

positive relationship quality may strengthen as care receivers physically deteriorate, no studies exist regarding mother-daughter relationship quality in the end-of-life, home hospice dying context. Additionally, most researchers have addressed the perspectives of daughters only, rarely exploring the subjective, dynamically changing, and dyadic nature of mother-daughter relationship quality within home hospice. The second manuscript begins to fill this void, explicating a qualitative research approach that remains true at the dyadic level from research aims to recruitment, data collection, analysis and interpretation. The final work closes the circle, filling a gap and offering the first, qualitative dyadic view of women transacting lifelong relationships in the context of hospice at home. This work delineates a spectrum of relationship quality styles, from a peer-like, intimate and concordant Close Friendship through ambivalent and highly strained, discordant relationships, both at individual and dyadic levels. It is hoped this research creates a foundation for several future areas of study: assessing and intervening with troubled dyads; interrogating relationship quality in alternate end-of-life contexts (e.g., outpatient hospice, skilled nursing, acute care); facilitating mother-daughter relationship and life completion; and promoting qualitative dyadic research in its own right, as well as qualitative inquiry triangulating multiple family relationships.

**Conclusions:** As the “gray tsunami” continues to gather strength in the United States, allowing and empowering care recipients and family members to design the end-of-life course they choose is of great clinical and policy concern. Nonetheless, there exists a dearth of research on how relationship quality facilitates or detracts from protective outcomes in aging mothers and adult daughters. This is particularly true in hospice at home, when a lifelong relationship is ending due to the looming death of one member. In

toto, this manuscript dissertation explores, for the first time from the expert perspectives of mothers and daughters themselves, the nature of relationship quality in the context of hospice at home. It is hoped to: inform future hospice care; support women working towards life and relationship completion; open new avenues for qualitative and end-of-life relational research; and begin returning end-of-life care into the hands of the dying and their families.



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## **Chapter I**

### **Introduction to the Dissertation:**

### **Mother-Daughter Care Dyad Relationship Quality in the Context of Hospice at Home**

This section represents a significant contribution to the dissertation work: it replaces aspects of the traditional first chapter.



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**Title:** A developmental-contextual model of couples coping with chronic illness across the adult life span.

**Author:** Berg, Cynthia A.; Upchurch, Renn

**Publication:** Psychological Bulletin

**Publisher:** American Psychological Association

**Date:** Nov 1, 2007

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Over 60 million Americans provide care to a family member (Feinberg, Reinhard, Houser, & Choula, 2011). Roughly two-thirds of these Americans are women providing care to aging mothers (Feinberg et al., 2011). Informal caregivers are estimated to provide 90% of long-term care (Centers for Disease Control, 2011) and are essential to keeping aging women at home in the community (Fingerman, Pillemer, Silverstein, & Sutor, 2012; Grande et al., 2009; Payne & Grande, 2013). Yet the psychological burdens of offering care to a family member are well known and extensive and can adversely affect both partners along the caregiving trajectory (Williams & McCorkle, 2011). These psychological sequelae can include distress (Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Hudson, 2013; Zaider & Kissane, 2009), depression (Bookwala, 2009; Pinqart & Sörensen, 2006; Pinqart & Sörensen, 2004; Shim, Landerman, & Davis, 2011), anxiety (Henriksson, Carlander, & Årestedt, 2014; Linderholm & Freidrichsen, 2010; Singer, Bachner, Shvartzman, & Carmel, 2005; Zhang & Siminoff, 2003), and complicated bereavement (Barry, Kasl, & Prigerson, 2002; Wright et al., 2008).

Chief among factors found to protect the care dyad psychologically over time is relationship quality (Berg & Upchurch, 2007; Lyons, Zarit, Sayer, & Whitlatch, 2002; Merz, Schuengel, & Schulze, 2009). This emotional quality is known to be psychologically and physically protective against distress for both care partners in a variety of family care dyads, particularly in women (Birditt & Antonucci, 2008; Lyons, Stewart, Archbold, & Carter, 2009; Raschick & Ingersoll-Dayton, 2004; Schumacher, Stewart, & Archbold, 2007). Positive relationship quality has been associated with decreased caregiver stress, anxiety, depression, anger, fatigue, and increased quality of

life (Godwin, Swank, Vaeth, & Ostwald, 2013; Schumacher et al., 2008, 2007; Tanji et al., 2008).

However, literature on relationship quality in caregiving has been predominantly focused on spousal caregivers (e.g., Pinqart & Sörensen, 2006, for a review), or in studies of multiple kin relationship dyads, reporting in aggregate on spouses, adult children, and/or other family/informal caregivers (e.g., Ayres, 2000; Schumacher et al., 2008; Schumacher, Stewart, & Archbold, 2007; Sebern & Whitlatch, 2007; Sebern, 2008). Given the important distinctions between spousal and adult child caregivers on caregiving concepts such as distress (Davis et al., 2011; Lee, Yoo, & Jung, 2010; Pinqart & Sörensen, 2003), well-being and self-worth (Bachner, Karus, & Raveis, 2009; Martin Pinqart & Sörensen, 2011), and rewards (Raschick & Ingersoll-Dayton, 2004), it is important to understand how relationship quality differs among women in intergenerational care provision.

In addition to an emphasis on relationship quality experiences of spousal versus other family members providing care, the majority of relationship quality studies have focused on care recipients with dementia (Pinqart & Sörensen, 2007), or on aggregate analyses of care recipients with dementia and those without (Pinqart & Sörensen, 2004). This work has been critical to addressing impacts of the dementia context on many aspects of relationship between care partners (Quinn, Clare, & Woods, 2009; Steadman, Tremont, & Davis, 2007)—particularly the challenges of reciprocity, intimacy, and mutuality in the face of cognitive and behavioral hallmarks of the disorder (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Yet the effects of dementia on relationship

quality underscore the need to explore relationships in settings exclusive of cognitive impairment.

Finally, the bulk of relationship quality literature in caregiving skirts the end-of-life care trajectory, when relational stressors are known to increase (Hudson, 2013; Zaider & Kissane, 2009). This literature also overlooks the environmental context of dying at home (Topf, Robinson, & Bottorff, 2013; Ward-Griffin, McWilliam, & Oudshoorn, 2012). The vast majority of dying patients—up to 94% internationally and 87% in the United States—would prefer to stay home and die in place, surrounded by loved ones (Beccaro et al., 2006; Tang, 2003). The home dying context—with hospice—is known for its ability to facilitate relationship quality (Linderholm & Freidrichsen, 2010; Prince-Paul, 2008; Sand, Olsson, & Strang, 2010; Stajduhar, 2003; Strang & Koop, 2003; Ward-Griffin et al., 2012). Yet most patients die in ICU, acute care hospital, or long-term care settings, with only 25% to 31% percent of Americans dying at home (Muramatsu, Hoyem, & Yin, 2008; Teno et al., 2004). This gap between patient and care partner wishes for preferred place of death on one hand—a home hospice context designed to foster relationship quality—and actual place of death on the other, is of growing concern. The present work begins to fill this gap, giving voice to the most prevalent experts—mother-daughter care partners—so we may hear their needs and hope to meet them.

### **Philosophical Framework and Assumptions**

Berg and Upchurch's (2007) developmental-contextual framework of caregiving reinforced the dissertation research, as does the philosophy of palliative and hospice care. Berg and Upchurch's framework was originally developed in the context of spousal



couples coping with chronic illness, yet the authors proposed its use in any care dyad. The model codifies and advances a system of dyadic appraisal, coping, and adjustment, with each dyad member's appraisal, coping, and adjustment influencing, and being influenced by, the other's (see Figure 1). Dyadic appraisal includes both members' appraisal of illness ownership, representation, and shared stressors (in this writer's view, comprising both burden and gain). Dyadic coping follows a spectrum from uninvolved, to supportive, to collaborative (active engagement), to controlling forms of coping. Both dyadic appraisal and coping influence dyadic adjustment. Although all aspects of the model seamlessly intertwine and affect one another in a myriad of feedback loops, dyadic adjustment was the focus of this work, as it encompasses elements of both appraisal and coping, as well as how the dyad itself adjusts as a relational unit. Thus, dyadic adjustment of mother-daughter care partners was considered as an outcome, or marker of relationship quality.

Berg and Upchurch's (2007) model also rests on several other pertinent assumptions: chronic illness and its changes over time developmentally affect both patient and caregiving partner; relationship quality is naturally influenced by how each dyad member views herself in relation to and in interaction with the other; and the caregiving pair copes together in an interdependent, relational manner. These assumptions inform a naturally dyadic framework to conceptualize mother-daughter caregiving pairs as they journey from chronic illness towards end of life at home, and as the two of them socially construct their relationship at this time.

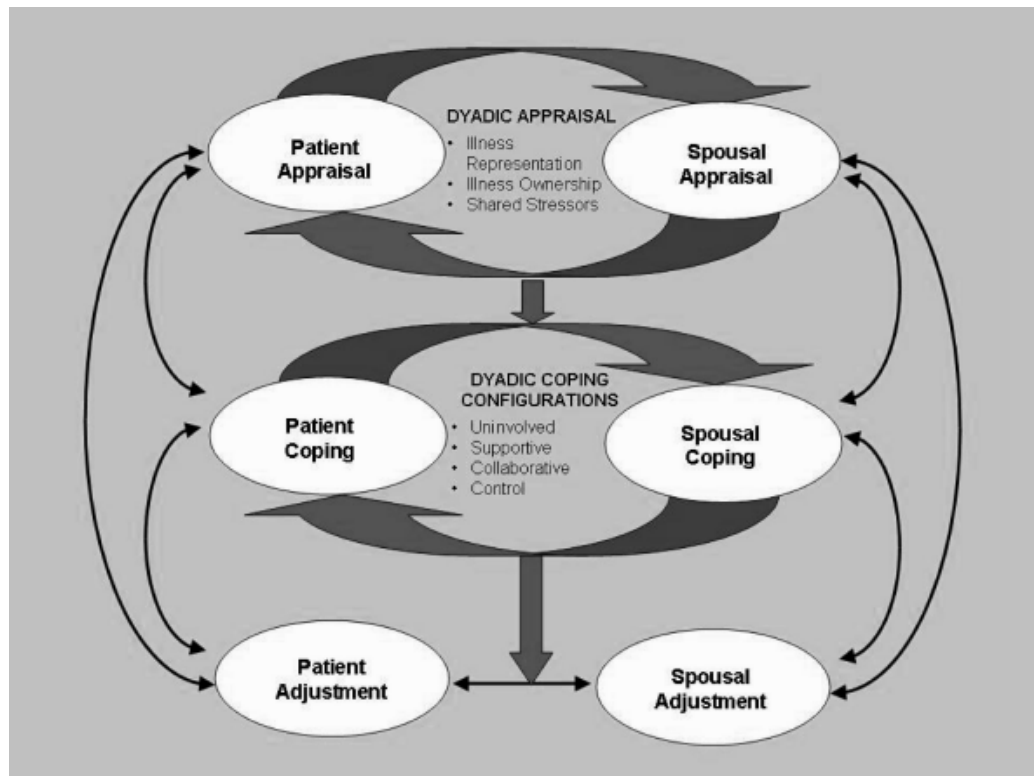


Figure 1. Berg and Upchurch's (2007) Model of Dyadic Appraisal, Coping, and Adjustment; © (2007) by the American Psychological Association

The framework further rests on assumptions of contextuality (including sociocultural [e.g., culture, gender] and proximal contexts [e.g., the home setting, relationship quality, the particular illness, hospice care]). Berg and Upchurch (2007) purport that context affects dyadic relationship quality, as well as the pair's adjustment to developing illness. Relationship development and context change across the lifespan and during different phases of illness. For all these reasons, this framework was well suited to exploring subjective, relational experiences and dyadic adjustment of mother-daughter caregiving pairs at end of life at home, and developmental changes that may affect both women, particularly in the changing end-of-life context. Berg and Upchurch's work is also consistent with the often cited literature on how interacting dyads emotionally affect and regulate each other, a process known to impact relationship quality between care

dyads throughout the lifespan, from infancy (Beebe & Lachmann, 1998; Stern, 2000) through older age (Carstensen, 1991).

The philosophy of hospice and palliative care (National Hospice and Palliative Care Organization, 2015) was used as a complementary frame to underscore and emphasize a relationship quality view at end of life. This frame, which champions patients and families (including family relationships) as the focus of care during hospice (Lokker, van Zuylen, Veerbeek, van der Rijt, & van der Heide, 2012; Strohbuecker, Eisenmann, Galushko, Montag, & Voltz, 2011; Teno et al., 2004), further underscored and reinforced Berg and Upchurch's (2007) view of caregiving relationships across the adult lifespan.

## **Background**

### **Relationship Quality in Mother-Daughter Caregiving Dyads**

Daughters now outnumber spouses as the largest group of family caregivers in the nation (Wolff & Kasper, 2006). Although aging mothers enjoy tight-knit intergenerational relationships with adult children of both genders (Bengston, 2001), they hold the deepest, most emotionally enduring kinship bonds throughout life with daughters (Bengston, 2001; Fingerman, 1998; Suito & Pillemer, 2006). As mothers age and outlive spouses, they depend on daughters as family caregivers three to one over sons (Horowitz, 1985; Johnson & Wiener, 2006; Raschick & Ingersoll-Dayton, 2004).

Family caregiver distress often exceeds distress of patients (Godwin et al., 2013). This is especially true as chronic illnesses and the care trajectory progress and patients near end of life (Williams & McCorkle, 2011). This increased distress is particularly experienced by female caregivers, whether they are wives or daughters (Archbold,

Stewart, Greenlick, & Harvath, 1990; Hagedoorn et al., 2008; Pinquart & Sörensen, 2006; Raschick & Ingersoll-Dayton, 2004). Positive relationship quality in the family care dyad is known to be protective for both members, however, and again, especially for women (Berg & Upchurch, 2007; Birditt & Antonucci, 2008; Lyons et al., 2009; Raschick & Ingersoll-Dayton, 2004; Schumacher et al., 2007).

It is the dyadic, dynamic reciprocity in the relationship that is most important to relationship quality; the way a mother and daughter, for instance, respond to and are affected by each other emotionally; the bi-directionality of the relationship (Berg & Upchurch, 2007; Williams & McCorkle, 2011). The strength of emotional interdependence, another term for this complex phenomenon, has been noted as particularly important to successful female-female relationships, both outside and within a care context (Berg & Upchurch, 2007; Taylor et al., 2000). This balance of support from both sides of the intergenerational care dyad improves caregiver well-being and the caregiving experience (Habermann, Hines, & Davis, 2013). Adult child caregivers express appreciation of caring for—as well as being reciprocally emotionally cared for by—their parent (Habermann et al., 2013). And parents, unless they believe they can give back reciprocally in the relationship, suffer greater depression and emotional distress (Davey & Eggebeen, 1998; Sebern, 2008).

What is known about mother-daughter caregiving relationship quality has often been investigated solely from the viewpoint of daughters (e.g. Carpenter, 2001; Raveis & Pretter, 2005). Some (Sheehan & Donorfio, 1999; Walker, Pratt, Shin, & Jones, 1990; Walker, Shin, & Bird, 1990; Walker et al., 1992; Walker, Pratt, & Oppy, 1990) have analyzed mothers collectively and daughters collectively, then compared the two groups.

Only a few investigators have considered each woman's perceptions in relation to the other's, triangulating two individual views to achieve something overarchingly dyadic and greater (Hollis-Sawyer, 2001; Kim, Wellisch, & Spillers, 2008; Martini, Grusec, & Bernardini, 2001; McGraw & Walker, 2004; Shawler, 2007; Walker & Allen, 1991; Walter, 1991).

Although literature investigating both mother and daughter care partner perspectives is sparse (McGraw & Walker, 2004), increasing closeness and emotional depth may occur as cognitively intact mothers become progressively more ill (Carpenter, 2001; Kim, Wellisch, et al., 2008; Pohl, Boyd, Liang, & Given, 1995; Walker, Martin, et al., 1992). This finding contradicts the general family caregiving literature towards end of life, in which relational stressors are known to increase (Hudson, 2013; Zaidler & Kissane, 2009). Adult daughters in relationships with mothers not in need of caregiving often have some ambivalence toward mothers, and conflict is a normative part of the bond (Fingerman, 2003). Yet in the care context, daughters become more emotionally committed and more loving as mothers physically deteriorate (Kim, Wellisch, et al., 2008; Pohl et al., 1995; Walker, Martin, et al., 1992). These dyads work to minimize inevitable conflict through strategies such as emphasizing areas of agreement, apologizing, using tactful communication, or avoiding subjects known to be conflict-laden (McGraw & Walker, 2004; Shawler, 2007; Sheehan & Donorfio, 1999). Care provision can offer mothers and daughters an opportunity for deepening and transforming their relationship over the care trajectory (Hollis-Sawyer, 2001; Martini et al., 2001; Pohl, Boyd, & Given, 1997; Raveis & Pretter, 2005; Shawler, 2007; Sheehan & Donorfio, 1999), yet not all are so lucky (Hollis-Sawyer, 2001). How each woman perceives this

dynamic relationship quality landscape, both historically and over the changing and challenging illness and hospice context, is virtually unknown. This inquiry is essential if we are to support mother-daughter dyads when successful, and inform future interventions for dyads when relationships falter or fail.

### **Relationship Quality in Cognitively Intact Caregiving Dyads**

Compared to caregivers of those without a dementia disorder, caregivers of patients with dementia experience markedly greater emotional strain and decreased relationship quality (Braun et al., 2009; Pinquart & Sörensen, 2004; Pinquart & Sörensen, 2003, 2007; Tanji et al., 2008), poorer physical health (Pinquart & Sörensen, 2007; Wright & Aquilino, 1998) and greater mortality (Steadman et al., 2007). Alterations in many aspects of the relationship (Quinn et al., 2009; Steadman et al., 2007), as well as behavioral problems characteristic of the disease (Li & Seltzer, 2003; Pinquart & Sörensen, 2007), make relationship quality within a dementia context different than without. Additionally, many investigations of relationship quality include patients with illnesses such as Parkinson's disease (Lyons et al., 2009; Tanji et al., 2008) or post-stroke (Haley et al., 2009; Lee et al., 2010), which also include long term cognitive, memory, and behavioral challenges.

Relationship quality in chronic or terminal illness—exclusive of cognitive disorders—is less understood. Researchers focused on cancer caregiving discovered positive relationships were pervasively associated with decreased caregiving tension, stress, anxiety, anger, fatigue, depression, and other negative outcomes (Schumacher et al., 2008). Relationship quality in these caregivers was also found to be protective against caregiver burden (Schumacher et al., 2007). Conversely, negative relationship quality

predicted worsening emotional wellbeing and physical health in caregivers following care recipient coronary artery bypass surgery (Halm & Bakas, 2007). In one work focused on unspecified chronic illnesses largely exclusive of cognitive disorders, researchers discerned that positive relationships with partners or children actually delayed mortality in care recipients (Birditt & Antonucci, 2008). Although it is generally accepted that positive relationship quality is protective to both members of the caregiving dyad (Archbold et al., 1990; Lyons & Sayer, 2007), the bulk of literature continues to focus on care recipients with dementia or other cognitive disorders, or on only one member of the dyad, making the need for studies of relationship quality in cognitively intact dyads—where both members are active emotional participants with their own dyadic story to tell—especially pronounced.

### **Relationship Quality in the End of Life, Home-Hospice Context**

One setting—home hospice—offers a context for investigating dyadic mother-daughter relationship quality at a critical point in the caregiving trajectory. Fifty to 94% of terminally ill patients express a desire to die at home, surrounded by family in a familiar environment (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013; Higginson & Sen-Gupta, 2000). Dying at home almost always depends upon a care partner and home-based palliative and hospice care, increasingly the focus of care given at end of life (Shepperd, Wee, & Straus, 2012). Patients enrolled in hospice have a far greater chance of dying at home (Gomes, Calanzani, & Higginson, 2014) and a significantly decreased symptom burden relative to usual care (Gomes et al., 2014). In 2014 alone, hospice served over 1.6 million patients in the United States (National Hospice and Palliative

Care Organization, 2015), 54% of whom were women (National Hospice and Palliative Care Organization, 2015).

Further, the philosophy of palliative and hospice care centers the patient and family as unit of care (National Hospice and Palliative Care Organization, 2015), focusing on patient and family needs and wishes (National Hospice and Palliative Care Organization, 2015). This philosophy privileges emotional support and respect for patients and family members (Teno et al., 2004) while they move toward life and relationship completion (Byock, 1996; Irwin & Ferris, 2008). Emphasis is placed on family relationships (von Gunten, 2012) and human development through end of life (Salmon et al., 2005; Steinhauser et al., 2000; Teno et al., 2004). Unlike other environments, home hospice aspires to create comfort and intimacy, and a foreground for enriching and empowering patients to enjoy normal life and relationships (Stajduhar, 2003). These findings dovetail well with what has begun to be discovered in mother-daughter caregiving dyads—that relationship quality may deepen and develop in the context of increasing illness and debilitation (Kim, Kashy, et al., 2008; Pohl et al., 1995; Walker, Martin, et al., 1992). Yet how mothers and daughters personally perceive and socially construct care relationships towards end of life at home with hospice has not been explored. These women's voices and perspectives need to be heard—particularly in relationships that may differ from the norm, suffering from ambivalence or strain. It is only then that healthcare providers may successfully respond to unique needs women at home with hospice may have.



### Purpose and Specific Aims

Specific Aim	Corresponding Paper
Synthesize existing literature on aging mother-adult daughter care dyads and: <ol style="list-style-type: none"> <li>1. Examine the role of relationship quality on the wellbeing of cognitively intact, aging mother and adult daughter care dyads.</li> <li>2. Investigate how this relationship may be impacted by the care context.</li> </ol>	Chapter 2: <i>Relationship Quality in Aging Mother-Adult Daughter Care Dyads: A Systematic Review</i>
Describe and interpret how aging mother-adult daughter care dyads: <ol style="list-style-type: none"> <li>3. Perceive relationship quality</li> <li>4. Perceive the other dyad member experiences relationship quality</li> <li>5. Perceive how relationships have developed over time for both partners through health, chronic illness, and end of life</li> </ol>	Chapter 3: <i>Mother-Daughter Care Dyad Relationship Quality in the Context of Dying at Home</i>
Use short narrative vignettes to: <ol style="list-style-type: none"> <li>6. Explore and reveal the deeply-embedded social construction of relationships between aging mothers and adult daughters, in the context of dying at home</li> </ol>	Chapter 4: <i>The Narrative Turn: Mutually Constructed Stories of Mother-Daughter Care Dyads in the Context of Dying at Home</i>

**Table 1. Proposed Specific Aims and Corresponding Manuscripts**

It was the purpose of this dissertation to explore implications of relationship quality on adult daughters and their aging mothers without neurocognitive disorders in the context of dying at home with hospice. Relationship quality was evaluated qualitatively, as to its transactional and dynamic, dyadic nature between mothers and daughters. It is hoped this work serves as a foundation for informing clinical practice and policy, improving outcomes for the burgeoning numbers of dying mothers and the daughters who care for them.

Using systematic literature review and qualitative methodology, I composed three manuscripts that identified and addressed, in a stepwise progressive fashion, unanswered questions regarding relationship quality between cognitively intact mothers and adult daughters in the context of dying at home. Table 1 describes original aims.

The first aims (Chapter 2) were to conduct a systematic review to examine the role of relationship quality on the wellbeing of cognitively intact, aging mother and adult daughter care dyads and to investigate how this relationship may be affected by the care context. The aims in the second manuscript (Chapter 3) were to interpret and describe how mothers and daughters perceive relationship quality both for themselves and each other, as well as how they perceived their relationship quality may have changed over time. Berg and Upchurch's model of dyadic adjustment was originally used as a lens for this work. Complementary qualitative methods—interpretive description (Thorne, 2008) and dyadic analysis (Eisikovits & Koren, 2010)—were also used. The third manuscript (Chapter 4) was to use both structural (King & Horrocks, 2010) and dyadic analysis, privileging the narrative turn in social constructivism to create composite narratives of mother-daughter dyads in the context of dying at home. Through compelling stories giving voice to both women, it was hoped this body of work would resonate with patients, families, clinicians, and researchers, contributing to improved understanding and practice.

### **Conclusion**

In sum, these manuscripts comprise a progression from identification of knowledge gaps, through initial research, to a paper concretizing and underscoring signal patterns in relationship quality between mothers and daughter care dyads in hospice at

home. It is anticipated this work adds to existing knowledge and highlights future directions for nursing and interprofessional practice, policy, and research. It is hoped the work may, in some way, illuminate the inevitable and poignant end-of-life transition for mothers and daughters into the future.

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doi:10.1207/S15327027HC1504

## Chapter II

### **Relationship Quality in Non-Cognitively Impaired Mother-Daughter Care Dyads: A Systematic Review**

Authors: Diane N. Solomon, Lissi Hansen, Judith Baggs, and Karen Lyons

This manuscript represents a significant contribution to the dissertation work: it addresses Aims 1 and 2, and replaces aspects of the traditional methods and results chapters. A very slightly edited version of this manuscript has been published: Solomon, D. N., Hansen, L., Baggs, J. G., & Lyons, K. S. (2015). Relationship quality in non-cognitively impaired mother-daughter care dyads: a systematic review. *J Fam Nurs*, 21(4), 551–578.

doi:10.1177/1074840715601252 (see permission to reproduce, below). The *Journal of Family Nursing* is a quarterly indexed and peer-reviewed journal devoted to nursing research, practice, education, and policy, as well as empirical and theoretical work regarding family health, with an impact factor of 1.342. Support for this manuscript included the OHSU School of Nursing Dean's Award (2014).

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**Purpose and aims:** To explore the role of relationship quality on the wellbeing of aging mothers and adult, care-partnering daughters. Specific aims are to explore how relationship quality may: 1) affect the wellbeing of the mother-daughter care dyad; and 2) influence, as well as be influenced by, the care trajectory.

**Review of Literature and Conceptual Basis:** Adult daughters providing care to aging mothers comprise the most prevalent caregiving dyad, yet little is known about relationship quality and its impact on care in these dyads. Discovering and empowering the unique needs of cognitively intact, chronically ill and aging mothers and adult daughters may be essential to the health of both women throughout the care trajectory.

**Design and Methods:** A systematic appraisal of peer-reviewed, English language research was conducted. Nineteen articles met criteria.

**Data Analysis:** Articles were reviewed in depth. Author(s), purpose and/or theoretical frame, sample, setting, diagnosis, measures, method, and findings were extracted using the Matrix Method (Garrard, 2007).

**Human Subjects Protection:** NA

**Results, Discussion:** When relationship quality is positive, mother-daughter dyads enjoy rewards and mutuality, even when conflict occurs. Daughters grow more emotionally committed to mothers' over the care trajectory, despite increasing demands. Daughters' commitment deepens as mothers decline, and mothers remain engaged, emotional partners. When relationship quality is ambivalent or negative, burden, conflict, and blame conspire, creating a destructive cycle. Continuing study, including utilizing the dyad as the unit of analysis, troubled dyads, longitudinal assessment, and end-of-life context

are needed before interventions to improve mother-daughter relationship quality may be successfully designed.

Relationship Quality in Non-Cognitively Impaired Mother-Daughter Care Dyads:  
A Systematic Review

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Keywords: mothers; adult daughters; relationship quality; intergenerational relations; caregiving; systematic review

**VERSION 2 final version of the manuscript prepared for publication by Dr. Janice M. Bell, Editor, Journal of Family Nursing, in collaboration with Diane Solomon**



### **Abstract**

Over 60 million Americans provide care to a family member; roughly two-thirds are women providing care to aging mothers. Despite the protective nature of relationship quality, little attention has been given to its role in mother-daughter care dyads, particularly in mothers without cognitive impairment. A systematic appraisal of peer-reviewed, English language research was conducted. Nineteen articles met criteria. When relationship quality is positive, mother-daughter dyads enjoy rewards and mutuality, even when conflict occurs. Daughters grow more emotionally committed to mothers' over the care trajectory, despite increasing demands. Daughters' commitment deepens as mothers decline, and mothers remain engaged, emotional partners. When relationship quality is ambivalent or negative, burden, conflict, and blame conspire, creating a destructive cycle. Avenues for continuing study, including utilizing the dyad as the unit of analysis, troubled dyads, longitudinal assessment, and end of life context are needed before interventions to improve mother-daughter relationship quality may be successfully designed.

Acknowledgements: The first author gratefully acknowledges financial support from the Oregon Health & Science University Hartford Center for Geriatric Nursing Excellence.

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Over 60 million Americans provide care to a family member (Feinberg, Reinhard, Houser, & Choula, 2011). Roughly two-thirds of these family care providers are women in dyadic relationships with aging mothers (Feinberg et al., 2011). These care providers are estimated to provide 90% of long-term care outside of facilities (Centers for Disease Control, 2011), and are essential to keeping aging women at home and in the community (Fingerman, Pillemer, Silverstein, & Sutor, 2012; Grande et al., 2009; Payne & Grande, 2013).

Relationship quality—often known as mutuality (Archbold, Stewart, Greenlick, & Harvath, 1990), attachment (L. Thompson & Walker, 1984), or reciprocity (Sebern & Whitlatch, 2007) is known to positively affect psychological health of family care dyads (Berg & Upchurch, 2007; Lyons, Zarit, Sayer, & Whitlatch, 2002; Merz, Schuengel, & Schulze, 2009). The bulk of research on care dyad relationship quality, however, has focused not on mothers and daughters but on spouses (Berg & Upchurch, 2007; Pinquart & Sörensen, 2006).

Research on spouses and couples has found relationship quality protects against burden and depression for both members of the couple (Tanji et al., 2008) and helps decrease tension, anxiety, and fatigue (Schumacher et al., 2008). For spouse caregivers, positive relationship quality has been shown to buffer strain over the protracted care trajectory, particularly for women providing care (Lyons, Stewart, Archbold, & Carter, 2009). Conversely, negative relationship quality has been shown to increase distress in couples (Carmack Taylor et al., 2008) and stress (Godwin, Swank, Vaeth, & Ostwald, 2013) in care-providing spouses. When relationship quality suffers, spouses experience increased burden and depressive symptomology (Davis, Gilliss, Deshefy-Longhi,

Chestnutt, & Molloy, 2011), as well as poorer caregiver outcomes (Halm & Bakas, 2007).

Relationship quality has also been studied in mixed samples that included more than 75% spouses plus other family members (e.g., Schumacher et al., 2008; Schumacher, et al., 2007; Sebern, 2008; Sebern & Whitlatch, 2007), or dyads wherein care recipients have cognitive impairment (Pinquart & Sörensen, 2007). These works have been critical to addressing marital stressors of care provision and understanding the context of dementia-related personality changes. Investigations in the context of intergenerational care partners, however—and studies wherein both care partners are cognitively intact—are much less prevalent (Pinquart & Sörensen, 2006, Pinquart & Sörensen, 2004).

Research on intergenerational family care dyads is especially critical in an environment where two-thirds of care dyads are intergenerational aging mothers and adult daughters (Feinberg et al., 2011). These dyads differ from spousal dyads in multiple ways, including the complexities of a lifelong, genetic relationship (Fingerman, et al, 2012). And though care recipients experience improved wellbeing and greater longevity in intergenerational dyads with positive relationship quality (Birditt & Antonucci, 2008; Davey & Eggebeen, 1998; Sebern, 2008), one in five intergenerational relationships is marred by destructive conflict (Bengston, 2001).

Discovering the unique needs of cognitively intact, chronically ill and/or aging mothers and adult daughters may be essential to the health of both women throughout the care trajectory. Thus, it is the purpose of this systematic review to explore the role of relationship quality on the wellbeing of this unique dyad. Relationship quality is

conceptualized broadly to encompass positive or negative aspects of the emotional relationship such as—but not limited to—attachment, emotional exchange, emotional support, intimacy, love, mutuality, reciprocity, or relationship satisfaction. Specific aims are to explore how relationship quality may: 1) affect the wellbeing of the mother-daughter care dyad; and 2) influence, as well as be influenced by, the care trajectory itself.

## **Methods**

### **Search Strategy**

A systematic appraisal of published, peer-reviewed, English language research on relationship quality in non-cognitively impaired, aging mothers and their adult caregiving daughters was completed in April 2015. To capture the greatest number of possibly salient articles, the MeSH terms “Aging” or “Chronic Disease” were combined with “Mothers,” “Adult Children” (inclusive of the term “adult daughter[s]”), and “Caregivers” (inclusive of the term “carer”) in MEDLINE. Subject headings as closely identical to these as possible were applied to CINAHL, PsycINFO, and Google Scholar.

Due to the recognition of positive aspects of relationship quality in care provision beginning in 1990 (Archbold et al., 1990) and recognition of caregiving rewards in addition to burden (Kramer, 1997), dates of publication from 1990-present were employed. The majority of care recipients are aging women, whose relationship with an adult child is frequently the most important emotional tie in their lives (Fingerman et al., 2012). Thus, studies of mothers aged 65 and older were included. Finally, because relationship quality has been found to be protective regardless of amount of instrumental

support given (Merz et al., 2009), any amount of care or aid provided by an adult daughter to an aging or chronically ill mother was used.

Inclusion criteria for studies were:

1. Mothers  $\geq 65$  (Aging Statistics; Administration on Aging, 2013; in works wherein mothers were aging or ill, and most mothers were age 65 or older, articles were included).
  - a. In need of any amount of support or assistance.
  - b. Without cognitive impairment (in studies where cognitive status was not noted, but cognitive impairment was not a focus of the work, research was included).
2. Adult daughters who self-identified or were identified by mothers as family care partners.
3. Relationship quality within the mother-daughter dyad was a major focus of the study.

One hundred fifty-six articles were retrieved. Review of titles and abstracts resulted in exclusion of 19 duplicates (see Figure 1). One hundred eleven articles were further excluded due to focus on: 1) aging mothers caregiving for adult children; 2) no focus on mother-daughter relationship quality; 3) lack of a caregiving component; 4) inclusion of cognitively impaired mothers; 5) bereavement issues without focus on relationship quality; or 6) pediatric caregiving (see Figure 1). Nine articles were added through hand searching of reference lists and author searches. Thirty-five articles were reviewed in depth. Author(s), purpose and/or theoretical frame, sample, setting, diagnosis, measures, method, and findings were extracted using the Matrix Method (Garrard, 2007). No reviews evaluating relationship quality among non-cognitively

impaired aging mothers and care providing daughters were found. Sixteen articles were further excluded as: 1) mother-daughter relationship quality was not an emphasis; 2) mothers did not require assistance; 3) no actual participants were included; 4) psychometrics was the focus; 5) caregiving relationships with both parents were studied (these were used for additional context, but not in the included sample); or 6) multiple articles used the same participant sample and methods. In this last case, the most comprehensive article was chosen for inclusion. Nineteen articles remained.

[insert Figure 1 about here]

## **Findings**

### **Study Characteristics**

A summary of 19 included publications can be found in Table 1. Research on aging mother-adult daughter relationships in the care context, exclusive of cognitive impairment, has been conducted by researchers from varied professions and published in professional and inter-professional journals. Disciplines of authors included nursing, family studies, gerontology/aging studies, psychology, and oncology. One research group originated from Canada (Martini, Grusec, & Bernardini, 2001); all others issued from the United States. Seven researchers were named as authors on multiple studies; 29 authors have published in this field. Fifteen studies were published in or before 2004 and only four in the past decade.

[insert Table 1 about here]

As for the studies, 10 were quantitative. All these studies employed cross-sectional methods. No intervention studies were discovered. Fourteen measures of relationship quality were used throughout, with ten measures consisting of 2-17 items and

four measures containing 30-61 items. Only two relationship quality instruments were used more than once (see Table 1). One of these, a 16-item attachment scale devised by Cicirelli (1993) was cited (Cicirelli, 1995) and used by Carpenter (2001). Another measure, also investigator-devised (Walker & Thompson, 1983), was used in three publications (Walker, Pratt, Shin, & Jones, 1990; Walker, Shin, & Bird, 1990; Walker, Martin, & Jones, 1992). No other measures of relationship quality overlapped in this review. Sample sizes in quantitative works ranged from 78 daughters (Cicirelli, 1993) to two studies investigating the identical sample of 174 mother-daughter dyads (Walker, Pratt, et al., 1990; Walker, Pratt, & Oppy, 1992).

Seven studies were qualitative, and one of these was longitudinal (Shawler, 2007). In the qualitative works, six employed interviews, with one also using focus groups (Shawler, 2007). In the seventh, McGraw and Walker (2004) analyzed mother-daughter interactions. Qualitative sample sizes ranged from eight daughters (Pohl, Boyd, & Given, 1997) to 31 mother daughter dyads (McGraw & Walker, 2004).

Two additional works used mixed methods (Hollis-Sawyer, 2001; Walter, 1991). Both were cross-sectional. In the quantitative portions, both authors used investigator-devised scales as well as standardized measures that were not replicated in other studies. For the qualitative portions, structured interviews were used to categorize care dyad relationship quality (Hollis-Sawyer, 2001) or support quantitative findings with exemplars (Walter, 1991). Walter (1991) employed a sample of 48 mother-daughter dyads and Hollis-Sawyer (2001), 122 dyads.

Global themes emerged throughout the 19 articles, including both positive and negative effects of relationship quality on mother-daughter care dyad well being, and

bidirectional influences of relationship quality and the care trajectory. These themes are explored in detail below.

### **Effects of Relationship Quality on Mother-Daughter Care Dyad Well Being**

**Relationship quality as a protective factor.** When mothers played an active role as full emotional partners in the care dyad, relationship quality significantly mitigated costs and burden for daughters (Walker, Martin, et al., 1992; Walter, 1991). Daughters in these partnerships reported lower depressive symptoms and intrusive thoughts (Vodermaier & Stanton, 2012), as well as decreased burden, strain, and stress (Carpenter, 2001; Cicirelli, 1993; Pohl, Boyd, Liang, & Given, 1995). Active emotional exchange also offered protection through increasing daughters' reported resilience (Vodermaier & Stanton, 2012). These intrinsically positive, relational rewards of relationship quality (Allen & Walker, 1992), which the majority of dyads enjoyed (Walker, Pratt, et al., 1990), were associated with daughters giving care out of affection and enjoyment, rather than obligation (Carpenter, 2001; Walker, Pratt, et al., 1990). These daughters demonstrated greater emotional commitment to care (Pohl et al., 1995), even when both connection and conflict were prevalent in the relationship (Pohl et al., 1995). Daughters were committed to care regardless of the number of care tasks or their mother's functional status (Pohl et al., 1995).

In turn, mothers experienced a greater sense of autonomy (Walter, 1991) when relationship quality was positive. They reported higher appreciation from daughters (Allen & Walker, 1992; Walker, Martin, et al., 1992) and enjoyed an active part in giving back emotionally (Walker, Pratt, et al., 1992). All this led to a seemingly positive



sequence, with daughters putting aside other obligations and demands to spend additional time with mothers (Allen & Walker, 1992).

Mothers were also found to exert a lifelong emotional influence on daughters when distress was measured (Kim, Wellisch, & Spillers, 2008). Although levels of distress due to a mother's illness were similar for both women in the dyad, mothers' distress disproportionately predicted daughters', but the opposite did not hold true (Kim et al., 2008). Daughters grew more emotionally committed and attentive as mothers physically deteriorated (Pohl et al., 1995), particularly if relationship quality remained high. Even when distress issued from interpersonal conflict, relationship quality was also protective to well being (Martini et al., 2001). Mother-daughter dyads with better relationship quality were able to take the other woman's perspective and maintain interpersonal control, successfully resolving conflict together (Martini et al., 2001).

**A positive to negative relationship quality spectrum.** Three investigator groups delineated a spectrum of positive to negative relationship typologies, yet all three (Hollis-Sawyer, 2001; McGraw & Walker, 2004; Walker & Allen, 1991) noted a need to investigate the multi-dimensional complexities of relationship quality, not simply a binary, positive-negative calculus of human relationships. The majority of mother-daughter dyads reported what Walker and Allen (1991, p. 392) dubbed an "overwhelmingly positive" relationship, marked by great rewards, mutuality, responsiveness, and well-handled conflict. These positive dyads negotiated autonomy and connection for both women (McGraw & Walker's 2004), and both enjoyed personal growth, openness, adaptation, and novel-problem solving (Hollis-Sawyer, 2001).

Many pairs, however, only enjoyed moderate relationship quality, struggling with ambivalence, higher relational costs, conflict, and blame (Walker & Allen, 1991). These dyads lacked emotional mutuality, with daughters believing they gave more to the relationship than mothers gave (McGraw & Walker, 2004).

All three investigators (Hollis-Sawyer, 2001; McGraw & Walker, 2004; Walker & Allen, 1991) found a substantial minority of dyads that endured difficult relationships, from 13% (McGraw & Walker, 2004) to 30% in co-residing dyads (Hollis-Sawyer, 2001). These women were inattentive to each other (McGraw & Walker, 2004), descended into blame, conflict, and/or unconcern (Walker & Allen, 1991), and lacked the ability to handle disputes (McGraw & Walker, 2004).

Other investigators also noted a minority of dyads wherein relationship quality was negative. In these dyads, daughters were more likely to report providing care out of obligation, rather than warmth and affection (Walker, Pratt, et al., 1990). Offering care largely because of obligation significantly increased the level of burden reported by daughters (Cicirelli, 1993). In these more negative dyads, mothers experienced more anger (Walker, Martin, et al., 1992), and daughters expressed more anxiety and frustration (Walker, Martin, et al., 1992).

### **Relationship Quality as Influencing—and Being Influenced by—the Care Trajectory**

Relationship quality in the mother-daughter dyad affected, and was affected by, the care trajectory. The sole longitudinal work addressed the initial 15 months of care provision (Shawler, 2007). When relationship quality was at least moderately positive, mother-daughter dyads reported the care trajectory exerted a helpful or even

transformative effect on their relationship, intensifying and deepening this lifelong bond (Shawler, 2007). Although relationships involved tensions, women worked to resolve them. Many dyads with a prior precarious relationship actually noted improvement (Shawler, 2007).

Cross-sectional works reinforced this positive effect across the care trajectory. In newly formed partnerships, daughters who had provided care for an average of 7.5 months (Raveis & Pretter, 2005) and approximately one year (Pohl et al., 1997) were asked to reflect on relationships before and during care provision, and to comment on the first year. Daughters ascribed a deepening relationship to a greater amount of time spent with mothers, and to understanding this time was limited (Raveis & Pretter, 2005). A foreshortened future became a motivator to prioritizing mother-daughter bonds—regardless of competing demands (Raveis & Pretter, 2005).

Although relationships were naturally stressful in the initial year, daughters reported having worked through past issues, and were determined they would provide similar care again (Pohl et al., 1997). Some daughters used defensive strategies, however—such as avoiding mothers so daughters would not miss them after their death (Raveis & Pretter, 2005)—or shielding mothers from the daughters' feelings (Raveis & Pretter, 2005). These strategies were emotionally costly for daughters (Raveis & Pretter, 2005).

Studies in which mothers and daughters had been in care partnerships for an average of 6.5 years (Sheehan & Donorfio, 1999) and 7.8 years (Walker, Shin, et al., 1990), respectively, reinforce these early findings. Both mothers and daughters in long-term partnerships spoke of further deepening relationships (Sheehan & Donorfio, 1999;

Walker, Shin, et al., 1990). They ascribed this to a greater amount of time spent together due to care provision (Sheehan & Donorfio, 1999, Walker, Shin, et al., 1990), just as women in newer partnerships had (Pohl et al., 1997; Raveis & Pretter, 2005). Women reported they set aside differences or minimized conflict at about 6 years into the care trajectory (Sheehan & Donorfio, 1999). They adapted to and accepted changes in each other and under the pressures of care (Sheehan & Donorfio, 1999). Dyads with positive relationship quality reported continued relationship improvement (Walker, Shin, et al., 1990).

Most mothers and daughters expressed rewards garnered from longtime partnerships (Sheehan & Donorfio, 1999; Walker, Shin, et al., 1990), with only a 3-5% minority claiming relationship quality was attenuated through the stressors of care (Walker, Shin, et al., 1990). Daughters wished to offer something back to mothers who had given them—and were still giving them—so much, even 6 years later (Sheehan & Donorfio, 1999). This additional time together increased emotional intimacy and relationship quality over the years (Walker, Shin, et al., 1990), creating a positive, bidirectional cycle for the dyad.

### **Discussion**

Healthy relationship quality in mother-daughter dyads is at least as protective in buffering strains of care provision as in studies of other family care dyads (Lyons et al., 2009; Schumacher et al., 2008). This finding is a strength of this review. Although studies included were largely cross-sectional, findings echo existing evidence on non-care-partnering, healthy aging mothers and daughters (Fingerman, 2003). Within the care context, cognitively intact, aging mothers and daughters enjoy a positive, multi-

dimensional relationship, with rewards and high mutuality, even as conflict forms a natural part of the bond.

Relationship quality affects and is affected by the care trajectory. Daughters report growing more emotionally committed to mothers as the trajectory progresses from months into years, despite increasing demands. Daughters' commitment further deepens as pressures of time underscore a mother's physical decline. Meanwhile, mothers remain autonomous and engaged emotional partners in dyads with strong relationship quality. In doing so, they contribute something emotionally powerful to daughters for whom they care. Yet if relationship quality is ambivalent at best—or negative, at worst—burden, conflict, blame, and unconcern for one's partner conspire to create a destructive cycle. Under the demanding pressures of care, avoidance strategies, resentment, anxiety, and defensiveness can ensue.

### **Limitations of the Literature and Recommendations**

Findings in this review point repeatedly to a multi-dimensional, emotional give and take between mothers and daughters. Quantitative researchers tended to focus on discrete aspects of relationship quality (e.g., attachment, satisfaction, burden, caregiving motives), ADLs/IADLs, or other aspects of relational exchange apart from the emotional aspect. Although these factors are important, relationship quality has been found to offer resilience against these more instrumental aspects of care (Merz et al., 2009; Pohl et al., 1995). One group using quantitative methods (Walker, Shin, et al., 1990) asked women how the care trajectory affected the complexities of relationship quality after an average of eight years, but measured variations as *positively affected*, *no change*, or *negatively affected*. The data from these studies reveal the need for more complex examinations of

relationship quality. Similarly, only one qualitative researcher (Shawler, 2007) targeted multidimensional, interdependent perspectives of aging mothers and care partner daughters on their relationship and the care trajectory itself. Shawler focused on dyads in the aftermath of a hip fracture, and found strength in these dyads vis-à-vis the transition back to full health.

The present review reveals several additional areas in which mother-daughter care dyad relationship quality science could be scaffolded. Conceptually, the dyad itself as the unit of analysis needs exploration. The unique experience and needs of troubled dyads, as well as the needs of women at end of life, also deserve attention. Methodologically, several aspects call for consideration and will likewise be discussed.

**The dyad as the unit of analysis.** Seven of the included studies did not include both members of the dyad as participants, sampling daughters alone, without sampling mothers. Only one of these touched on daughters' perceptions of mothers' experiences: Vodermaier and Stanton (2012) asked daughters to quantify emotional support received from mothers on a 4-point scale. In research that sampled the mother-daughter dyad as the unit of analysis, four analyzed mothers collectively, daughters collectively, and then compared the two groups (Walker, Pratt, et al., 1990; Walker, Shin, et al., 1990; Walker, Martin, et al., 1992; Sheehan & Donorfio, 1999). Eight investigations analyzed mothers and daughters as dyadic pairs.

Quantitative investigators analyzed dyads using traditional methodologies that do not control for the interdependent nature of dyadic data (e.g. separate regression equations). Only one (Kim et al., 2008) used a more comprehensive and appropriate multilevel modeling approach for dyadic data. This method has been widely described in

the literature over the past decade and commonly used in dyadic research (Cook & Kenny, 2005). Three qualitative studies presented data on positive or negative dyads (Walker & Allen, 1991), developed a grounded theory to create one master narrative of all dyads (Shawler, 2007) or viewed dyads as a complex unit, but without employing qualitative dyadic analysis techniques (McGraw & Walker, 2004). Mixed method works (Hollis-Sawyer, 2001; Walter, 1991) qualitatively presented dyads as binary types and quantitatively used methods that are likewise limiting to a truly dyadic framework.

Future researchers would do well to focus on the dyad itself as the unit of analysis, exploring multi-dimensional and transactional aspects of relationship quality. Considering each mother-daughter dyad as a unit, the bi-directional associations of one member about the other can be explicitly assessed, either with advanced quantitative methods (e.g., the actor-partner interdependence model; Rayens & Svavarsdottir, 2003) or qualitatively (e.g., Eisikovits & Koren, 2010). This offers a deeper, more sophisticated and nuanced view of a family relationship between two individuals. And although it is conceptually possible to conduct dyadic research with daughters alone, asking them to focus on their own, as well as their mother's perceptions of dyadic concepts such as relationship (Cook & Kenny, 2005; Thompson & Walker, 1982), ideally both women and their perceptions would be sampled. Doing so reinforces the emotionally interdependent nature of relationship quality, a concept found to be especially salient to outcomes for women (Berg & Upchurch, 2007; Hagedoorn et al., 2008). Even in terminal and palliative settings the perceptions of mixed gender care recipients have been elicited successfully (Gardner & Kramer, 2009; Howell & Brazil, 2005). These care recipients especially value the ability to contribute to research (Andersson, Hallberg, & Edberg,

2008; Howell & Brazil, 2005). One can assume mothers would also wish to leave their imprint on research, even as they are aging or ill, and should be empowered to do so.

**Negative relationship quality.** Seven investigator groups noted a significant minority of relationships marked by ambivalent or negative relationship quality. No research was discovered, however, focusing exclusively on negative (or ambivalent) relationships in the care context, or on what transpires interpersonally to create or perpetuate negative cycles. In the future, understanding the experiences and needs of women in both negative and ambivalent mother-daughter dyads is critical to understanding what women require, and how relationships may be maintained and helped. These pairs experience prevalent conflict and blame (Walker & Allen, 1991). Unassisted, the burden of caregiving stressors might easily move them more negatively down the relationship quality trajectory. It is known close family members choosing not to provide care experience shame and guilt in the wake of that decision (Sand, Olsson, & Strang, 2010). Future researchers need employ purposive sampling to target troubled pairs, as well as pairs not yet partnered in care because interpersonal strife divides them.

**End of life.** Although the majority of mothers in this review had chronic conditions, only four studies noted mothers had a terminal diagnosis. No work could be found centering on—or even exploring—relationship quality in mother-daughter dyads at end of life. Poignantly, many participants expressed awareness that their relationships would end (Raveis & Pretter, 2005; Shawler, 2007; Sheehan & Donorfio, 1999). Research addressing this final developmental phase in mother-daughter relationships is critical to addressing the burgeoning demographics of the “silver tsunami.” The Institute of Medicine recently reinforced once more the significance of meeting needs of care



partners at end of life (Institute of Medicine, 1997, 2014). For mothers and daughters, this research might translate directly to better support for mothers in life completion, as well as healthier bereavement for daughters.

**Methodological issues.** Of quantitative works, many investigators devised scales for their own studies and/or did not employ established relationship quality measures with a wide range of items (see Table 1). Inconsistency of measurement makes it difficult to uniformly assess relationship quality across works. In future, more consistent, validated measures of relationship quality will serve to further the rigor of this science. Additionally, all quantitative (and mixed method) works in this review employed cross-sectional designs, obviating the ability to make causal inferences. A comprehensive, longitudinal perspective on the care trajectory is critical, whether quantitative, qualitative, or mixed method, to move the science forward.

Of qualitative works, only two sought to examine the bi-directional nature of the relationship (Sheehan & Donorfio, 1999; Walter, 1991). These investigators assessed how a mother's engagement helped create a peer-like relationship between both women (Walter, 1991), and how dyads mutually adapted to care, resolving past issues (Sheehan & Donorfio, 1999). An additional study focused on relationship quality in the context of complete recovery from hip fracture, a scenario not salient to the majority of mother-daughter care dyads (Shawler, 2007). Two others, while developing important typologies of relationship quality, approached research with a priori aims of viewing autonomy, connection, and conflict (McGraw & Walker, 2004), or discrete aspects of social exchange (Walker & Allen, 1991). Only one qualitative study sampled participants longitudinally (Shawler, 2007).

One of the benefits of qualitative research is to delve deeply, with prolonged engagement, into the lived experience of participants (Creswell, 2007). Even if it is not possible to collect data at more than one time point, participants could be queried regarding relationship history, how the relationship and its quality might have changed over the care trajectory, and what participants believe contributed to these changes. This is especially salient if researchers take into account the myriad possible changes along the care trajectory. For instance: What makes troubled pairs fare worse or better over time? What specific stressors strain even positive relationships?

Another methodological limitation in this research is sampling diversity. One researcher predominates over this body of work (Allen & Walker, 1992; McGraw & Walker, 2004; Walker, Pratt, et al., 1990, 1992; Walker, Shin, et al., 1990; Walker & Allen, 1991; Walker, Martin, et al., 1992), and all seven of her studies drew from a single sample of European American mother-daughter participants from the northwestern United States. All mothers in her sample were widowed or divorced. Nine of the 12 additional studies reviewed were similarly comprised of European American participants. The three investigators who employed a diverse sample either mentioned no differences in study variables between groups (Carpenter, 2001) or did not comment on ethnicity beyond describing the sample (Hollis-Sawyer, 2001; Raveis & Pretter, 2005). Valuing the rich diversity of mothers and daughter in forthcoming research is essential to honoring the complex needs of an ever more varied society.

Finally, no work in this body of research sought to intervene in mother-daughter dyads. Several avenues for intervention are intimated, however. Supporting mothers in contributing to the emotional relationship, even as their health deteriorates, might

facilitate better outcomes for both women and assist more troubled pairs. Interventions could intercede at the level of the dyad, increasing perspective-taking and interpersonal control skills to protect relationship quality (Martini et al., 2001). Intervention efforts might also focus on conflict resolution in dyads experiencing difficulties, or ameliorating defensive strategies so positive communication techniques can be employed. In all these ways—and others yet to be discovered—the needs of mother-daughter dyads partnering in care within the natural arc of a lifelong relationship might be met.

### **Conclusion**

The often positive, enduring mother-daughter care partner relationship is characterized by complexity and multi-dimensionality. The bulk of research shows mothers and daughters in a mutual, intensely emotional web of exchange, affection, and care, even as conflict comprises a natural part of their relationship. Within the caregiving context, mothers and daughters are often able to mediate stresses via closeness, and often transform this family relationship to a deeper, more mature developmental level. Yet for some mother-daughter pairs, stresses outstrip rewards. How mothers and daughters dyadically view the relationship, how researchers and clinicians might help mitigate negative relationships, and relationship quality at end of life are unexplored. As care for aging mothers assumes a growing place in the lives of middle-aged women, rigorous exploration of this complex, rich relationship through—and until—its endpoint are essential before mothers and daughters can be offered the sensitivity and care they deserve.

**Table 1. Results Matrix**

<b>Authors</b>	<b>Purpose/Theory</b>	<b>Sample, Setting, and Diagnosis (if noted)</b>	<b>Measures or Method</b>	<b>Findings</b>
Allen & Walker, 1992, USA	To examine caring labor of adult daughters for aging mothers; theory of attentive love.	29 European American, caregiving daughters. Mean age of mothers: 80; daughters: 55. Daughters lived with or within 45 miles of mothers. Mothers suffered chronic health issues such as arthritis, vision and hearing problems, cardiovascular, and circulatory disorders.	Qualitative, cross-sectional: In-depth interviews, including questions about present and prior relationship with mother.	Caregiving intrinsically relational for daughters; relationship quality high. All worked to foster mothers' growth and independence. Mothers as central to daughters' lives, despite multiple competing demands on daughters.
Carpenter, 2001, USA	To examine attachment and caregiving provided by adult daughters to aging mothers; attachment theory.	80 daughters; 40 African American, 40 European American. Mean age of mothers: 79; daughters: 50. Mothers lived with daughters or alone. <i>Some mothers apparently had cognitive impairment.</i>	Quantitative, cross-sectional: Semi-structured interviews; Adult Attachment Scale, Relationship Questionnaire, Multidimensional Functional Assessment Questionnaire, 7-item caregiver burden scale (Cicirelli, 1993), assessment of instrumental and emotional caregiving, demographics, family structure.	Attachment dimensions unrelated to instrumental care. High secure and low anxious attachment associated with more emotional care; high secure attachment related to less caregiver burden. Stress of caregiving mediated by positive attachment to mother.
Cicirelli, 1993, USA	To clarify effects of attachment and obligation as motives for adult daughters' caregiving and burden; attachment theory.	78 daughters. All European American. Mean age of mothers: 84; daughters: 56. Mothers and daughters lived together (34%) or mothers lived in community within 50 miles of daughter.	Quantitative, cross-sectional: Interviews; Investigator-devised 7-item burden scale, Adult Attachment Scale, Obligation scale; ADL and IADL scales, demographics.	Higher attachment significantly decreased burden for daughters; higher obligation increased burden. Attachment associated with maintaining ongoing positive relationship.

Hollis-Sawyer, 2001, USA	To assess factors underpinning positive, growth-promoting caregiving relationships.	122 aging mother/caregiving daughter pairs. 45 percent European American, 28% African American, 27% Hispanic. Mean age of mothers: 73; daughters: 47. All mothers lived with daughters and were physically impaired.	Mixed methods, cross-sectional: Separate interviews of mothers and daughters with investigator-devised scales to elicit perceived family role changes due to caregiving, perceived role relations (e.g., physical, emotional, closeness); perceived personal growth, understanding, acceptance of relationship changes, perceived role congruency; fluid intellectual ability measure (from Culture Fair Intelligence Matrices), NEOAC personality dimension measure.	Four typologies: positive pairs (both rated caregiving relationship as positive; 38%), negative (both rated relationship as negative; 30%), neutral (both rated as neither positive or negative; 17%) and mixed (lack of congruence; in almost all pairs, mothers viewed relationship as positive while daughters viewed as negative; 15%). Positive pairs significantly more optimistic on role relations, changes, personal growth, and lower on neuroticism. For mothers, novel problem solving and openness to experience strongly predicted both mothers' and daughters' positive feelings regarding relationship.
Kim, Wellisch, & Spillers, 2008, USA	To examine (dis)similarities in emotional experiences between aging mothers with cancer and adult caregiving daughters; Actor Partner Interdependence Model.	98 mother/adult daughter pairs. 90% European American. Mean age of mothers: 67; daughters: 41. Several cancer diagnoses, most predominantly breast.	Quantitative, cross-sectional: Self-completed survey data; Profile of Mood States—Short Form to discern (dis)similarity in psychological distress, (mental and physical) quality of life Medical Outcomes Study scale; age and cancer stage.	Psychological distress as strongest predictor of one's own quality of life; mothers' higher psychological distress disproportionately predicted better mental health, but poorer physical health, in daughters. Daughters' distress did not predict mothers'.
Martini, Grusec, & Bernardini,	To examine variables expected to affect satisfaction in caregiving	44 mother/daughter dyads. All but two dyads apparently European American. Mean age	Quantitative, cross-sectional: Separate structured interviews of mothers and daughters with	Ability to perceive partner's feelings about relationship predicted both partner

1991, Canada	dyads: perceptions of interpersonal control, perspective-taking, and attributions made about self and other in both positive and negative caregiving interactions.	of mothers: 73; daughters: 44. Dyads lived within 100 km of one another; mothers relatively healthy and living alone.	investigator-devised, separate daughters' and mother's perceptual accuracy scale, helping attribution scale, helping satisfaction scale, and daughter's caution scale; Interpersonal Sense of Control Scale, Self-Dyadic Perspective-Taking Scale.	satisfaction and one's own feelings of interpersonal control. Interpersonal control associated with higher satisfaction in both self and other. Strongest predictor of satisfaction: attributions made about partner during negative situations and interpersonal control. Mothers had better perspective-taking than daughters (and daughters more satisfied in relationships wherein mother had better perspective-taking). Mothers generally more satisfied with relationship.
McGraw & Walker, 2004, USA	To explore how aging mothers/caregiving daughters negotiate connection, autonomy, and conflict: feminist social constructionist perspective.	31 mother/daughter pairs. All European American. Mean age of mothers: 79; daughters: 49. Pairs lived within 45 miles of each other; mothers had chronic health issues.	Qualitative, cross-sectional: Two videotaped mother daughter interactions—one discussing an issue or conflict and one involving a joint care activity.	Mothers and daughters were largely attentive, responsive, preserving of mothers' autonomy, minimizing of open tension and conflict. Three relationship patterns: symmetrically connected (42%), asymmetrically connected (more focus on mother's than daughter's needs—45%), and symmetrically constrained (neither partner attentive—13%). Balancing autonomy and connection as essential to relationship quality.
Pohl, Boyd, & Given, 1997, USA	To examine mother/daughter relationships in the first year of caregiving: attachment theory.	Eight daughters. All European American. Mean age of mothers: 79; daughters: 51. Four pairs co-resided and four mothers lived alone. Mothers	Qualitative, cross-sectional: Open-ended interviews, including questions about prior and present relationship quality.	Mother/daughter relationships were stable and included transitional conflicts. Decision to give care included strong lifelong relationship; daughters became

had fractures, colostomy care, dialysis, or other physical or cognitive changes.

closer through caregiving. Daughters who lived with mothers expressed more conflict, yet conflict itself strengthened attachment in some cases. Caregiving stressful, but all would do it again; can be transformative to relationship.

Pohl, Boyd, Liang, & Given, 1995, USA	To examine the impact of mother/daughter relationship on caregiving commitment; commitment to caregiving model.	98 daughters during the first three months of caregiving. 84% European American. Mean age of mothers: 77; daughters: 49. Mothers lived in community with or without daughters; primary diagnoses were circulatory, musculoskeletal, respiratory, or cancer.	Quantitative, cross-sectional: Telephone interviews with investigator-devised ADL, instrumental and affective commitment to caregiving, conflict, negative beliefs scales; Thompson and Walker's (1984) Mother-Daughter Attachment scale, demographics.	Strain, stress, and caregiving commitment were predicted as much or more by relationship quality than by instrumental caregiving or mothers' limitations. Relationship quality powerfully predicted caregiving commitment; particularly affective commitment. Both attachment and conflict were central in relationships.
Raveis and Pretter, 2005, USA	To examine experiences and reactions of daughters to their mothers' breast cancer diagnosis	50 caregiving daughters (mean age 38) of older women with breast cancer. 70% European American, 24% Hispanic, and 4% African American.	Qualitative, cross-sectional: Open-ended interviews focused on caregiving, reactions to mothers' diagnosis, changes in mother/daughter relationship.	Mothers' diagnosis precipitated changes in relationship, particularly intensifying mother/daughter bond, with daughters valuing anew time left with mothers and increasingly motivated to be with them, or in rare cases avoiding time together to protect self against missing mother. Most shifted entire life priorities to focus on mother. A few shielded mothers from their feelings, which was emotionally costly to daughters.

Shawler, 2007, USA	To describe and develop a theoretical model following aging mothers' and caregiving daughters' transition through mother's hip fracture trajectory, and discover perspectives on relationship; grounded theory.	Six mother/daughter dyads. All European American. Mothers ranged in age from 76-85; daughters 49-67. Three mothers lived with spouses, three alone.	Qualitative (Grounded Theory), longitudinal: 19 individual, 6 dyadic, and 2 focus group semi-structured interviews over 15 months; each dyad member interviewed separately, then together; then in focus groups.	Evolutionary Empowerment-Strength Model. Relationships underwent maturation and transformation. Lifelong close dyads felt attachment and connections further intensified. If relationship was precarious before hip fracture, it improved in wake of health crisis. Pairs reported transformation in themselves and in relationship. Several dyads reported tension, disagreement; all worked to resolve difficulties.
Sheehan & Donorfio, 1999, USA	To identify major themes or meanings caregiving daughters and aging mothers ascribe to their caregiving; grounded theory.	11 mother/daughter pairs, 10 European American, one African American. Mean age of mothers: 82; daughters: 58.	Qualitative, longitudinal: In-depth interviews with daughters, then mothers.	Themes included increased relationship tolerance or acceptance: dyads mutually adapted to caregiving relationship, putting conflicts aside or minimizing them, and experiencing increased interpersonal comfort. Awareness of time-limited relationship powerfully altered bond. Relationships were mutually rewarding and daughters prioritized them, even with competing demands. Caregiving relationship offered time to rework relationship and resolve past issues.
Vodermaier & Stanton, 2012,	To study associations between mothers' cancer context and familial cancer	147 women at high familial risk for breast cancer, taking part in a chemoprevention	Quantitative, cross-sectional: Survey packets including demographic and cancer-related	Cancer context and engagement in caregiving were not associated with psychological adjustment.



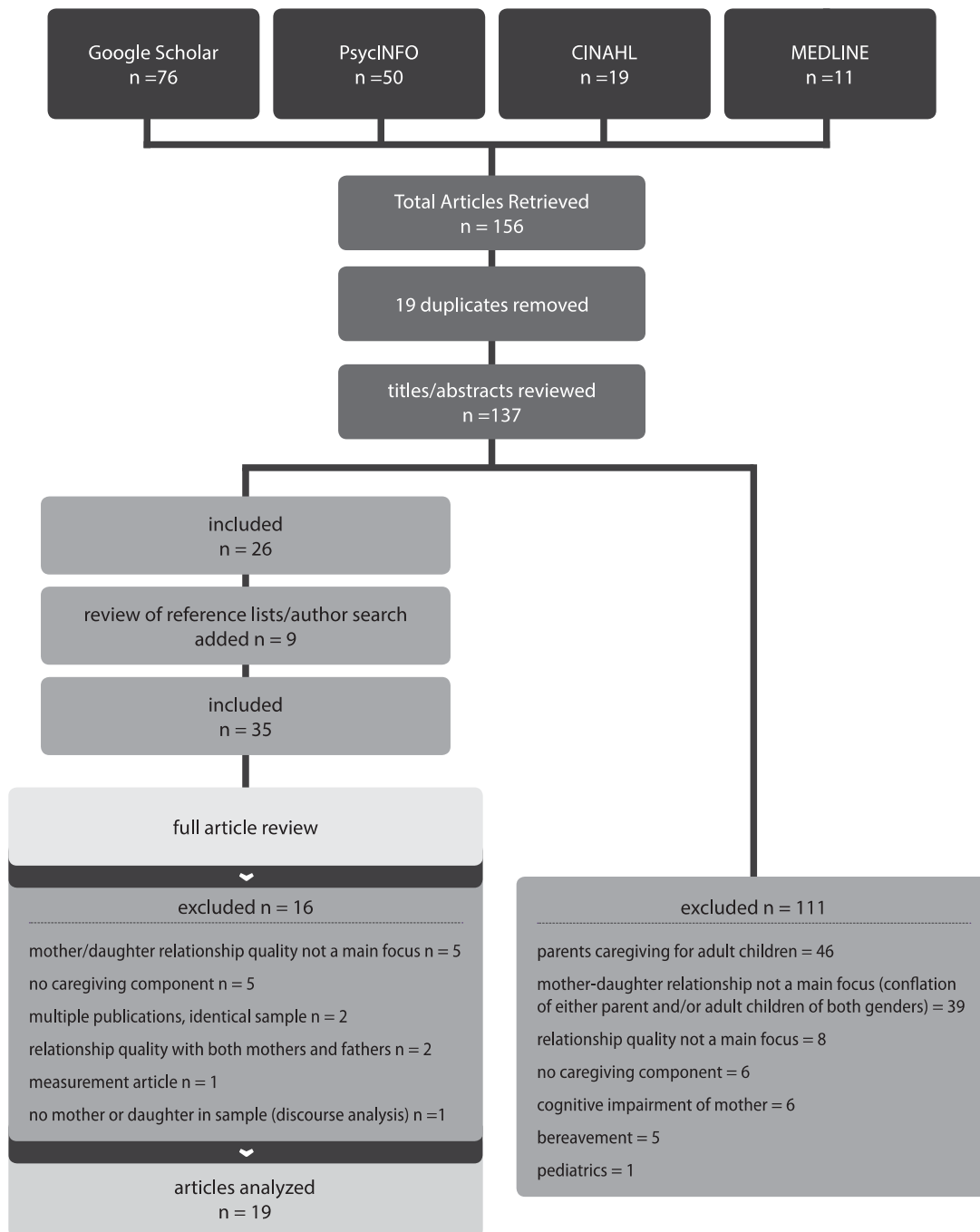
Canada, USA	experience with daughters psychological adjustment.	trial. Mean age: 47. 97% European American. Half of mothers had died, and all had been diagnosed, on average, 18 years prior.	variables; familial cancer experience via investigator-devised scale assessing involvement in mother's illness, emotional support provided and received; CES-D, and Impact of Event Scale.	Daughters who reported providing and receiving emotional support to/from mothers experienced lower depressive symptoms. Daughters who provided emotional support to mothers diagnosed in past 5 years reported less intrusive thoughts relative to daughters who did not. Emotional support given/received apparently represents a form of resilience.
Walker and Allen, 1991, USA	To identify relationship types in mother-daughter caregiving pairs; social exchange theory	29 widowed/divorced mother/adult daughter pairs. All European American. Mean age of mothers: 81; daughters: 55. Mothers lived within 45 miles of daughters.	Qualitative, cross-sectional: Separate semi-structured interviews with mothers and daughters focused on their relationship, mothers' health, caregiving activities, and positive and negative aspects of caregiving and care receiving.	45 percent of pairs labeled as intrinsic, with mutual rewards and activities, few costs, little to no conflict, and mutual concern for the other. 35 percent labeled as ambivalent, with rewards within the context of costs, few joint activities, lack of mutuality, much conflict, and only one evincing concern for the other's wellbeing. 21 percent labeled as conflicted, with few rewards, many costs, no mutual activities, prevalent conflict, and lack of mutual concern.
Walker, Martin, & Jones, 1992, USA	To examine caregiving outcomes in aging mother/caregiving daughter relationships; social exchange theory.	141 widowed/divorced mother/adult daughter pairs. All but two dyads European American. Median age of mothers: 84; daughters: 52. Mothers lived within 45 miles of daughters.	Quantitative, cross-sectional: Separate interviews with mothers and daughters using investigator-devised scales measuring intimacy (Walker & Thompson, 1983), caregiving costs/benefits, demographic and	Daughters with better relationships experienced fewer costs. Mothers experienced benefits from feeling loved. Lack of emotional intimacy in relationship predicted mothers' anger. For daughters, more

			situational variables and, for daughters, perceived need for care.	frustration or anxiety were connected with poorer relationship quality, but intimacy and opportunity to interact with mother mitigated costs.
Walker, Pratt, & Oppy, 1992, USA	To examine whether care receiving mothers were perceived to be reciprocal contributors in relationship to caregiving daughters; social exchange theory.	174 widowed/divorced mother/adult daughter pairs. All but four dyads European American. Mean age of mothers: 81; daughters: 52. Mothers lived within 45 miles of daughters. Variety of impairments: arthritis, vision, hearing, circulatory, gastrointestinal, bone.	Quantitative, cross-sectional: Interviews with mothers and daughters using investigator-devised measures of perceived reciprocity and mothers' health/need for care; demographics.	Large majority of mothers and daughters perceived reciprocity in relationship. Most common aid given by mother was love, with over 90% of mothers and daughters perceived love was given from mother to daughter. 87% of daughters who received aid felt it valuable. Mothers and daughters were both active participants in relationship.
Walker, Pratt, Shin, & Jones, 1990, USA	To examine connections between obligatory and discretionary motives for caregiving and relationship quality in aging mother/caregiving daughter pairs.	174 widowed/divorced mother/adult daughter pairs. All but three dyads European American. Median age of mothers: 84; daughters: 53. Mothers lived within 45 miles of daughters.	Quantitative, cross-sectional: Separate interviews with mothers and daughters using investigator-devised intimacy (Walker & Thompson, 1983), and mothers' health problems scales; mothers' perception of health scale (for mothers); perceived motives for caregiving scale (for daughters).	More than 4/5ths of mothers and 2/3rds of daughters believed daughters gave care for discretionary (affection, closeness, enjoyment of the relationship), not obligatory, motives. Women who reported daughters did not give care for discretionary reasons reported lower emotional intimacy in the relationship. Daughters mean ratings of intimacy: 4.0 out of 5.0; mothers: 4.72.
Walker, Shin, & Bird,	To study impact of caregiving on the aging	133 widowed/divorced mother/adult daughter pairs.	Quantitative, cross-sectional: Separate interviews with	95% of daughters and 97% of mothers noted no change or

1990, USA	mother/adult daughter relationship and associate these effects with satisfaction; social exchange theory.	All but two dyads European American. Median age of mothers: 84; daughters: 53. Mothers lived within 45 miles of daughters. Variety of impairments: arthritis, vision, hearing, circulatory, gastrointestinal, bone.	mothers and daughters including investigator-devised scales measuring intimacy (Walker & Thompson, 1983), perceived effect of care on the relationship; and for daughters, need for care, degree of bother/difficulty providing care, quality of care provided; caregiving Domain Satisfaction Scale.	positive effects of caregiving on relationship. Approximately half of women who noted positive impact attributed change to greater amount of time together. Daughters noted enjoyment and rewards, and daughters who noted no change or positive effects were satisfied with caregiving. Higher emotional intimacy positively associated with relationship quality.
Walter, 1991, USA	To examine dynamics of aging mother/adult daughter caregiving relationships that contribute to caregiver stress.	48 mother/daughter dyads. Almost 90% European American. Mean age of mothers: 77; daughters: 49. All mothers lived within one hour of daughters. Health impairments included circulatory/cardiac dysfunction, arthritis, osteoporosis, diabetes, emphysema, thyroid dysfunction, etc.	Mixed methods, cross-sectional: Structured interviews with mother and daughters. Included investigator-devised questionnaire assessing type of relationship, demographic and situational variables, and for daughters, assessment of stress and caregiving activities; modified Zarit's Burden Interview.	The more equal and peer-like the mother/daughter relationship, with mutual exchange, the less stress experienced by caregiving daughters. Mothers' autonomy also connected with less caregiver stress.

Figure 1

## Systematic Review Process Flowchart



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## Chapter III

### Unexplored Territory: Qualitative Dyadic Relational Research

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This manuscript represents a significant contribution to the dissertation work: it addresses Aims 3 and 4, and replaces aspects of the traditional methods chapter. The target journal for submission summer 2016 is *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, a bi-monthly indexed and peer-reviewed journal of the Gerontological Society of America that comprised the first journals on aging published in the United States, with an impact factor of 3.213. The journal solicited and accepted an abstract for this manuscript. If the manuscript is rejected, a second choice will be made for revision and resubmission in line with rejection feedback. Funding in part for this manuscript was supported by the Hartford Center of Gerontological Nursing Excellence, OHSU School of Nursing (Hartford Award for Research and Practice, 2015) and the OHSU School of Nursing Dean's Award (2014)

## **Unexplored Territory: Qualitative Dyadic Relational Research**

**Purpose and aims:** The purpose of this work is to review current developments in dyadic relational research methods, and offer a comprehensive, replicable qualitative dyadic approach, from conceptualization through aims, methods, analysis, and interpretation of findings.

**Review of Literature and Conceptual Basis:** Quantitative techniques such as Multilevel Modeling successfully capture dyadic perceptions of two individuals in one relationship, yet no well-developed qualitative dyadic approach exists. Such an approach is needed to honor, empower, and increase understanding of socially constructed relationships in aging and healthcare.

**Design and Methods:** Using a dyadic exemplar of aging mother-adult daughter care dyads, a methods template is described. This includes: 1) qualitative and dyadic conceptualization and aims; 2) a systematic process of data collection, including a dyadic vignette, 3) coding and cross-person analytic techniques specific to the intradyadic relationship, including data matrices, 3) derivation of dyadic findings, and 4) rigorous attention to trustworthiness.

**Data Analysis:** A novel method of qualitative dyadic analysis was developed.

**Human Subjects Protection:** OHSU IRB approval #10828. Determination of decisional capacity was conducted with all mothers, and an informed consent form was signed by each participant prior to her interview.

**Results, Discussion:** A qualitative dyadic approach provides an overarching picture of the dyad beyond and in addition to individual views, including a deeper understanding of

the essential emotional nature of relationships. Advantages are discussed, including ways a qualitative dyadic approach can enhance caregiving and gerontological interventions and outcomes.



In the 1980s researchers advanced conceptualization and examination of interpersonal relationships by investigating them as a dyadic unit (Linda Thompson & Walker, 1982). Exploring patterns of interaction or behavior between two people can be done through the lens of one individual respondent or both (Thompson & Walker, 1982). Yet when considering data on relational aspects of the dyad, such as mutuality, companionship, relationship quality, or strain, the report of one individual may be incomplete in comparison to a well developed understanding of a bi-directional relationship (Linda Thompson & Walker, 1982). Triangulating two respondents' perceptions offers a richer, more nuanced dyadic perspective—a picture of relationship beyond what can be seen from an individual alone. Whether relational perspectives are concordant or discordant, perceptions from both individuals provide dual levels of data: individual, or “first-order” data—direct responses of two individuals—and dyadic, “second-order” data—an overarching interpretation of the relationship (Linda Thompson & Walker, 1982). This conceptualization undergirds the qualitative dyadic research template presented here: collecting data from two respondents best captures and verifies both individual and dyadic levels of relationship.

Since Thompson and Walker (1982), focusing on the dyad as the unit of analysis has gained increasing utility in social and psychological sciences to explore interdependent, bi-directional nuances of interpersonal relationships, including in caregiving, chronic illness, and aging (e.g., Godwin, Swank, Vaeth, & Ostwald, 2013; Moser, Künzler, Nussbeck, Bargetzi, & Znoj, 2013). Quantitative researchers first adapted traditional methods for dyadic research, such as intraclass correlations and ANOVAs (HLM; Maguire, 1999). In the current century, sophisticated actor and cross-

partner effects investigating interdependence nested within the dyad have been developed (e.g., the Actor-Partner Interdependence Model [APIM]; Cook & Kenny, 2005).

Rationales for using qualitative and quantitative dyadic research in families and gerontology include capturing complexities of family (Carr & Springer, 2010) and intergenerational relationships (Hogerbrugge & Komter, 2012); exploring contextual relationships within aging and dementia (Ward-Griffin, Oudshoorn, Clark, & Bol, 2007); or viewing relationship conflict within hospice (Betty J. Kramer & Boelk, 2015). A dyadic view of patients and family members increases appreciation of relational interdependence both cross-sectionally and longitudinally across the illness or caregiving course (Lyons & Sayer, 2005). This second-order view offers something additional to what can be seen on an individual level (Lyons, Zarit, Sayer, & Whitlatch, 2002). How individuals perceive relational strain within the dyad, for example, can be explored on a first-order, individual level; how individual perceptions intersect on a “second-order,” dyadic level can be deduced and interpreted as well.

Concurrent to developments in dyadic research, both quantitative and qualitative researchers have endorsed greater use of qualitative inquiry in the study of families and gerontology. Qualitative research has been recommended to explore nuances of family interaction embedded within natural contexts (Ganong & Coleman, 2014). Gerontologists have suggested qualitative investigations of negotiation in intergenerational relationships (Bengston, Giarrusso, Mabry, & Silverstein, 2002), in depth exploration of family interactions (Warren-Findlow, 2013), and outlier relationships that quantitatively skew toward the mean (Bengston et al., 2002). Suggestions for qualitative research include investigating family adjustment to life-limiting illness (Petrin, Bowen, Alfano, &

Bennett, 2009; Wong, Ussher, & Perz, 2009); reciprocal care needs of patients and care recipients (Lingler, Sherwood, Crighton, Song, & Happ, 2008); and relational influences on end-of-life care (Funk et al., 2010).

### **The State of Qualitative Dyadic Science**

Yet endorsements for qualitative inquiry have not explicitly suggested a comprehensive dyadic relational approach, and only a single publication explicates qualitative dyadic analysis in detail (Eisikovits & Koren, 2010). Although this model is excellent for one method of dyadic analysis, it does not attempt to provide a detailed template for qualitative dyadic conceptualization and methodology, from aims through interpretation. A well conceptualized qualitative dyadic approach—two individuals reporting on one relationship—is lacking.

Such an approach to investigating emotional relationships requires integrated dyadic and qualitative aims, data collection, analysis, and interpretation. Although qualitative dyadic methods may be well suited to siblings negotiating care roles for a local parent, or for aging couples preparing to say goodbye when one is dying, qualitative researchers have rarely combined qualitative methods with a well-embedded dyadic approach. Starting from aims, many use dyadic interviews to answer non-dyadic, non-relational questions. They may utilize a joint spousal interview to explore the support system surrounding and external to the couple (Messersmith, Kunkel, & Guthrie, 2015), or to describe privacy management issues with extended family (Lannutti, 2013). These are constructive reasons to interview two people together; yet speaking to two interviewees at one moment in time does not ensure data is collected on a dyadic,

relational aim (Kenny, Kashy, & Cook, 2006)—an interpersonal facet such as companionship, complementarity, intimacy, or communication.

With the exception of Eisikovits and Koren (2010), qualitative dyadic researchers have not addressed detailed description of, or conceptual rationale for, data collection. Individual or joint interviews each offer advantages and limitations when focusing on relationships. Yet researchers often report separate or joint interviews without explicit rationale or timing for such choices (e.g., Ben-Ari & Lavee, 2007; Retrum, Nowels, & Bekelman, 2013). Well-described qualitative dyadic analysis is also difficult to discern (e.g., Forbat, 2003; Gardner, 2008; Hellstrom, Nolan, & Lundh, 2005; McGraw & Walker, 2004; Walker & Dickson, 2004; Ward-Griffin et al., 2007). This is understandable considering constraints of a findings-based research paper, yet limits advancement of qualitative dyadic methods. Recent researchers have proposed several new qualitative dyadic analytic methods—multiadic, collaborative autoethnographic, and affective (Manning & Kunkel, 2015)—but how to conduct these methods or integrate a dyadic design focused on a relational question is absent. Standard texts on qualitative methods also lack dyadic methods or coding (e.g., Creswell, 2013; Saldana, 2013).

Thus, an in-depth, processual qualitative dyadic approach—using the dyad as the unit of analysis—is unexplored, yet vital. To capture this process, a research exemplar is presented to illustrate issues of qualitative dyadic conceptualization, specific aims, methods, analysis, and interpretation.

## **Methods: A Data Exemplar**

The present exemplar focuses on dyadic perceptions of relationship quality between cognitively intact mothers in home hospice, and their adult daughters partnering in their care.

### **Dyadic conceptualization**

Conceptualization as a dyadic study was most appropriate to explore a highly interdependent construct, relationship quality, from the individual perspectives of both mothers and daughters, as well as at the level of the dyad. A qualitative study of individuals (daughter caregivers or more rarely, mothers in hospice), might explore a relational question (e.g., how does communication with the other dyad member affect that individual's assessment of relationship quality?) This could allude to the dyadic relationship, yet multi-dimensional complexities and distinctions in perceptions between partners would be lost, unheard. A sole respondent inevitably speaks from lived experience, informed by unique historical and cultural assumptions (John W. Creswell, 2013). Each constructs thoughts, feelings, and behaviors, yet co-creates one relationship in a social context (Berg, Meegan, & Deviney, 1998; Townsend, Miller, & Guo, 2001).

Thus from an individual, or first-order level, one can inquire as to dyadic constructs (such as how one individual in a dyad perceives complementarity in the relationship). Yet with data from two respondents, individual perspectives can be compared and contrasted, offering dyadic findings on both first-order (individual-perspective) levels, and second-order levels—an overarching, interacting interpretation of relationship unattainable from one perspective alone. Triangulating two accounts allows a sophisticated, second-order interpretation greater than the sum of two parts.

On the qualitative side, a level of sophistication and interpretation regarding relationship—not simply qualitative description—was also sought. A novel qualitative dyadic approach was required to address all these functions.

### **Aims**

Two dyadic questions constituted specific aims in the present exemplar: To describe and interpret how mothers and daughters:

- Perceive relationship quality
- Perceive their relationship has developed over time through health, chronic illness, and hospice at home

These questions, though intended to stimulate findings at both individual and dyadic levels, are dyadic in nature. They inquire as to how each individual feels and thinks about the relationship, and the relationship over time. Second, they ask at the dyadic level what meta-view of the relationship (and the relationship over time), each reveals that may or may not be visible at the individual level. In other words, what picture of the dyadic relationship emerges from viewing, analyzing, and interpreting two individual reports that refer to one relationship? Is one respondent's story concordant or discordant with the other? If two dissimilar portraits emerge, what can be interpreted from or above two individual accounts to create an overarching, second-order picture of the relationship? This allows for qualitatively interviewing both partners on individual and dyadic relational perspectives. By comparing one individual's account intimately to the other, something further appears that remains invisible via one informant's report alone.

## **Sample**

Purposive sampling (Patton, 2002) was chosen in the study to capture diversity in relationship quality. As with any dyadic study, recruiting dyads proved more difficult than recruiting individual participants. Yet such a strategy was requisite to answering dyadic aims embedded in the design, and to promoting emergence of second-order data—an overarching interpretation, or essence, of relationship quality beyond each individual informant’s response. Two participants in one dyad also inherently offered qualitative rigor, with multiple data sources providing triangulation of responses (Patton, 2002) regarding a single relationship. This approach substantiated qualitative findings and trustworthiness in the end-of-life context.

## **Data collection**

Several methods of interview<sup>1</sup> data collection exist in qualitative dyadic research. These include joint and individual interviews, consecutive individual interviews, individual interviews with time transpiring between for conversation and cross-fertilization of data between respondents, or interviews conducted by two researchers, each interviewing one dyad member and then comparing notes. For a summary of advantages and disadvantages of each, see Eisikovits & Koren, 2010, p. 1643; Manning & Kunkel, 2015, p. 188; Morris, 2001. The impact of data collection decisions should be carefully articulated within the context of dyadic study aims. In addition, potential ethical issues must be considered (Liz Forbat & Henderson, 2003), such as when a researcher learns something that might impact the health of a second respondent.

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<sup>1</sup>Qualitative data collection options can include video, photovoice, music-, and art-based approaches; focus groups, etc., yet are beyond the scope of this paper.

In the present exemplar, multiple rationales existed for individual interviews. Emotionally, the hospice context signified complex life completion issues for mothers, and relationship completion issues for both women (Byock, 1996; Erikson & Erikson, 1998). Mothers and daughters are known to minimize conflict and discussion of difficult subjects when interviewed together (McGraw & Walker, 2004). The dying context is also acknowledged as taboo in western society (Carlander, Ternstedt, Sahlberg-Blom, Hellström, & Sandberg, 2011; Walker, Read, & Priest, 2011). Yet empowering each mother and daughter to fully and openly share their story was the data collection goal. This included discovery of perceptions each respondent held of her relationship with the other within and outside the hospice context, as well as how perceptions of one qualitatively echoed or diverged from her partner's. Joint interviews—acknowledged to give a more real-time picture of relational interaction—may have precluded this disclosure and compromised study findings.

To further enhance disclosure, the consent process assured each respondent of confidentiality. She could freely respond how she liked; the interviewer was not allowed to discuss one dyadic respondent's comments with the other. One interviewer scheduled and conducted audio-recorded interviews with one respondent, then interviewed the second dyad member immediately following. Identical interview guides were used to enhance comparison of dyadic responses to relational probes.

### **Data analysis**

Because qualitative research is interpretive, iterative and reiterative, analysis and interpretation began as soon as interviews were conducted (John W. Creswell, 2013). Phases of analysis overlapped or even occurred simultaneously, yet are described here



sequentially. After separate interviews were completed with both participants in a dyad, the researcher etched a field note focused on dyadic impressions, a vignette. This diverged from a traditional field note by privileging nuances of the dyadic relationship. All exemplars have been edited for clarity and de-identification.

Dyad W: (Before separate interviews, the pair sat together.)

The mother appeared painfully frail and thin, in pants and a sweatshirt on a muggy, hot morning. The daughter sat straight, at attention beside the mother, a coffee table before them with steamy croissants, French jams, and two glasses of sparkling lemonade, as though a tableau out of *Sunset*. The mom was clearly hard of hearing, and often closed her eyes, seemingly straining to hear, or conserving energy in order to speak. It was difficult to read her affect (the daughter had said earlier she had “frozen face,” due to her disease). I watched the daughter trace her arm around her mother’s shoulders, bend down, gently kiss her several times on the forehead. She asked her mother if she needed a wrap, if she was cold; then, satisfied her Mom was okay, she left us alone. As I interviewed the mother, she labored to speak. In little puffs of phrases and breath, her words about her daughter glowed. When I interviewed the daughter, she revealed the same supportive, lifelong relationship story the mother had, yet had the energy to richly embroider it in a way the mother may have liked to but no longer physically could. In this dyad, the mother seems so corporeally frail, yet still so powerfully emotionally mothering. And the daughter was unrelentingly devoted, doing whatever it takes for as long as it takes, to enjoy the precious time left them to heal any old family wounds and complete a life and a treasured bond.

Each dyad’s transcripts were verified against audio files for verbatim accuracy, and de-identified. This allowed reflection on initial impressions and preliminary analysis on first order and second order levels through “listening” to each—and both—responses regarding the dyadic story. For the initial six dyads, the principal investigator (DNS) and a qualitative, end-of-life expert researcher (LH) commenced analysis. Independent reading of both transcripts per dyad in toto ensued, encouraging further dyadic impressions and early interpretation. Transcripts were compared side-by-side in close parallel.

A “crossover,” intradyadic coding technique developed, tightly comparing one respondent’s response to interview probes with her partner’s through constant comparison (Charmaz, 2006). Preliminary open coding centered broadly on categorizing references to relationship quality. “Perception of the Relationship” was assigned to any data evoking a woman’s relational perceptions. For example:

Dyad X: Mother’s perception of the relationship (MPR): I tried to protect her and I would spend a lot of time with her, try to make her feel better. I just love my children, was so happy to have children. I just thought it was a precious privilege. She knows I love her and I know she loves me.

Dyad X: Daughter’s perception of the relationship (DPR): I like our relationship better now... because I’m not asking anything of her. I’m a friend and a helper. (It) seems to work better because I’m very nurturing. It’s just, as a daughter, there was a little something missing. She’s not equipped. She just doesn’t have the tools to follow through.... She can be empathetic, (but) to somebody else....

Either respondent’s mention of contextual elements impinging on the dyadic relationship were also coded. These factors included hospice features, financial exigencies, or extended family relationships within which the dyad was embedded, such as this first-order, individual response:

Dyad Y, Daughter: Hospice context: I’m struggling with it right now because of the way she’s declining. I even told hospice I’m never going to get to a point where I’m like, you need to find somewhere for her to go. I will never make that decision, ever. Even if I physically cannot do it, I would rather someone help me do it here than take her somewhere else. I really don’t want that to happen. There’s a lot of things on top of me. I feel like there’s just so much tremendous guilt if I were to ever do that. It’s just too difficult for me to make that decision.

Coders assiduously assessed concordance and/or discordance in responses regarding relationship quality. Did both women socially construct and describe an identical relationship, whether positive or negative? Or were they experiencing two mutually exclusive relationships? Were they somewhere between? The first dyad, as a unit,

revealed a unique position on a nascent relationship quality spectrum, serving as a critical case (Creswell, 2013). Each subsequent dyad was analyzed staying true to the crossover analytic template, comparing individual transcripts intradyadically and interpreting for relational concordance or discordance. Coding discrepancies were resolved through discussion and clarification of perceptions, possible biases, and alternate explanations until agreement was reached.

After both coders had analyzed six dyads and reached consensus on broad “Perception of the Relationship” references, the first author commenced a deeper iteration of coding and analysis for dyads to date. MPR and DPR dyadic categories were enriched and “feathered” with descriptors suggesting dyadic relationship quality styles (e.g., “friends,” “neutral,” or “obligatory partners”). Further iteration and induction evinced multi-dimensional emotional processes comprising dyadic themes within relational styles (e.g., “coping,” “caring,” or “strained”), and dyadic subthemes (e.g., “communication”) within themes. As new codes arose, the first author recursively re-read all prior transcripts, updating preliminary codes to capture an emergent understanding of relationship quality. Each dyad fell into preliminary position on an emergent relationship quality spectrum. Alternate explanations were again explored and discussed.

Subsequent dyads were analyzed in this way. QSR International’s NVivo 11 qualitative software for Macintosh was utilized for data management and matrix creation of “Perception of Relationship” categories, as well as for in depth interrogation of dyadic styles, themes, and subthemes. Identical codes extracted intradyadically were compared side-by-side in NVivo via the crossover technique. In this way, discordance in two

women's narratives could be realized easily, as in the exemplar above, or strikingly concordant narratives could be grasped, as in the wording here:

Dyad Z, Daughter: We are extremely close and have been forever. She is my best friend. And I tell her everything. I call her every single day. If I don't, it's every other day. We are extremely close.

Dyad Z, Mother: I think we're very, very close. Very close... I love her dearly. We're very close.

Matrices were also used for frequency counts (Creswell, 2013) of dyadic styles, themes, and subthemes in each transcript. Numbers were compared intradyadically to analyze whether one woman revealed a particular dyadic theme more or less frequently than her partner, and/or which themes occurred most or least prevalently, both within and across dyads. Frequency counts served to verify intradyadic interpretations. Every dyad's story was compared interdyadically, across dyads, to verify and refine dyadic styles, themes, and subthemes. Interpretations were recursively verified with initial dyadic vignettes and impressions. Findings were discussed in depth between first, second, and third authors, and with qualitative and end-of-life (JB) experts to verify interpretations and reach rich, thick description of the essential nature of relationship quality across the spectrum. Dyads were compared interdyadically a final time to ensure firm grounding in the data, consistency, and applicability (Noble & Smith, 2015).

Finally, each dyad's perceptions of relationship development over time—the study's second aim—were integrated onto the relationship quality spectrum, adding consistency and multi-dimensionality. The ability (or inability) of dyads to adapt and negotiate changing stresses of care, absorb extended family pressure over time, or ameliorate strains of co-residing also fell along the spectrum of relationship quality. With this,

interpretations were verified and finalized. See Figure 1 for a summary of the analytic process.

### **Findings**

Each dyad found a unique place on the emergent relationship quality spectrum. Five dyads exemplified a relationship style at one end of the spectrum, two integrated elements of two styles at different points approaching the middle of the spectrum, two comprised a relationship quality style farther down the spectrum, and one dyad, encompassing its own style, resided at the far end. While focus here is not on actual findings, qualitative dyadic analysis and interpretive description (Thorne, 2008) informed both first- and second-order interpretations of relationship quality. Interpretations emerged naturalistically during analysis, embedded within the distinct context of each dyad. A multi-dimensional, dyadic relational spectrum comprised the result. This spectrum offered a complex array of concordant to discordant dyadic relational styles at both individual and dyadic levels. Each dyad's style, layered by emotional processes (themes) and sub-processes (subthemes), was embedded as well with a capacity to adapt relationships (or not) to the rapidly changing trajectory of hospice care.

### **Rigor**

Many criteria exist with which to evaluate qualitative rigor, all of them offering legitimacy (e.g., Lincoln & Guba, 1985; Maxwell, 2013). None, however, have been developed specifically for a dyadic approach. Well-chosen qualitative strategies to ensure trustworthiness and validity were needed (Maxwell, 2013; Noble & Smith, 2015). All necessitated adaptation through a dyadic lens. Rigor criteria employed in the present dyadic approach included, among others: 1) Reflexivity—attending systematically to

elements of the research process and the researchers' own possible influence thereupon—in dyadic conceptualization and methodology, from aims through dyadic sampling, data collection, analysis, and interpretation; 2) Purposive sampling to elicit a wide range of emotional relationships; 3) Identical interview guides for both mothers and daughters to promote individual responses to matching probes; 4) An initial dyadic “vignette” field note written immediately following interviews to provide a touchstone for interpretation, comparison and/or negation; 5) Reflective listening during interviews to test and secure general dyadic impressions, preliminary findings, and participant feedback; 6) Audio-recorded interviews with verbatim transcription to check original wording, inflection, and dyadic tone; 7) Dyadic coding with consistency and consensus between two coders; 8) Triangulation of each dyadic account via two individual respondents regarding one relationship; 9) Expert debriefing throughout with qualitative, dyadic, and substantive (here, end-of-life) experts to ensure credibility of dyadic approach, analysis and interpretation; and to decrease bias; 10) Decision and audit trails; memoing, including NVivo, to ensure interpretations were consistent and transparent with dyadic data; 11) Comparing discrepant dyadic cases; 12) NVivo matrices to scrutinize coding frequencies and verify intra- and interdyadic interpretations.

### **Discussion**

The present template for dyadic qualitative research is simply one template. Using qualitative methods applied for decades with individual respondents, we adapted them creatively to craft a novel dyadic approach. It is hoped this rudimentary beginning and basic structure might provide scaffolding upon which more advanced qualitative dyadic methods can be invited, discovered, and built.

Discovery using qualitative dyadic conceptualization and methodology offered insight into relational processes at an over-arching, interpretive level well beyond what might be discovered from one respondent. Interpretation of first-order data from two individual respondents provided second-order data (Linda Thompson & Walker, 1982), both within and across dyads (Ayres, Kavanaugh, & Knafl, 2003). In the brief exemplars embedded here, it is evident how two people in one relationship might offer echo-like concordant accounts—or accounts so discordant it is difficult to imagine they refer to the same interpersonal bond.

The evidentiary benefit of two triangulated accounts of one relationship holds implications at both individual and dyadic levels. At the individual level, interpersonal findings and interpretations of respondent's roles—mother/patient, or daughter/caregiver—emerged along a spectrum. In this work, in difficult relationships daughters humbly, diligently persevered in caring for mothers who had not necessarily met an ideal of good mothering. Mothers, in positive relationships, were seen as powerful, psychologically supportive care partners to emotionally or logistically struggling daughters. Comparing and triangulating the transactional, interdependent nature of individuals within a dyad evinced a rich, thick description of individual roles. These findings were robust enough to, for instance, call into question the way a term such as “care recipient” is used. Imagine the mother almost too debilitated to speak, yet still powerfully in emotional command of her relationship with her daughter. “Care recipient” a passive term, minimizes the dedicated strength and enduring nature of active mothering she tried to accomplish even as her body failed.

The dyadic lens offers great potential for clinical applicability, intervention, and discovery imperceptible at the individual level. Imagine the Dyad X exemplar, above, of a daughter describing her mother as unsupportive emotionally, while the mother speaks of a loving, supportive bond. If the daughter alone had responded, her mother's seeming invalidation would remain undetectable. Yet through a dyadic lens, one might intervene. The daughter could be supported for want of a more physically or emotionally affectionate mother—and for this desire being apparently suppressed within her relationship. The mother's discordant view suggests avenues for intervention on her behalf as well, or a dyadic-level, brief therapy intervention targeting bi-directional relational improvement.

In certain circumstances, interviewing one individual regarding the dyadic relationship may be the sole option. This occurs in cases of caregiving, for example, with a severely cognitively impaired patient; a bereaved care provider; or when feasibility issues intervene. One informant's response concerning her or his dyadic experience, as well as perception of the partner's experience, would suffice. Yet the assumptions, biases, and lived experience of one individual would be evident, and could not be triangulated against perceptions of a dyadic partner's. This could suggest a second-order portrait of the relationship in constrained circumstances, but not offer the ideal in qualitative dyadic research.

Qualitative dyadic approaches offer a potent way to view dyads in context as well. In the present study, contextual factors affecting each dyad served to elucidate secondary aims of perceived relationship quality through health, illness, and hospice. Emergent factors included financial pressures forcing daughters into extended work and separation



from dying mothers, thus influencing relationship quality. Multi-generational maternal patterns of women “sticking together” while men “came and went” informed relational patterns as well. Known pressures on relationship quality found in co-residing pairs (Pohl et al., 1997), or rewards of reconciliation discovered in the caregiving context (Shawler, 2007), were also revealed. Situationally locating each individual, pair, family, or group within its historical, proximal, and natural contexts is a strength of qualitative discovery. Such a contextualized lens can be applied to answer any dyadic aims.

### **Future directions**

Advancing the complexity of dyadic science to include more than one relationship is essential. In caregiving, desired (or gratuitous) contributions of friends, siblings, and far-flung kin are so well acknowledged as to be dubbed “coming out of the woodwork” (Betty J. Kramer & Boelk, 2015). Methods to study three-person or larger family systems have been conducted in several illness contexts across the lifespan (Ayres et al., 2003; Carlander et al., 2011). Yet approaches to capture this phenomenon on a relational level—how does a relationship with a sibling impact a caregiving relationship with a parent, for instance?—have yet to be developed.

Mining and exploring dyadic contextual elements in successive ways—both qualitatively and quantitatively—is also recommended. Questions remaining to be explored may include: How are relationships embedded within contexts and influenced by contexts in which they are embedded? How do sibling or spousal involvement (or absence) impact an intergenerational care dyad? How might a cross-cultural view of caregiving impact a particular dyad when generations of family have cared for each other

but are geographically constrained from doing so? How might one diagnosis impact a care dyad vs. another? And so on.

Finally, qualitative dyadic research is essential to complementing quantitative dyadic methods such as Multilevel Modeling (Sayer & Klute, 2005). Mixed methods can advance qualitative dyadic approaches while contextualizing quantitative insight into family relationships in hospice, gendered differences in caregiving, or strain and reward in dementia dyads. Collaborative innovation enriches qualitative and quantitative investigators and disciplines, offers a comprehensive picture of aging and more precise foci for research, and moves gerontology forward as a field. Countless relational and role permutations in natural contexts await, open to discovery.

## Figure 1

## Steps Conducted in Qualitative Dyadic Relational Analysis

- 1) Initial, written field note/vignette of dyadic impressions following dyadic data collection
- 2) Verbatim sound check of transcripts (first-order data) against audio-files with reflective, nuanced listening for preliminary dyadic interpretation (second-order data)
- 3) Transcripts uploaded in qualitative analytic software for ease of data management
- 4) Two independent coders analyzing data via intradyadic crossover technique, comparing 60% of dyads side by side
  - a. Initial read-through for emergent interpretation of dyad as a unit
  - b. Open coding for perception of the relationship categories (or alternate relational construct), as well as additional contextual elements
  - c. Comparing dyadic responses to each interview probe for agreement/disagreement in relational perceptions
  - d. Preliminary placement of first critical case on emerging dyadic spectrum; use of this template to compare and contrast each subsequent dyad
  - e. Resolving coding disagreements through discussion, exploring alternate explanations throughout
- 5) Principal investigator reiteratively reanalyzing dyads to date and remainder of dyads
  - a. Intradyadic crossover technique as above
  - b. Feathering of broad “perception of relationship” categories with descriptors denoting dyadic relational styles
  - c. Inductive coding denoting dyadic relational themes within relational styles
  - d. Inductive coding denoting dyadic subthemes (emotional sub-processes) within relational themes
  - e. Recoding earlier transcripts; applying emergent codes in later dyads reiteratively as appropriate
  - f. Preliminary placing each dyad on emerging dyadic relational spectrum
  - g. Discussing alternate explanations between investigators throughout
- 6) NVivo verification:
  - a. Matrices used to sort references to relational construct (e.g., “Perception of Relationship”), dyadic styles, themes, and subthemes per each dyad
  - b. Crossover technique to verify intradyadic responses under each dyadic type, theme, and subtheme
  - c. Coding frequency counts to assess/verify concordance/discordance of intradyadic styles, themes, subthemes
  - d. Coding frequency counts to assess/verify interdyadic (across dyad) styles, themes, subthemes
  - e. Comparing final intradyadic conceptualization/interpretations interdyadically for refinement/verification
  - f. Comparing final intradyadic conceptualization/interpretation with initial dyadic vignette
  - g. Final debriefing with experts to ensure credibility of dyadic approach, analysis and interpretation
  - h. Final interdyadic comparison to ensure groundedness, consistency, applicability
  - i. Integration of contextual elements suggesting longitudinal changes in relationship quality
  - j. Final placement of dyads into position on dyadic relational spectrum

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## Chapter IV

### **It's All About the Relationship: A Qualitative Exploration into Non-Cognitively Impaired Mother-Daughter Care Dyads in Hospice at Home**

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This manuscript represents a significant contribution to the dissertation work: it addresses Aims 5 and 6, and replaces aspects of the traditional methods and results chapters. The target journal for submission summer 2016 is *The Gerontologist*, the bi-monthly indexed and peer-reviewed journal of the Gerontological Society of America that offers a multidisciplinary perspective on aging, with an impact factor of 3.231. The secondary target journal is *Qualitative Health Research*, a peer-reviewed, monthly journal with an impact factor of 1.441, which offers an international, interdisciplinary forum for enhancements in health care and furtherance of qualitative health research. Funding for this manuscript was supported in part by the Hartford Center for Gerontological Nursing Excellence, OHSU School of Nursing (Hartford Award for Research and Practice, 2015) and the OHSU School of Nursing Dean's Award (2014).

**It's All About the Relationship: A Qualitative Exploration into Non-Cognitively Impaired Mother-Daughter Care Dyads in Hospice at Home**

**Purpose of the study:** This interpretive descriptive work privileges the voices of terminally ill mothers and daughters in care provision in the context of hospice at home. Specific aims were to describe and interpret how mothers and daughters: a) perceive relationship quality, and b) perceive how relationships have developed over time through health, chronic illness, and hospice care.

**Background and Conceptual Basis:** Adult daughters providing care to aging ill mothers comprise the most prevalent caregiving dyad, yet little is known about relationship quality and its impact on care in these dyads, particularly in the context of cognitively intact patients in hospice at home.

**Design and Methods:** Semi-structured interviews were used to explore interdependent perceptions of relationship quality in 10 aging mother-adult daughter care dyads in the home hospice context.

**Data Analysis:** A novel method of qualitative dyadic analysis was developed to analyze mother-daughter dyads in close parallel at both individual and dyadic levels, staying true to qualitative rigor.

**Human Subjects Protection:** OHSU IRB approval #10828. Decisional capacity was assessed in all mothers and informed consent was signed by each participant prior to interviews.

**Results:** A relationship quality spectrum emerged from Close Friendship to Doing My Duty. Women in Close Friendships revealed concordant narratives and emotionally

satisfying relationships: women in more neutral or troubled relationships revealed diverging relational stories. In these latter dyads, mothers tended to disclose more positive narratives than daughters, who spoke frankly about problems in relationships.

**Implications:** This work suggests the need for deeper exploration of mother-daughter dyads within the hospice context, and interventions at both individual and dyadic levels.

As women in the United States approach end of life, it is adult daughters who provide two-thirds of their care (Feinberg et al., 2011). Although much is known regarding protective effects of relationship quality on spousal care dyads (e.g., Pinquart & Sörensen, 2006, for a review), or on aggregate groups of spouses and/or other kin providing care (Schumacher et al., 2007; Sebern & Whitlatch, 2007), much less has been revealed concerning relationship quality in aging mother-adult daughter dyads. This is especially true for cognitively intact mothers reaching end of life (Read & Wuest, 2007). Privileging the voices of women during the final transition in their relationship is essential to making their stories heard and to addressing unique needs they may have.

### **Relationship Quality in Care Dyads**

Much research has been conducted on relationship quality in care dyads wherein the care recipient has dementia or some other form of cognitive impairment (Habermann et al., 2013; Pinquart & Sörensen, 2007; M Pinquart & Sörensen, 2004). Relationship quality, psychological wellbeing, and care provider burden are known to be negatively impacted in the context of cognitive disorders (Aneshensel et al., 1995; Bookwala, 2009) especially for women (Karen S Lyons et al., 2009; Pinquart & Sörensen, 2003). This work has been essential to understanding relational needs of both care partners (Quinn et al., 2009). Yet discourse on relationship quality in care partners not confronting cognitive impairment is less well-studied (Pinquart & Sörensen, 2004), particularly at end of life. Interdependent intricacies of cognitively intact mother-daughter dyads transacting, negotiating, and approaching the end of a lifelong relationship—positively or negatively—are largely unexplored (Solomon, Hansen, Baggs, & Lyons, 2015).

### **The Home Hospice Context**

Voices of those offering and receiving care within home hospice have also been underrepresented (Shepperd et al., 2012), and a qualitative lens has been suggested for interrogating these relationships (Funk et al., 2010). Home is where most dying patients—up to 94% internationally and 87% in the United States—prefer to die in place, surrounded by loved ones (Higginson & Sen-Gupta, 2000). Yet only 25% to 31% percent of Americans are actually able to accomplish this (Teno et al., 2004). This breach between patient and family preferences for place of death versus actual place of death, is of increasing concern on personal, clinical, and policy levels (Institute of Medicine, 2015). Home-based hospice increases chances of dying at home by two-fold (Gomes et al., 2014) and serves a majority of female patients (NHPCO, 2012). Yet how quality of women's relationships may influence—or be influenced by—the hospice trajectory is unknown (Solomon et al., 2015), needing exploration to better support the dying and their families.

### **Conceptual Frame**

Underpinning the present study is the empowerment philosophy held within hospice and palliative care (Teno et al., 2004). This philosophy calls for empowering patients and families to drive their end-of-life course as they choose (Gomes & Higginson, 2006; Grande et al., 2009). The patient-focused, family-centered design promotes comfort so families may complete relationships before death (Stajduhar, 2003; Strang & Koop, 2003). Such a family and relational view is particularly salient to women (Berg & Upchurch, 2007; Birditt & Antonucci, 2008).

The interpretive turn, ascribing social construction to reality through lived experiences (Thorne, 2008), likewise infuses this work. “Truths” are assumed to be

subjective, co-constructed interdependently and personally, not objectively derived facts (Reissman, 2008). These assumptions are specifically suited to discourse on female-female relationships. Women construct meaning through an ethic of care (Gilligan, 1982), “therapeutic conversations” (Reissman, 1993, p. vi), and “relationship talk” in caregiving (Badr & Acitelli, 2005). Herein, we offer an overarching, interdependent dyadic view (Linda Thompson & Walker, 1982) of mothers facing death with daughters, socially constructing relationships in the home hospice setting. It is hoped this lens will foster understanding for participants, inform care for future families in hospice, and provide salient areas for emerging research.

### **Aims**

The present interpretive descriptive (Thorne, 2008) study aimed to explore and privilege voices of cognitively intact mothers and daughters actively caring for one another, completing a lifelong relationship in the context of hospice at home. The specific aims were to describe and interpret how mothers and daughters:

- Perceive relationship quality
- Perceive how relationships have developed over time for both partners through health, chronic illness, and hospice care

### **Design and Methods**

#### **Sample and Setting**

Inclusion criteria involved: English-speaking mothers aged 55 or older with decisional capacity and no dementia diagnosis; at home with hospice; with a daughter 21 or older providing any amount of emotional or physical support, both willing to participate. Mothers’ belief that a daughter offered emotional or physical support was



chosen as relationship quality, not physical or even proximate caregiving, served as focus of the study. Geographically distant daughters unable to offer instrumental care were also sought.

All 20 participants (10 dyads) identified as White. Mothers were aged 58-91 ( $M = 79.4$ ; Median = 84) and daughters were aged 31-65 ( $M = 55.3$ ; Median = 60.5). Sixteen participants (eight dyads) resided in the Northwestern United States. The remaining two dyads lived in other western states. Four dyads co-resided. In one of these, living together predated the mother's life-limiting diagnosis. In three, mothers had moved to daughters' homes for end-of-life care. Five of six additional dyads resided 6 to 17 miles apart. The final dyad lived 2500 miles apart. Frequency of contact in all dyads ranged from more than once a day to several times weekly.

### **Procedure**

Following Institutional Review Board approval from the authors' institution, purposive sampling (Creswell, 2013) was employed to elicit emotionally diverse mother-daughter relationships. Home hospice staff, expert informants, and social networking promoted identification of eligible dyads. The first author contacted mothers/daughters who had given permission for her to do so. She explained the study and reassured women participation was not connected to receipt of hospice services. Each woman was also assured as to the confidential nature of interviews, even from the other dyad member. Everyone who agreed to be contacted in this manner volunteered to participate. One in-person, semi-structured, open-ended interview was scheduled (when geographically feasible) at the location of the dyad's choice (usually the home of one or both women). The first author completed individual interviews with each participant from November

2014-November 2015. Due to geographical constraints, two dyads were interviewed via Skype, Facetime, and/or telephone.

Prior to initiating interviews, mothers and daughters signed informed consent. They were encouraged to stop or pause the interview at any time if needed, and no participant chose to do so. Additionally, before each mother's interview the researcher employed an IRB-approved Decision-Making Capacity Assessment protocol. This ensured participants were cognitively intact, able to participate freely and competently in decision-making, and understood consequences of participation. To capture relational perceptions from the same moment in time (and obviate intradyadic discussion of interviews), women were asked to choose who would be interviewed first, then the second woman was interviewed immediately following. Identical mother/daughter interview guides helped facilitate dyadically parallel reflection on relationships. Open-ended probes explored the embedded nature of mother-daughter relationship quality over time and uncovered relational perceptions from both dyad members. Women were asked to describe the story of their relationship, how they came to have this kind of relationship, and how the relationship may have changed from health, through illness, to hospice care. Interviews with mothers lasted from 7 to 52 minutes ( $M = 22.9$  min; Median = 13.5 min). Daughter interviews ranged from 14 to 51 minutes ( $M = 27.4$  min; Median = 24 min). Interviews were recorded via two password-protected devices to ensure capture, and transcribed verbatim. Transcripts were then de-identified and verified.

### **Data Analysis**

Interpretive description, a qualitative methodology developed within the health sciences (Thorne, 2008), uses a clinical lens to give credence to unique and particularistic

experiences of individuals, as well as interpreting across group patterns and commonalities. It is particularly well adapted to “clinically relevant human phenomena” (Thorne, 2008, p. 17) such as family relationships—in this case, dyadically-informed relationships between mothers and daughters in home hospice. Analysis is inductive and reductive; iterative and reiterative to reinforce and challenge initial coding, which is collapsed into categories. Phases of analysis occur simultaneously, yet are described here sequentially. Interpretive description was combined with qualitative dyadic analysis to conceptualize relational perceptions. Researchers used direct responses from two individuals and combined and triangulated these to arrive at an overarching interpretation of the dyadic relationship (Thompson & Walker, 1982). This novel qualitative dyadic approach revealed something overarching and greater than the sum of two parts; the method is described in greater detail elsewhere (Solomon, et al., in review).

Immediately after interviewing each pair, a dyadic vignette was created by the first author. This specialized field note captured impressions of the dyad as a relational unit within its naturalistic context. The first and second authors independently read both transcripts for preliminary interpretations. An intradyadic “crossover” technique developed, tightly analyzing one woman’s responses to interview questions alongside her dyadic partner’s, using constant comparison (Charmaz, 2006). Open coding at this stage focused broadly on categorizing relationship quality: Daughter’s Perception of the Relationship [DPR] or Mother’s Perception of the Relationship [MPR]). Repetitive attention was given to concordance and discordance between the two women’s narratives. Transcripts were also coded for context (e.g. hospice, extended family issues, financial).

The first dyad served as a critical case (Creswell, 2013): it was coded and re-coded for DPR/MPR categories and context iteratively and reiteratively. Coding disagreements were discussed and reflected upon and agreement reached. Co-investigators deliberated and analyzed this case until a distinct dyadic relational story began to emerge. This intradyadic, crossover template was applied identically to subsequent dyads. Several iterations ensued, with any new codes emerging in successive dyads being applied recursively to prior dyads as appropriate.

Transcripts for the first six dyads were uploaded into QSR International's NVivo 11 qualitative software. The first author recursively analyzed all these transcripts once more, "feathering" DPR and MPR categories with descriptors denoting emotional processes comprising relationship quality. These descriptor codes were collapsed into emerging relational styles, themes, and subthemes, until the essential dyadic story of each relationship materialized. This analytic technique was followed for four remaining dyads, with each pair enhancing what had been discovered before, and findings applied recursively to previous dyads as needed, until each fell into a natural place on a nascent relationship quality spectrum. To visualize the analysis along this spectrum, software matrices were created. Frequency counts of categories, styles, themes, and subthemes within and across dyads were compared within matrices to verify findings. Regular meetings between co-investigators and memoing were utilized to encourage reflexivity, to allow discussion of alternate interpretations, and to prevent early foreclosure. After 14 interviews, preliminary results suggested a relationship quality spectrum; interviews with three additional dyads were conducted to build on this scaffolding before recruitment and

data collection were deemed sufficient. Ultimately, interpretations were compared against initial dyadic vignettes and early interpretations. Final adjustments were made as needed.

### **Trustworthiness and Validity**

The following procedures were integral to enhancing rigor, reliability, and validity (Maxwell, 2013; Noble & Smith, 2015) and adapted for a dyadic approach: purposive sampling; identical interview probes to evoke two individual responses to each query; embedded triangulation (two participants reporting on one relationship); a preliminary dyadic vignette to recurse back to throughout for comparison, contrast, and verification; verbatim transcript verification through audio-playback; expert and peer-debriefing with dyadic, qualitative, and end-of-life experts to safeguard validity and decrease bias; decision and audit trails, including field notes, memos, and reflexivity.

### **Findings**

Women socially constructed three primary relational styles along a spectrum, from quite intimate to quite strained. A parallel trajectory emerged from dyads able to negotiate freely and work through difficult issues of life and relationship completion, to those who could not. These styles were named Close Friendship, “Neutral,” and Doing My Duty. All three were informed by interpersonal and emotional processes depicted by themes and subthemes.

#### **Close Friendship**

Five dyads described a relationship characterized by intimacy, enjoyment, and feelings of shared love and comfort. They often employed identical verbiage to describe feelings for one another. Concordant narratives indicated a singular, interdependent dyadic experience—the co-creation of a unique bond. This multi-dimensional, peer-like

relationship involved deep emotionality, understanding, and admiration, as well as an ability to work through inevitable conflict. Women flexibly adapted to meet demands of the changing illness and hospice trajectory. In the following exemplar, a mother with a terminal cancer diagnosis and her daughter describe their bond. (All exemplars have been edited for clarity and anonymity):

Mother: I always knew. It was just an instinct. An inner feeling that we were close. I just knew we were. We confide in each other.... More almost like friend to friend, as well as mother/daughter. Very close.... I guess I would just have to keep rephrasing how much I love her.

Daughter: Just truly, on a day-to-day basis, we are extremely close. To put it in a nutshell, she is my best friend. She's just somebody that—I just—I cherish.

In more than one case, Close Friendship was a change—an outcome of the chronic illness and hospice trajectory itself. In the following, a mother diagnosed with several life-limiting illnesses was motivated to repair her relationship:

Mother: We're very close. We're very good friends. She's a pretty remarkable woman.... I needed to mend bridges with my daughter. I didn't feel as though I had been a very good mother to her, and it was kind of a last opportunity. I started being honest but loving and she responded and we just started developing the relationship we have today. She goes to doctors with me. She takes notes. I bounce things off her all the time. We talk about death. We talk about money. We talk about everything.

Daughter: We've been best friends for the last... years. Before my Mom got sick we barely spoke to each other. She got sick and I moved from suburb to suburb, back home. We just—I took care of her. We've been through a lot together and now she's my best friend. She means the world to me. She's not just my Mom. I can go to her about anything, get her advice, just talk it out. She's everything.

In dyads experiencing Close Friendships, women repeatedly expressed three shared emotional themes bolstering relationship quality—Compassionate Care,

Cherishing Time, and Struggling Together. One subtheme within these themes, Open Communication, also pervaded these narratives.

**Compassionate care.** Mothers dying in hospice in Close Friendship offered active emotional mothering and caregiving to daughters, even while their bodies failed. Women cared for each other and were cared for out of love and desire, vs. duty and obligation:

Mother: It's a little easier now, not quite so much tears. In the beginning when she would talk about it (my dying), she would cry a lot. We're adjusting to each day. We know there's less time and we're adjusting to that as we go. I'm orchestrating.... I did sit down early, and started writing... you're busy, but this is what you're going—these are some things you're going to come across and I just wanted to tell you so you're not quite cold turkey when you go in there. And so... questions that might come up when you talk to the pastor about the funeral service, or when you go to the funeral home. Do you want her hair done? Do you want her nails done? See, I'm still mothering.

Daughter: I think if I was not in her life or I didn't live close, I think it would be very hard for her. I think it would be very hard for her because my Dad is... you know, they can only do so much and then they lose patience. I'm sure I'm a blessing to her because we can talk about how things went during the day when I was at work and just... somebody to talk to because she knows I'm going to call her... every single night. I wish I could be here 24/7 for her.

**Cherishing time.** A consistent theme in women experiencing Close Friendship was a shared perception that time spent with the other was precious and cherished. Time was acknowledged as finite, increasingly valuable due to shared realities of life and relationship completion. The following women lived approximately 2,500 miles apart, yet both committed to ensuring and improving relationship quality during the forshortened hospice trajectory:

Mother: We may be getting closer. She gets in there and gets things... kind of done. I love her.... I'm with hospice simply because of her. I don't know that I would have even known about hospice. I just love her. There

is no other way to say it. She's a super person and I love her to death, and I appreciate all she's doing for me and that's all I can say.

Daughter: We did not have an easy relationship through most of our lives. Because I had the hospice training... (I) was able to start talking to her about dying and things. I think she so appreciated that there was someone that would talk to her about it. And because of that our relationship was able to shift. That just broke everything open. Now we have a relationship that's wonderful. I think we can talk to each other about anything. We're more friends than we ever have been and like equals than we ever have been. I treasure and value her. I feel so grateful to have this time where we transformed our relationship... so grateful to be dropping into the preciousness of this time.

**Struggling together.** As in the last exemplar, women often acknowledged emotional struggles in the relationship and/or during the process of hospice care. But in Close Friendship, the partners struggled together, sharing the vagaries of a rapidly changing trajectory as a team, working through. In this exemplar, a mother's cancer eventuated in her move across the country to live with her daughter, son-in-law, and a grandchild in close quarters. Stresses were inevitable over time, but they chose an identical metaphor to describe both conflict and resolution:

Mother: Yeah, I get mad at her. Especially when she tells me I can't do something that I want to do. I pout. And (she) ignores it. It's like a reversal of mom and kid/teenager. Mom ignores it and kid pouts. And then after it's all out of the system, then it's all over with.

Daughter: Sometimes when she gets frustrated or upset about something, I feel like she lashes out at me because I'm easy. Because she knows I'm not going to be mad at her for long...It's not going to be a lasting thing. There's not going to be any retaliation, I'm going to understand. I compare it to having a teenager and when the teenager is mad at you they don't hate you but they're like, "I hate you. I don't feel good today and you're just being mean to me and I just yell at you"... and run to their room, but then the next day they love you again and you don't have to talk about it. It's just, they're a teenager.



*Open communication.* A prevalent subtheme of Open communication embedded itself within all Close Friendship themes. Each woman felt she and her care partner had always (or due to illness and hospice care had grown in ability to) discuss things freely, including difficult, taboo subjects. In the following exemplar, a severely debilitated mother spoke briefly, for only 7 minutes, yet she described a Close Friendship that her daughter took care to elaborate:

Mother: We have a great relationship.... She's a very warm, giving person.... She's always been a very important part of my life.... I think we both try to be as open with each other as possible.... We're both very reasonable.... (She) is open.... Listens to anything I have to say.

Daughter: If she's anxious about something, which usually happens during the night or late at night, we could talk about it and it just doesn't... it's not relaxing her, you know? I get in bed and just hold her; she puts her hand on my head and she's calm. And I'm calm. And then, one time, she was holding her ring, her engagement ring. And she said "Honey, pick up this ring. It's getting lost." And I said, "It's not lost, Mom. It's right on your finger." And she said, "No, I want it on *your* finger." And I said, "I know you want me to inherit this ring. I know you're leaving it for me, but you know, you're still alive, so I think it really belongs on your finger." And she said, "No, I want to put it on your finger right now. I want to feel it on your finger. It will be easier for me to die knowing it's there." And I said, "Okay." And we took it off her finger and she put it on my finger and she held on to it. And that's it. There it is.

Two dyads located themselves on the relationship quality spectrum at various positions between Close Friendship and "Neutral" (detailed below). These women expressed themes encompassing and intersecting both styles, verifying the interpretation of multi-dimensionality on the spectrum. Every pair earned a unique, unmatched position on the continuum.

### **"Neutral"**

In two dyads, women evoked an emotionally bland, flat quality in the way each responded regarding the relationship. Although they spoke neutrally, subtexts alluded to

something unsatisfying, or wistful. The beginning of an incipient discordance in narratives was distinctive. Instead of one mutually constructed tale, two were created. Also strikingly different from Close Friendships, all denied their relationship had changed in any way due to the longitudinal influences of health, illness, or the hospice context. The following themes and subtheme emerged:

**Emotional Disconnect.** Mild to moderately discordant views between one woman's appraisal of relationship quality and the other's.

**Struggling Apart.** In contrast to Struggling Together: emotional struggles in the relationship or with the process of care had a solitariness to them; an unshared or lonely feel.

**Everything's Rosy.** A theme emergent from mothers only, indicating the relationship was fine, lacking problems. Blanket statements that all was well belied something unspoken, hidden beneath.

**Lack of Communication.** A subtheme evoking the sense that either woman could not or would not discuss issues with her dyadic partner, including emotional and/or end-of-life subjects.

In the following exemplar, all "Neutral" themes and subtheme are evident. A mother with several daughters expressed an almost opposing construction of her relationship with her identified caregiving daughter:

Mother: We've always gotten along good. Our family is very close. We—I don't know what to say about my daughter.... Maybe the reason she took on to take care of me, she's the only one free. She and I don't have arguments, if that's what you mean. I don't know what it would be about. We get along good and we always hug and kiss each other and tell each other goodnight. I have never argued.

Daughter: We have a pretty... good relationship. Not... super, super close.... She wasn't the kind of mom that you didn't sit on her lap and she hugged you. I mean, I'm glad I'm able to spend time with her and help take care of her, but I don't think anything has changed.... I think she appreciates having me here.... The toughest thing is not knowing how long this will go on because it doesn't seem like she really has gotten a lot worse, although she has lost a lot of weight and her pain has increased— It would be nice if we knew, is she going to live 2 months or 2 years, or...?

### **Doing my duty**

In a single dyad no positive themes discovered in other relationships emerged.

Mother and daughter constructed two mutually exclusive, fully discordant narratives. All themes in “Neutral” relationships materialized in this dyad, as well as one additional theme:

**“Very Strained”** An in vivo statement by the daughter that her relationship with her mother had been and still was quite difficult, including past abuse.

In the following, the mother depicted a relationship with a caring and attentive daughter, then seemed to pause with fear, wondering what her daughter may have revealed that might contradict her story. Meanwhile, the daughter unburdened herself:

Mother: She's a very good nurse, an excellent nurse. She took care of me. She took me in her home. We didn't have a very close relationship for awhile, a little hard feelings there for a while, but then it got better, got better, got better. Oh yes, It's gotten a lot better. We talk. I think she'd do anything for me.... Oh, what did *she* say?

Daughter: My mother was more verbally abusive. Other than getting slapped around, you know, grabbed by the hair and shoved into the wall, things like that, she didn't actually cause physical damage. I have a lot of guilt because I feel like you should love your mother and want to take care of her, and that it shouldn't be a responsibility. It should be a love thing.... I have resolved some of my issues, because I needed to resolve the issues, for me. I can't live with that kind of anger. I will never have what you expected as a child. With a mother. I will never, I know now that I will never have that relationship. I went one time for 5 years without talking to her. It was a long time.... I try to be kinder to her than I was before

because I know she's got issues. I know she doesn't have any inner peace. I try to be as kind as I can, try to let the past go, and try to let her have as many choices as she can. I'm trying to do the best job I can with the tools I have and I would never be unkind to her.

And so, two women in a lifelong struggle worked to reconcile opposite narratives as the death of one loomed near.

### **Discussion**

To our knowledge, this is the first study to make vocal, from participants' own voices, a multi-dimensional, interdependent relationship quality spectrum between aging, cognitively intact mothers and care partnering daughters, embedded in the hospice context. Mothers and daughters reported a variety of relational styles along the spectrum, from identically concordant to vastly discordant experiences. Women in Close Friendships cherished time together, engaging open communication and even conflict in the service of bi-directional, compassionate care. Supportive partnerships were maintained and even bolstered along the trajectory of illness, hospice, and approaching death. Yet a minority of "Neutral" dyads failed to meet this ideal, moving along the spectrum with growing emotional disconnect. Relationships did not adapt and improve through the exigencies of care. Daughters endorsed strain while mothers cleaved to rosier narratives. And connections continued to falter, in one dyad suggesting a gaping, discordant halt.

These findings verify and locate themselves well within general caregiving. Healthy relationship quality, as in Close Friendships, is known to buffer incumbent and changing stresses of spousal care (Karen S Lyons et al., 2009; Schumacher et al., 2008). Specific to intergenerational relationships, parents report better relationship quality than children (Birditt, Hartnett, Fingerman, Zarit, & Antonucci, 2015), and a persistent

minority are torn by detachment or destructive conflict (Bengston, 2001). Although intergenerational care is oft-portrayed as unidirectional, moving upstream only from offspring to parent (Fingerman, Sechrist, & Birditt, 2012), mothers and daughters are known to evince bi-directionality, both emotionally and practically (Fingerman, 2003). Most enjoy positive relationships as well as normative conflict (Martini et al., 2001; Pohl et al., 1997), but a consistent minority are locked into negative bonds (Hollis-Sawyer, 2001; McGraw & Walker, 2004). And although deterioration to the level of caregiver abuse (Pickering, Moon, Pieters, Menten, & Phillips, 2015) was not uncovered here, distressed relationships were, suggesting a critical focus for further study and intervention.

A novel, multi-dimensional relationship quality spectrum would have remained invisible if a deeply immersive, dyadic and contextualized qualitative approach had not been employed. Although discrete styles of positive-negative mother-daughter caregiving relationships have been described (Hollis-Sawyer, 2001; McGraw & Walker, 2004; Walker & Allen, 1991), these approached relationships with a priori models of social exchange (Walker & Allen, 1991), autonomy and conflict (McGraw & Walker, 2004), or binary positive-negative relationships (Hollis-Sawyer, 2001). They all (Hollis-Sawyer, 2001; McGraw & Walker, 2004; Walker & Allen, 1991) called for deeper investigation of multi-dimensional aspects of relationship quality. The present spectrum, with layers of emotionally transacted processes contributing to (or detracting from) relationship quality, begins to fill this gap, as does discovery of how individual and dyadic perceptions qualitatively and steadily diverged along the continuum.

These findings contextually develop and locate mother-daughter relationships within and along the hospice trajectory. Spousal relationships, with primarily female caregivers in home hospice, have been shown to range in relationship quality, with healthy relationships being maintained or improving (Stajduhar, Martin, Barwich, & Fyles, 2008), and strained bonds maintained or deteriorating (Stajduhar et al., 2008). The present work reinforces this knowledge in the intergenerational context of mothers and daughters—the most prevalent caregiving dyad. Emotional support (Teno et al., 2004) identified as essential to quality of death within hospice, can now be applied to improving relational outcomes.

### **Implications for Practice and Research**

Relationship quality holds implications for caregiving in hospice, as well as beyond (into bereavement). Family caregivers already in home hospice (three-quarters of whom were women), enjoyed better emotional wellbeing in bereavement than caregivers of those who died in hospital, with less complicated grief, post-traumatic distress (Wright et al., 2010) and depression (Bradley et al., 2004). Although these prior researchers did not specifically address relationship quality, women in “Neutral” and Doing My Duty relationships deserve future assessment for psychiatric sequelae. The caregivers appeared emotionally detached, struggling to reconcile a rosy maternal narrative against their own. Mothers glossed over or concealed, conceivably even from themselves, troubled relationships daughters revealed. Perhaps mothers rewrite lives and relationships to make peace with themselves before death, denying the truth of daughters’ experience. These women deserve hospice identification and possible treatment. Although deathbed transformation of a long-troubled relationship is unlikely, small professionally facilitated

efforts might offer comfort to one or both women, including daughters after a mother's death.

This study employed individual relational perspectives to construct singular as well as dyadic views of mother-daughter relationship quality in hospice. What was revealed at the individual level—whether concordant or vastly discordant narratives—could be triangulated at the dyadic level to offer a rich, deeply textured picture of relationships. Such complexity would have remained largely invisible at the level of individual informants (e.g., caregivers) alone. This individual and dyadic approach to relationship quality might be carried forward and refined qualitatively, then applied to further dyadic and family constellations. Qualitative avenues could inform mixed methods dyadic work, using Multilevel Modeling (Sayer & Klute, 2005) or the Actor-Partner Interdependence Model (Cook & Kenny, 2005). For example, poorer relationship quality predicts unwillingness in future family caregiving (Rohr & Lang, 2016). Might “Neutral” or Doing My Duty relationships negatively predict preferred place of death, and Close Friendships predict preferred place? Answering such questions can help patients and families craft the end-of-life course they desire. A longitudinal view, following patient and caregiver relationships across the hospice trajectory (including bereavement), and/or intervening to improve relationship quality, would also be beneficial.

### **Limitations**

The present study, as qualitative, is limited by size. Although additional participants were sought, the fragile, insular context of end-of-life hospice care at home complicated recruitment. A homogeneously white sample cannot speak to multi-cultural

or cross-cultural experience, perspectives essential to explore. Likewise a multiplicity of diagnoses and geographic locations is needed. The work is also cross-sectional and captures relationship quality from one subjective point in time, even as respondents were probed regarding long-term changes.

Yet this study described and interpreted a multi-dimensional, mother-daughter relationship quality spectrum within the dynamic, interdependently transacted context of hospice, adding to what is known regarding needs of mother-daughter care dyads at end of life. A spectrum has been sketched, and future work can more firmly map divergent voices upon it. It is hoped healthy life completion for mothers—and relationship completion for mothers and daughters—lies in closer reach for women dedicating themselves to the emotional richness of caregiving at life's end.

### **Conclusion**

A qualitative, dyadic approach to aging mothers in hospice and adult daughters revealed a multi-dimensional relationship quality spectrum. Along this spectrum women worked toward life and relationship completion, emotionally struggling together or struggling apart. Sometimes fundamentally transforming relationships for the better during the illness and hospice trajectory, a minority could not, leaving women at risk for emotional distress, possibly into bereavement. Individual as well as dyadic approaches to further assessing mother-daughter dyads in hospice—particularly in troubled pairs—is called for to meet any unique needs they may have.



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## **Chapter V**

### Summary and Discussion:

This section represents a significant contribution to the dissertation work: it replaces aspects of the traditional discussion chapter. It will summarize findings across manuscripts and discuss implications for research and practice.

By 2060, the population of Americans over 65 will more than double, the majority of whom will be women (Administration on Aging, 2016). Currently, 60+ million Americans provide care to these older adults; a full two-thirds of these, women caring for aging mothers (Feinberg, Reinhard, Houser, & Choula, 2011). Fifty-four percent of hospice recipients are also women (National Hospice and Palliative Care Organization, 2015)—an untold number of them mothers. It has long been known relationship quality in care dyads is critical to emotional outcomes such as distress (Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Hudson, 2013; Zaider & Kissane, 2009), depression (Bookwala, 2009; Pinquart & Sörensen, 2006; Pinquart & Sörensen, 2004; Shim, Landerman, & Davis, 2011), and anxiety (Henriksson, Carlander, & Årestedt, 2014; Linderholm & Freidrichsen, 2010; Singer, Bachner, Shvartzman, & Carmel, 2005; Zhang & Siminoff, 2003). Yet how relationship quality impacts mother-daughter care dyads remains underexplored, particularly in dyads not impacted by cognitive disorders, in the hospice context (Solomon, Hansen, Baggs, & Lyons, 2015). Increased understanding of how this caregiving dyad transacts lifelong relationships, for better or worse, within hospice, is essential to addressing their needs and improving care for the dying and their families (IOM, 2015).

The overarching purpose of this body of work was to describe and interpret how cognitively-intact mother-daughter dyads perceive relationship quality within the hospice context. The manuscripts synthesize extant literature, privilege mothers' and daughters' voices, describe their relationships, and interpret how relationships may change along the health, through illness to hospice trajectory. Originally, aims were: a) to conduct a

systematic review to examine the role of relationship quality on the wellbeing of cognitively intact, aging mother and adult daughter care dyads and to investigate how this relationship may be affected by the care context; b) to interpret and describe how mothers and daughters perceived relationship quality both for themselves and each other, as well as how they perceived relationships may have changed over time; and c) to use the narrative and interpretive turn to create composite narratives of mother-daughter dyads in the home-hospice context.

**Table 1. Specific Aims and Corresponding Manuscripts**

Specific Aim	Corresponding Paper
Synthesize existing literature on non-cognitively impaired aging mother-adult daughter care dyads and explore how relationship quality may: <ol style="list-style-type: none"> <li>1. Affect the well-being of the mother-daughter care dyad and</li> <li>2. Influence, as well as be influenced by, the care trajectory itself</li> </ol>	Chapter 2: <i>Relationship Quality in Non-Cognitively Impaired Mother- Daughter Care Dyads: A Systematic Review</i> ; Solomon, D. N., Hansen, L., Baggs, J. G., & Lyons, K. S. (2015). <i>J Fam Nurs</i> , 21, 551–578. doi:10.1177/1074840715601252
<ol style="list-style-type: none"> <li>3. Review the state of the science on qualitative dyadic research</li> <li>4. Develop a replicable, qualitative approach for capturing the rich nuances of dyadic relationships</li> </ol>	Chapter 3: <i>Underexplored Territory: Qualitative Dyadic Research</i>
Describe and interpret how non-cognitively impaired aging mother-adult daughter care dyads in hospice: <ol style="list-style-type: none"> <li>5. Perceive relationship quality</li> <li>6. Perceive how relationships have developed over time for both partners through health, chronic illness, and end of life</li> </ol>	Chapter 4: <i>It's All About the Relationship: A Qualitative Exploration into Non-Cognitively Impaired Mother-Daughter Care Dyads in Hospice at Home</i>

However, during the dissertation research, certain aims shifted (see Table 1). A literature review was published, with aims as planned, on non-cognitively impaired aging mother-adult daughter care dyads, exploring how relationship quality may affect well-

being of the dyad and the care trajectory. A method was needed, however, for a comprehensive approach to the qualitative dyadic dissertation research and none was found in the literature, so one was developed in a second manuscript to review the state of the science and develop a replicable template for future research. This manuscript replaced the original third, composite narrative manuscript as described in the introduction to the dissertation, which had aimed to explore and reveal social constructions of relationship between mothers and daughters in hospice. Finally, the original second manuscript—with aims to dyadically describe and interpret how women perceived relationship quality for themselves and each other, as well as how relationships may have changed over time within hospice—became the third and last manuscript. While it was hoped this manuscript could describe and interpret how women perceived the other dyad member perceived relationship quality, findings were not robust enough to do so, and this original aim was dropped. The present chapter will summarize findings across manuscripts in a narrative fashion, and discuss salient contributions of the work, contextualized within the science.

## **Discussion**

### **Systematic Review of Literature on Relationship Quality in Non-Cognitively**

#### **Impaired Mother-Daughter Care Dyads**

Consistent with literature on relationship quality in non-caregiving mother-daughter dyads, in 19 articles surveyed, when relationship quality was positive, women enjoyed rewards and mutuality even as conflict occurred (Fingerman, 2003). Yet novel to this review, relationship quality impacted the care trajectory: daughters grew more emotionally committed to mothers' over the care course, despite increasing demands.

Daughters' commitment deepened as mothers further declined. Meanwhile, as mothers physically deteriorated, they remained active emotional partners to daughters throughout.

Yet in a minority, relationship quality proved ambivalent or negative. Burden, conflict, blame, and unconcern for one's partner predominated. These dyads remain understudied, deserving investigation before successful interventions might be designed. Further, only eight studies investigated both mothers and daughters on the level of the dyad (Hollis-Sawyer, 2001; Kim, Wellisch, & Spillers, 2008; Martini, Grusec, & Bernardini, 2001; McGraw & Walker, 2004; Shawler, 2007; Walker & Allen, 1991; Walker, Pratt, & Oppy, 1992; Walter, 1991). Finally, not a single article of 19 focused on end of life—a context imperative to providing adequate, if not improved, care to the dying and their families (IOM, 2015). Future studies dyadically exploring mother-daughter relationship quality in hospice—and qualitative methods to do so—were found wanting.

### **Methods: A Comprehensive Qualitative Dyadic Relational Research Approach**

Coherent with qualitative research and emergent design (Creswell, 2013), an approach was required to analyze data qualitatively while staying true to the dyad as the unit of analysis. Although quantitative science has advanced methods of dyadic analysis such as the Actor-Partner Interdependence Model (APIM; Cook & Kenny, 2005) and Multilevel Modeling (Lyons & Sayer, 2005), only one extant qualitative dyadic analytic method exists (Eisikovits & Koren, 2010). Further, Eisikovits and Koren (2010) did not integrate dyadic conceptualization, aims, procedures, and interpretation throughout. A comprehensive approach was developed for the dissertation, and then captured for the first time in a manuscript to serve future research.

To accomplish this, Thompson and Walker's approach (Thompson & Walker, 1982) was adapted as a template. "First-order" individual transcript data was extracted and triangulated into a "second-order" researcher's dyadic interpretation. Traditionally, Thompson and Walker (1982) endorsed using one or two respondents—either or both reporting on relational constructs (e.g., complementarity, mutuality, interdependence). They also outlined (Thompson & Walker, 1982) several ways to elicit individual (not relational) characteristics about the other dyadic respondent that did not apply to relationship quality. Within the dissertation, a more streamlined adaptation of Thompson and Walker was maintained: two respondents were required to report on dyadic relationship quality in all cases—not to report on individual or personality characteristics—but on the relationship itself. Two respondents reporting on one relationship was assumed herein to offer the ideal in dyadic research, as interdependence cannot be studied fully at the level of the individual. Dissertation transcripts provided exemplars to conceptualize dyadic aims, a systematic process to data collection, a replicable coding and cross-person analytic template, interpretation, and attention to qualitative rigor. The exemplar offered an overarching portrait of the dyad beyond and in addition to what individual transcripts can provide.

### **It's All About the Relationship: An Exploration into Non-Cognitively Impaired Mother-Daughter Care Dyads in Hospice at Home**

A prospective, descriptive, qualitative dyadic investigation of relationship quality in ten aging mother-adult daughter hospice dyads culminated the work. Specific aims were to describe and interpret how women perceived relationship quality, and how they perceived relationships had changed over time from health, through illness, to hospice.

Interpretive description (Thorne, 2008)—a qualitative methodology focused on discrete relationships while making discovery transferable to the health sciences—underpinned the study. Likewise the philosophy of social constructivism (Reissman, 2001) and the philosophy of hospice and palliative care. The palliative/hospice philosophy centers patient and family as the unit of care (National Hospice and Palliative Care Organization, 2015), providing emotional support and empowering patient and family wishes (National Hospice and Palliative Care Organization, 2015). With an emphasis on life and relationship completion (Byock, 1996; Irwin & Ferris, 2008), family relationships (von Gunten, 2012), and human development through end of life (Salmon, Kwak, Acquaviva, Brandt, & Egan, 2005; Steinhauser, Christakis, Clipp, & McIntyre, 2000; Teno et al., 2004), the precepts of hospice and palliative reinforced the study of relationship quality between mothers and daughters in the home hospice setting.

For a small qualitative study, findings were robust. They reinforced what is known regarding healthy mothers and daughters in caregiving (Merz, Schuengel, & Schulze, 2009), what had been found in the literature review on cognitively intact mother-daughter care dyads (Solomon et al., 2015), and what is known about mother-daughter dyads outside the caregiving context (Fingerman, 2003). The qualitative lens revealed something new, however: a multi-dimensional spectrum of care dyad relationships across the hospice trajectory. In home hospice, where family relationships (National Hospice and Palliative Care Organization, 2015; Stajduhar, 2003), human development through end of life (Salmon et al., 2005; Steinhauser et al., 2000), and life and relationship completion (Irwin & Ferris, 2008) are prioritized, mothers and daughters struggled together or struggled apart. Relational styles diverged along a continuum from



intimate, concordant narratives in Close Friendships, to increasingly strained, discordant relational perceptions in “Neutral” and Doing My Duty dyads.

### **Methodological, Theoretical, and Practical Contributions**

**Methodological contributions.** Within the context of the “silver tsunami” and this ubiquitous, mother-daughter caregiving dyad, implications of understanding dyadic relationship quality cannot be underestimated. Calls for dyadic research have been fairly consistent in quantitative science (Carr & Springer, 2010), and employed with increasing sophistication (e.g., Lyons & Sayer, 2005). But qualitative science has not kept pace. Evident in the systematic review, less than half of studies employed the dyad as the unit of analysis. Only one quantitative work did so (Kim et al., 2008), and no qualitative researchers engaged a well explicated, qualitative dyadic method.

The present work moves science forward, particularly qualitatively, towards a comprehensive dyadic approach to relationships in any dyad. This approach emphasizes overarching, triangulated views of two informants reporting on one relationship. With an individual view, life and relational biases of a single individual preempt a full dyadic portrayal. During triangulation with a partner’s report, however, individual perceptions are revealed in relief, compared and contrasted alongside a partner’s. Hearing from both members makes the intangible tangible. Something greater appears: an interpretive, higher order relational portrait.

Further, the novel qualitative dyadic approach offers a template for replicability. Such an approach can be applied to additional dyads—intergenerational, spousal, educational, and so on. This approach can inform quantitative discovery as to deeper emotional processes impacting relationships. In the future, it may be expanded to multi-

adic investigations as well, wherein relationships affecting more than two family members can be empirically triangulated and richly revealed.

**Theoretical contribution.** Theoretically, one particular conceptual model—Berg and Upchurch’s (2007) Developmental-Contextual Model of Couples Coping with Chronic Illness Across the Adult Lifespan—was originally employed to conceptualize mother-daughter relationship quality at the level of dyadic adjustment and coping. But in line with emergent design (Creswell, 2007), a concern developed that fitting emerging data to test Berg and Upchurch’s (2007) well-developed model of dyadic coping and adjustment may have excluded findings arising in the field. In consultation with the dissertation chair, the lens was widened and opened to social constructivism. The social constructivist, bi-directional, interdependent view of relationships in real time has been purported from cradle to grave (Beebe & Lachmann, 1998; Berg & Upchurch, 2007; Carstensen, 1991; Charmaz, 2006). After the fact, Close Friendship, “Neutral,” and Doing My Duty relationship styles suggest interaction with Berg and Upchurch’s (2007) Developmental-Contextual Model. These implications will be addressed below, alongside Bengston and Kuyper’s (1971) Intergenerational Stake Hypothesis.

**Practical contribution.** A qualitative dyadic approach gave birth to an unprecedented spectrum of mother-daughter relationship quality styles within hospice. While it was known troubled dyads existed, both intergenerationally (Bengston, 2001; Birditt et al., 2015) and in the mother-daughter literature review (Solomon et al., 2015), previous typologies (Hollis-Sawyer, 2001; McGraw & Walker, 2004; Walker & Allen, 1991) did not focus discretely on relationship quality, and were set outside the end-of-life context. The present work located itself within and reinforced prior research (Solomon et

al., 2015). Yet this research expanded upon what was known, advancing a dyadic, relationship quality approach and findings within hospice. Clinically, this qualitative dyadic approach—and end-of-life contribution—is essential to improving care to mothers in hospice and daughters. The intimate, relational view of what transpires when life's end looms can increase sensitivity of hospice staff. Understanding positive and fulfilling relationships, as well as emotionally challenging ones, is essential to compassionate and individualized care for every dyad.

Contemporaneously, critical and intersecting tensions exist in current end-of-life care. On one side lies medicalization of death and dying (Poulose, Do, & Neo, 2013); on another: human development through end of life (Teno et al., 2004). On a third: exploding demographics of aging and dying (Administration on Aging, n.d.); and a fourth: the vast majority of terminally ill, who prefer to stay home and die in place, surrounded by loved ones (Beccaro et al., 2006; Gomes, Calanzani, Gysels, Hall, & Higginson, 2013; Tang, 2003). The present work contributes to timely discourse. Listening to narratives and needs of experts—patients and family members themselves—is essential if they are to reclaim the power, dignity, and ability to drive their end-of-life course in the way they choose.

## **Summary and Implications**

### **Summary**

This manuscript dissertation integrated what is known on cognitively-intact, aging mother-daughter care dyad relationship quality, and created an innovative method for interrogating women's intimate (and not-so-intimate) dyadic constructs of relationships in hospice. While prior work intimated what occurs in aging mother-adult daughter

relationships outside the care context, and even within it, the present work evinced relational styles along a spectrum, from quite intimate, concordant Close Friendships, to discordant “Neutral” and Doing My Duty pairs. Layers of emotional processes were revealed within styles. Women struggled—together or apart—toward life and relationship completion.

As an integrated whole, these three manuscripts queried relationship quality through distinctive avenues called for by gaps in the literature. Initially, an original relationship quality literature review was conducted on this most prevalent caregiving dyad, and no literature regarding end-of-life was found. Second, a comprehensive, replicable qualitative dyadic approach did not exist, but was created to explore and empower the underrepresented family voices within hospice (Shepperd, Wee, & Straus, 2012) of mothers and daughters. Third, a prospective, descriptive, qualitative dyadic work, for the first time, privileged mothers and daughters constructing relationships in hospice, both reinforcing and extending existing knowledge. These steps were essential to discern and meet present and future research and clinical needs of patients and families at end of life (IOM, 2015). Within the context of what was found scientifically wanting—inquiry into relationship quality in the most prevalent caregiving dyad; qualitative dyadic methods to explore the dyad within hospice; and a spectrum of relationship quality to guide future care and research—this dissertation answered questions. Further, it did so within the frames of social constructivism and hospice at home.

### **Implications for Healthcare**

A qualitative dyadic approach centered mothers and daughters as experts of care in a context—home hospice—which aims to do the same (National Hospice and

Palliative Care Organization, 2015). Healthcare providers would do well to keep them there. Providers can identify relational styles, prioritizing life and relationship completion within the developmental and supportive frame of hospice (Shepperd et al., 2012). In Close Friendships, perhaps not much needs to be done. Assisting dyadic communication of deeply held thoughts and feelings may foster end-of-life work so nothing remains unsaid (Prince-Paul, 2008). Likewise, mothers might be educated regarding importance of their emotional contributions to daughters, even as they physically decline (Solomon et al., 2015). This may relieve a sense of burden, and increase feelings of lifetime accomplishment.

Yet in “Neutral” and Doing My Duty dyads, nursing and mental health staff could enhance these approaches, identifying those at risk for emotional sequelae. Implications for mothers and daughters may differ. If receptive, gently-facilitated discussion and life-review (Steinhauser et al., 2000) might foster mothers’ developmental work toward life and relational healing (Byock, 1996; Irwin & Ferris, 2008). Composition of tolerable end-of-life narratives—while being encouraged to listen to daughters’ perspectives—may prove fruitful as well (Byock, 1996). For daughters, valuing caregiving as an important contribution while accepting personal limits may be critical to preventing elder abuse or a need to relinquish care (Pickering, Pieters, Mentes, Moon, & Phillips, 2015). Daughters in strained relationships could be assessed and cared for in bereavement, as they may be especially at risk for psychological sequelae (Barry, Kasl, & Prigerson, 2002; Wright et al., 2008). As opposed to mothers whose emotional needs cease at death, living past the demise of a lifelong relational partner may leave daughters naturally more vulnerable.

It must be acknowledged that in many relationships, mothers or daughters—or both—may not invite intervention. Dyads might be mismatched by personality (Irwin & Ferris, 2008), attachment style (Carpenter, 2001), or life circumstance. Yet perhaps they have made peace, accepting a less emotional bond (Hollis-Sawyer, 2001; McGraw & Walker, 2004) or using self-protection against emotional distress (Pickering, Moon, Pieters, Mentes, & Phillips, 2015). One may be willing to work toward improvement of relationship quality and the other not (McGraw & Walker, 2004). Hospice staff must honor each where they are, remaining open to individual or dyadic changes in receptivity to emotional intervention all along the hospice trajectory.

### **Implications for Research**

**Dying at home and bereavement.** While most prefer to die at home (Higginson & Sen-Gupta, 2000), roughly half of Americans die in hospitals, and a quarter in long-term care (Gruneir et al., 2007). Family members, often surveyed, report care in acute and long-term settings is inferior to home hospice (Wright et al., 2016). Yet patients are frequently excluded from this debate (Andersson, Hallberg, & Edberg, 2008). Evolving medical needs (Andersson et al., 2008), end-of-life developmental work of focusing inwards (Andersson et al., 2008), and protection of vulnerable populations makes this understandable. Yet dyadic approaches, both qualitative and quantitative, across all end-of-life settings and trajectories, are essential to fostering quality of death and dying. To elicit a complete view of human relationships, we must ask dyads themselves—both in hospice and contexts less likely to foster family support (Teno et al., 2004)—what creates, improves, or detracts from relationships, and what facilitates optimal end-of-life care. This includes during crises such as symptom management, family pressures, or

setting transfers. This research can help move the needle back, from the current medicalized approach to death to a home-based, patient- and family-centered end-of-life transition (Ward-Griffin, McWilliam, & Oudshoorn, 2012). This is especially important to make hospice accessible to the majority still unable to avail themselves of hospice—diverse and marginalized populations (National Hospice and Palliative Care Organization, 2015).

Following daughters into bereavement—in both healthy and troubled dyads—is also essential to emotional recovery beyond a mother’s death. Perhaps Close Friendships quantitatively predict better bereavement outcomes than “Neutral” and Doing My Duty dyads. Meanwhile, “Neutral” and Doing My Duty relationship styles might predict daughters at risk for post-traumatic grief and other psychological consequences (Wright et al., 2010). Healthcare providers could then target bereavement efforts toward these daughters at risk, thereby improving outcomes. Tackling these questions is essential to improving numbers of those able to die at home as they wish, as well as improving outcomes for patients and family members within hospice and beyond.

**Methodological implications.** Dyadic triangulation of one account with another reveals higher-order findings that can and do influence the care trajectory. A patient’s individual perception of—for example—communication with hospice staff may differ from a care partner’s, and impact quality of care (Holdsworth & King, 2011). Triangulating these views—and the inherent complexity of insight that emerges—may streamline end-of-life care and/or relational repair more rapidly than a traditional individual approach to research might.

Inquiring into higher levels of relational complexity are also called for by a qualitative dyadic view. In this work, one partner's perceptions of the other's relational view was probed, yet findings were not robust enough to interpret. Further investigation into cross-perceptions of relationship quality could affect feelings of emotional safety within a relationship (Berg & Upchurch, 2007) and should be pursued. A qualitative dyadic view into additional understudied, non-spousal dyads (Pinquart & Sörensen, 2011) also deserves investigation, as needs may differ (Pinquart & Sörensen, 2011). These dyads might include added intergenerational permutations, and fictive kin. Moving beyond dyads to triangulating multiple family relationships is essential, as family systems impact care (Ayres, Kavanaugh, & Knafel, 2003). Utilizing qualitative dyadic analysis to inform quantitative inquiry in mixed methods research offers possibilities as well. In addition to ideas outlined above for daughters in bereavement; for mothers, Close Friendships might predict ability to die in one's preferred place of death. Or, "Neutral" and Doing My Duty dyads might predict greater likelihood of being transferred to long term care. Finally, methodological challenges of recruitment in hospice deserve attention. Principal investigators who work in or are experienced with hospice or end-of-life settings, and staff involvement as recruitment contributors, can enhance future work.

**Theory.** Although emergent themes (e.g., Compassionate Care, Cherishing Time, or Emotional Disconnect) broadened beyond dyadic adjustment and coping as in Berg and Upchurch's (2007) well-developed Developmental-Contextual Model, Berg and Upchurch's (2007) Model offers research potential. The model encompasses dyadic coping configurations of *uninvolved*, *supportive*, *collaborative*, and *controlling*. While these differ from relational styles discovered herein, they may overlap. Close Friendships



and collaborative configurations both involve shared problem-solving. Dyads between Close Friendship and “Neutral” styles could hold similarities to Berg and Upchurch’s supportive partnerships, where partners offer support, but are not actively involved. While no dyads suggested uninvolved or controlling partnerships, perhaps with greater numbers of respondents, similar dyads would have emerged in the present work. Berg and Upchurch’s configurations could be tested with relational styles found herein, or vice versa. For instance, might differences between relational styles discovered here and Berg and Upchurch’s coping configurations be a function of gender (two women in a dyad here, vs. heterosexual couples, as in Berg and Upchurch)? Or of family relationship (intergenerational here, vs. intimate partnerships in Berg and Upchurch)? Further investigations could strengthen and clarify both the relationship quality spectrum here and Berg and Upchurch’s Model, advancing the science.

Theoretically, the tendency for mothers to view relationships more positively than daughters in “Neutral” and Doing my Duty relationships also evokes the Intergenerational Stake Hypothesis (Bengston & Kuypers, 1971; Birditt et al., 2015). This theory assumes parents perceive relationships as more healthy and important than adult children do (Bengston & Kuypers, 1971). Quantitatively, multilevel modeling has recently been used to support and expand this theory (Kim, Zarit, Birditt, & Fingerma, 2014). Dyadically digging down into relationships with a qualitative lens, however, exploring exactly *how* parent-offspring perceptions differ, could further expand the reach and utility of the Intergenerational Stake Hypothesis, potentially improving quality of life for families through end of life.

For example, knowing mothers and daughters comprise the largest number of care dyads (Feinberg et al., 2011), and informed by the mother-daughter relationship quality spectrum here, intergenerational gender differences in the Intergenerational Stake could be explored. Mothers, as opposed to fathers, are known to hold greater intergenerational stake as they tend to provide lifelong caregiving and identify with parenting more than fathers do (Fingerman, Sechrist, & Birditt, 2012; Rossi, 1993). Qualitatively exploring how the Intergenerational Stake is different in mother-daughter dyads along the care trajectory might lead to advanced relational interventions in this most prevalent dyad. Further, outlier dyads provide ideal focus for qualitative exploration (Warren-Findlow, 2013). Mother-daughter dyads who, for instance, reveal a reverse pattern—with daughters viewing relationships more positively than mothers—could provide a perfect target for qualitative dyadic research as well as further testing and development of the Intergenerational Stake.

### **Strengths and Weaknesses**

As with all transitions, the present work creates a beginning. Many of its strengths have been delineated. Reinforcing and expanding the mother-daughter—and qualitative dyadic—literature into the caregiving and hospice trajectory provided additional power. While most mothers and daughters enjoy positive, though complex relationships, we now know more. In hospice, some work to deepen and complete relationships due to a foreshortened future. A minority emotionally disconnect, with increased burden, less rewards, and a tendency for mothers to hold more positive views than daughters. While strained dyads exist outside the end-of-life context, this is the first study to reveal how women perceive relationships as death approaches: rosier for mothers, while daughters

may long for a relationship that never was. These findings expand the knowledge base for further discovery.

Yet limitations and weaknesses are inherent. Greater diversity and deeper views of troubled dyads are essential to develop relational styles so knowledge of these styles might improve care. Recruitment in hospice proved challenging, and more dyads are essential to deepen the work. Although participants retrospectively spoke to changes along the health through illness to hospice trajectory, this work was cross-sectional. A longitudinal lens is needed to explore how healthy relationships prosper, where troubled ones diverge and falter, and what might offer promising targets for intervention.

Sampling diversity is at issue, as well as in the pre-existing literature on mothers and daughters. Few researchers recruited a diverse mother-daughter sample (Carpenter, 2001; Hollis-Sawyer, 2001; Raveis & Pretter, 2005), and none focused on differences in populations. Yet nearly one-quarter of Americans now identify as non-White (United States Census Bureau, 2014). If researchers themselves do not reflect this, it is imperative they reflect it in their work. This includes diversity in age, gender, race, ethnicity, religion; geographic location and cultural context; diagnoses and life expectancy, to name a few. As noted, those who die at home are predominantly White, with greater resources and access to social support (Gruneir et al., 2007). It is not until we hear voices of those unlike ourselves that we might be able to understand; and only then forward knowledge and human outcomes for the dying and their families.

In these ways and others, the science of relationship quality in one prominent caregiving dyad has begun. A dyadic approach revealed more than an individual lens can offer, and is championed as a tool for discovery well beyond this dyad and setting. The

rewards of discovery—and of revealing stories from the experts who have much to tell if they are privileged to do so—are untold and waiting.

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## Appendix A

### Consent Form for Human Subjects



**IRB#: 10828**

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### Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later.

1. The purpose of this study is to learn more about relationships between mothers and adult daughters when the mother is in hospice, and how this relationship might have changed over time.
2. We want to learn how mothers and daughters:
  - Perceive relationship quality
  - Perceive how their relationship has developed over time for both partners through health, chronic illness, toward the end of life, including the ability to stay at home with hospice
3. Everyone who joins the study will be interviewed separately and privately, in-person or over telephone, Skype, or FaceTime, as she prefers, at a time that is most convenient for them. Interviews with mothers will be shorter, about 15-20 minutes, unless she wishes to speak longer. Interviews with daughters will be approximately 40-50 minutes, unless the daughter wishes to speak longer.
4. If you join the study, you will complete one interview, and possibly two if you would like a second interview, or if the investigator thinks it may be helpful, but only if you agree.
5. Every care will be taken to make sure audio-recorded interviews are kept completely confidential. They will be kept on a password-protected computer or iPhone, uploaded to a secure website for transcription, and doubly password-protected after transcription. There is a small risk of breach of confidentiality. There is also a risk that an interview about personal relationships may be upsetting. If you do become uncomfortable for any reason during an interview you may ask the investigator to take a break or turn off the audio recording.
6. If you agree, information collected during the study may be saved for future research





**IRB#: 10828**

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### **Research Consent and Authorization Form**

**TITLE: Mother-Daughter Care Dyad Relationships in the Context of Hospice at Home**

**PRINCIPAL INVESTIGATOR:** Lissi Hansen, PhD, RN (503) 418-3357

**CO-INVESTIGATORS:** Diane Solomon, MSN, CNM, PMHNP (503) 329-8315

**PURPOSE:**

You have been invited to be in this research study because you are a mother in hospice or you are an adult daughter of a mother in hospice. The purpose of this study is to learn more about relationships between mothers and adult daughters when the mother is in hospice, and how this relationship may have changed over time. About 12-20 mothers and daughters will participate.

**PROCEDURES:**

Enrollment in this study involves participation in one, or two, interviews. The interview will be conducted in person or by telephone, Skype, or Facetime at a location of your choice, usually at home. These interviews will be done with you alone, unless you prefer your daughter (or mother) also be present. You will be invited to speak freely and asked, for instance, to "tell about your relationship with your mother/daughter," and any changes that may have occurred in your relationship over time. The interview will be shorter if you are a mother, about 15-20 minutes, to conserve your energy, unless you choose to speak longer. If you are a daughter, the interview will last approximately 40-50 minutes. You may request a second interview for any reason, if you like, or the research investigator may ask for a brief second interview to clarify or get further information, but only if you are willing. Interviews will be very conversational and will be audio recorded and transcribed for analysis.

You may stop the interview at any time for any reason. You may also request audio recording be turned off, and are welcome to refuse to answer any question. Your interviews will be completely confidential from each other, though of course you may share whatever you like with each other.

If you have any questions, concerns, or complaints regarding this study now or in the future, you may contact Lissi Hansen, PhD, RN (503) 418-3357 or Diane Solomon, MSN, CNM, PMHNP (503) 329-8315.

**RISKS AND DISCOMFORTS:**

Some interview questions may seem personal or embarrassing. This may upset you. You can refuse to answer any question you do not wish to answer. If the questions make you upset, we can take a break or even, with your permission, help you to find a counselor.

**BENEFITS:**

You may or may not personally benefit from being in this study. However, by serving as a participant, you may help us learn how to benefit mothers and daughters in the future. Research has shown that mothers and daughters may benefit from reflecting on their relationship as well.

**ALTERNATIVES:**

You may choose not to be in this study.

**CONFIDENTIALITY:**

We will take all steps to keep your personal information confidential. Every care will be taken to make sure audio-recorded interviews are kept completely confidential. They will be kept on a password-protected computer or iPhone, uploaded to a secure website for transcription, and doubly password-protected after transcription. There will be no personal identifiers on any hard copy or electronic files.

The investigators may use the information we collect for this research study and/or future research or writings such as articles or books. We will not release information about you to others, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes, unless we have your special permission.

**COMMERCIAL DEVELOPMENT:**

Unidentified parts of interviews obtained from you in this research may be used for commercial purposes, such as making a book, which could result in a possible financial benefit to that company, OHSU, and its researchers. There are no plans to pay you if this happens. You will not have any property rights or ownership or financial interest in or arising from products or data that may result from your participation in this study. Further, you will have no responsibility or liability for any use that may be made of your information.

**COSTS:**

There will be no cost to you or your insurance company to participate in this study.

**LIABILITY:**

If you believe you have been injured or harmed as a result of participating in this research and require treatment, contact Lissi Hansen, PhD, RN (503) 418-3357 or Diane Solomon,

MSN, CNM, PMHNP (503) 329-8315. If you are injured or harmed by the study procedures you will be treated. OHSU does not offer any financial compensation or payment for the cost of treatment if you are injured or harmed as a result of participating in this research. Therefore, any medical treatment you need may be billed to you or your insurance. However, you are not prevented from seeking to collect compensation for injury related to negligence on the part of those involved in the research. Oregon law (Oregon Tort Claims Act (ORS 30.260 through 30.300) may limit the dollar amount that you may recover from OHSU or its caregivers and researchers for a claim relating to care or research at OHSU, and the time you have to bring a claim. If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

**PARTICIPATION:**

This research is being overseen by an Institutional Review Board (“IRB”). You may talk to the IRB at (503) 494-7887 or [irb@ohsu.edu](mailto:irb@ohsu.edu) if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research subject.
- You want to get more information or provide input about this research.

You may also submit a report to the OHSU Integrity Hotline online at <https://secure.ethicspoint.com/domain/media/en/gui/18915/index.html> or by calling toll-free (877) 733-8313 (anonymous and available 24 hours a day, 7 days a week).

You do not have to join this or any research study. If you do join the study and later change your mind, you have the right to quit at any time. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled, including being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the study.

If in the future if you decide you no longer want to participate in this research, we will have removed your name and any other identifiers from your information, but the material will not be destroyed and we will continue to use it for research.

We will give you any new information during the course of this research study that might change the way you feel about being in the study.

**SIGNATURES:**

Your signature below indicates that you have read this entire form and that you agree to be in this study. We will give you a copy of this signed form. Thank you!

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Subject Printed Name

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Subject Signature

---

Date

---

Person Obtaining Consent Printed  
Name

---

Person Obtaining Consent Signature

---

Date

## Appendix B

### IRB-Approved Minimal Risk Protocol, Including Mother-Daughter Interview Guides

## Minimal Risk Protocol

### INSTRUCTIONS:

#### 1) Protocol Title

Mother-Daughter Care Dyad Relationships in the Context of Hospice at Home

#### 2) Objectives

The purpose of this descriptive, dyadic study using qualitative methods is to interpret and describe relationship quality between cognitively intact mothers toward end of life and their adult caregiving daughters, in the context of home-based hospice care. Perceptions of relationships will be elicited from 12-15 mothers and their 12-15 caregiving adult daughters.

The specific aims are to interpret and describe how mothers and daughters:

- Perceive relationship quality
- Perceive how their relationship has developed over time for both partners through health, chronic illness, and toward end of life, including the ability to stay at home with hospice

#### 3) Background

Much is known about caregiver burden and distress, but mostly from the perspective of spousal caregivers, and from caregivers providing care to those with neurocognitive disorders. Much less is known regarding non-spousal (adult child) caregivers, and those caring for patients who are cognitively intact. In these dyads, little is known of how relationships function and change over time, and how the quality of these relationships impact, and are impacted by, the care trajectory, either positively or negatively, including the ability to stay home with hospice. Furthermore, the great majority of care dyads are aging mothers and adult daughters. A systematic review was undertaken on adult daughter-aging mother care dyads. Only 19 articles exist on relationship quality in these dyads, and none address end of life care. This gap needs to be filled before we may address the pertinent needs of mother-daughter care dyads both toward end of life for mothers, and during bereavement for daughters.

#### 4) Study Design

Descriptive and qualitative, using interpretive description, narrative methods, and dyadic analysis.

#### 5) Study Population

##### a) Number of Subjects

Approximately 12-15 terminally ill mothers with adult daughter primary caregivers will constitute each dyad.

##### b) Inclusion and Exclusion Criteria

Terminally ill mothers will be included if they:

- Are older adults (= $>$ 65-years-old)
- Are cognitively intact per determination of a member of the hospice team

- Have an adult daughter whom they identify as:
  - Providing any amount of physical or emotional care
  - Over age 21
  - And who is willing to participate

### **c) Setting**

Free standing home hospice services in Portland, without in-house IRBs, such as Hospice and Palliative Care Partners of Washington County, will be contacted (see Letter of Willingness to Participate, attached). The Providence Portland hospice staff will identify potential participants and pass fliers on to them and, with their permission, pass contact info on to me as outlined in an email from the Providence Portland IRB director (attached).

### **d) Recruitment Methods**

Hospice clinical staff will be asked to identify eligible mother-daughter pairs from patients without a neurocognitive diagnosis currently admitted to home-based hospice. The hospice team will verbally gauge interest of potential participants, then follow up by giving them a written pamphlet (attached) explaining the study, including a sign up sheet to fill out if they are interested (attached). This sheet will be collected by the researcher who will then contact willing mothers and daughters and offer to meet, either individually or in dyads, at a time and location of their choice. No financial or other incentives will be used.

Recruitment will also be performed through social media outlets such as Facebook, LinkedIn, Instagram, Twitter, etc. An independent Facebook page in strict alignment with OHSU social media policy (<https://o2.ohsu.edu/communications/channels/social-media.cfm#some3>) and “event”(s) inviting potential participants to contact the researcher securely through OHSU email will be posted on Facebook (sample text and photo detail attached), and a link to this page will be noted on other social media platforms (LinkedIn, Instagram, Twitter, etc.), with updates as needed. The text will explicitly ensure confidentiality and ask potential participants to contact the researcher to learn more and confirm eligibility.

To further promote recruitment, unscripted radio, TV, or other media appearances will be sought to discuss the benefits of hospice and discuss recruitment/participation. If any events are to be scripted, scripts will be first approved by the IRB. Guest blog posts will also be sought and, if secured, will also be first approved by the IRB before posting.

### **e) Consent Process**

After initial contact, if participants are interested, they will be reassured the researcher/research is not in any way connected to the hospice organization or to receipt of hospice services. The investigator will describe the study’s purpose, protocol, benefits, and risks, and provide this information in writing. Participants will sign written informed consent, and be asked for assent at the commencement of the first and/or any subsequent interviews.

### **6) Procedures**

Per participant preference, an in-person, telephone, Skype, or FaceTime interview will be

scheduled at a time of their choosing. The purpose of the study will be reiterated at the beginning of each individual interview, and participants will be reminded they may stop at any time for any reason. They may also request audio recording be turned off, and are welcome to refuse to answer any question(s). They will be reassured as to the confidential nature of the interviews and transcripts, even from the other dyad member, unless they choose otherwise. If at any time participants appear physically or emotionally fatigued, a break in the interview or rescheduling will be offered as appropriate. If significant emotional distress is noted, referral for mental health or healthcare services may be recommended with participant permission.

Interviews will be conducted separately with mothers and daughters to encourage confidentiality and speaking freely, unless participants request to be interviewed together. One semi-structured, audio-recorded interview (and any additional interviews, if deemed necessary) will be scheduled with each mother and daughter. The mother's interview will last approximately 15-20 minutes, and the daughter's, approximately 40-50 minutes. At initiation of the mother's interview, the researcher will use OHSU's Determination of Decisional Capacity protocol to further ensure the participant is cognitively intact, able to participate freely and competently in decision-making, and can understand and appreciate consequences of her participation. If she is not determined to be cognitively intact, the interview (and research participation) will cease. Due to physical limitations of most hospice patients, the mother's interview will be targeted and brief. If mothers desire to speak at length, they will be welcomed to do so, but only a few direct questions will be asked, as noted in Appendix A. Interviews with daughters will take place as soon as possible after interviews with terminally ill mothers, so as to capture relational perceptions from the same moment in time. If logistically difficult to schedule concurrently, daughters' interviews will be scheduled as close in time to mothers' interviews as possible, preferably within a 1-2-week window. Daughters' interviews will include more extensive probes but roughly identical questions, so both mother and daughter interviews parallel one another well for dyadic comparison (see Interview Guide in Appendix A). If for any reason an interview with the daughter cannot be obtained, the mother's research data will still be used, if appropriate.

Demographic data (e.g., age, religion, insurance status, ethnicity, diagnosis, number and gender configuration of other family members, frequency of contact; see Appendix B) will be obtained. Open-ended questions will be used to explore the embedded, dyadic nature of mother-daughter relationship quality and to uncover relational perceptions from both members. As is standard with qualitative, inductive research, interview probes may evolve as interviews progress, comprising what is known as emergent design. Subsequent interviews may be scheduled only if needed, for follow-up clarification, or if further probes are deemed necessary for data completion. Field notes will be recorded and/or written immediately following interviews. These field notes will include initial impressions of the dyadic relationship, the caregiving environment, the emotional tone between the two members of the dyad, and reflections on the part of the researcher.

If any participant chooses to withdraw from the study, their transcripts will not be used.

## **7) Data and Specimens**

### **a) Sharing of Results with Subjects**

If participants request, they will be sent a copy of the final research report, and any questions they have will be answered.

### **b) Data and Specimen Banking**

Audio-recordings of interviews will be done through a password-protected computer and/or iPhone, then uploaded to a secure and password-protected Internet transcription site. Through this site, a local service compliant with OHSU confidentiality and HIPAA requirements will transcribe interviews. All

transcripts will be doubly password protected. During the initial verification reading, identifiable information will be de-identified and each participant will be given a code based on random numerals. For added confidentiality, in the final written product, names and identifying characteristics will be altered. Only the investigators will have access to all stored, de-identified data, which may be used in the future for additional analysis and further publications. It is not anticipated data will be available for release to others. If future researchers request data, consent of (living) participants and a release and IRB approval from the researcher(s)' institution will be required.

## 8) **Data Analysis**

Data will be analyzed in line with standard qualitative techniques, including coding, categories, themes, interpretations of data, and narrative analysis of dyadic "stories."

## 9) **Privacy, Confidentiality and Data Security**

Potential participants will only be contacted if they express interest in participation. Hospice staff or other contacts (e.g., through social media) will then give their name and contact information to investigators. If potential participants choose not to participate, contact information will be destroyed. Only participants interested in participating will be consented and interviewed, and both consent and interviews will be conducted one-on-one to protect privacy. Privacy and data will be further protected as in "Data and Specimen Banking," above. Waiver of HIPAA Authorization Requirement attached.

## 10) **Risks and Benefits**

### a) **Risks to Subjects**

Interviews about personal relationships may be upsetting. However, research has shown that those approaching end of life can also gain benefits from participation in research, both for personal and altruistic gain. If participants become uncomfortable during an interview they may ask the investigator to turn off audio-recording and/or to take a break. No unforeseeable risks are anticipated to participants or others.

### b) **Potential Benefits to Subjects**

Participants may not personally benefit from participating. However, participants often find sharing their stories benefits them through increased personal understanding. Mothers and daughters may benefit from reflection on their relationships, which they may put to use as they are completing these relationships in preparation for the mother's death.

## **Appendix A**

### **Interview Guide for Mothers**

- Tell me about your relationship with your daughter?
- How did you and your daughter come to have this type of relationship?
- What role does this daughter have to play in your life compared to other family members?
- How do you think your daughter thinks about her relationship with you?



- How has your relationship changed over time from when you were healthy, to when you became sick, to now; and how have the two of you adjusted?
- How do the two of you manage your illness?
- How do you talk about your illness?
- When you have had big decisions to make in the past, how do you manage them?
- And more recently?
- How do you think your relationship may have affected your ability to stay at home at this time, and/or how do you think staying home may have affected your relationship?
- Is there anything else about your relationship, or about your daughter, you wish to say?

### **Interview Guide for Daughters**

Questions asked of mothers will be used with daughters, and in addition:

- Tell me about your relationship with your mother?
- Can you share some stories that exemplify this relationship, both before and since she has become ill?
- How did you and your mother come to have this type of relationship?
- What role does your mother have to play in your life compared to other family members?
- How do you think your mother thinks about her relationship with you?
- Can you give some examples?
- How has your relationship changed over time from when your mother was healthy, to when she became sick, to now; and how have the two of you adjusted?
- How do the two of you manage her illness?
- Examples?

- How do you talk about her illness?
  - Examples?
- When you have had big decisions to make in the past, how do you manage them?
  - And more recently?
  - Examples?
- How do you think your relationship with your mother may have affected her ability to stay at home at this time, and/or how do you think staying home may have affected your relationship?
  - Examples?
- Is there anything else about your relationship, or about your mother, you wish to say?

## **Appendix B**

### **Demographic Information to be elicited from mothers and/or daughters, including but not limited to:**

- Age
- Education
  - Highest level reached
- Ethnic identification
  - African American
  - American Indian or Alaska Native
  - Asian
  - Native Hawaiian or Other Pacific Islander
  - White

- Unknown
- More than one race
- Religious Affiliation
  - Catholic
  - Protestant
  - Jewish
  - Muslim
  - Other
- Marital status
  - Married
  - Single
  - Widowed
  - Divorced
- Living arrangements
  - With spouse
  - With other(s) (whom?)
- Geographic distance between mother and daughter
- Frequency of contact
  - More than daily
  - Daily
  - Several times weekly
  - Weekly
  - Less than weekly

**Additional questions to be asked of mothers:**

- Life-threatening diagnosis
- Insurance status
  - Medicare only
  - Supplemental insurance
- Additional children
  - Number
  - Gender