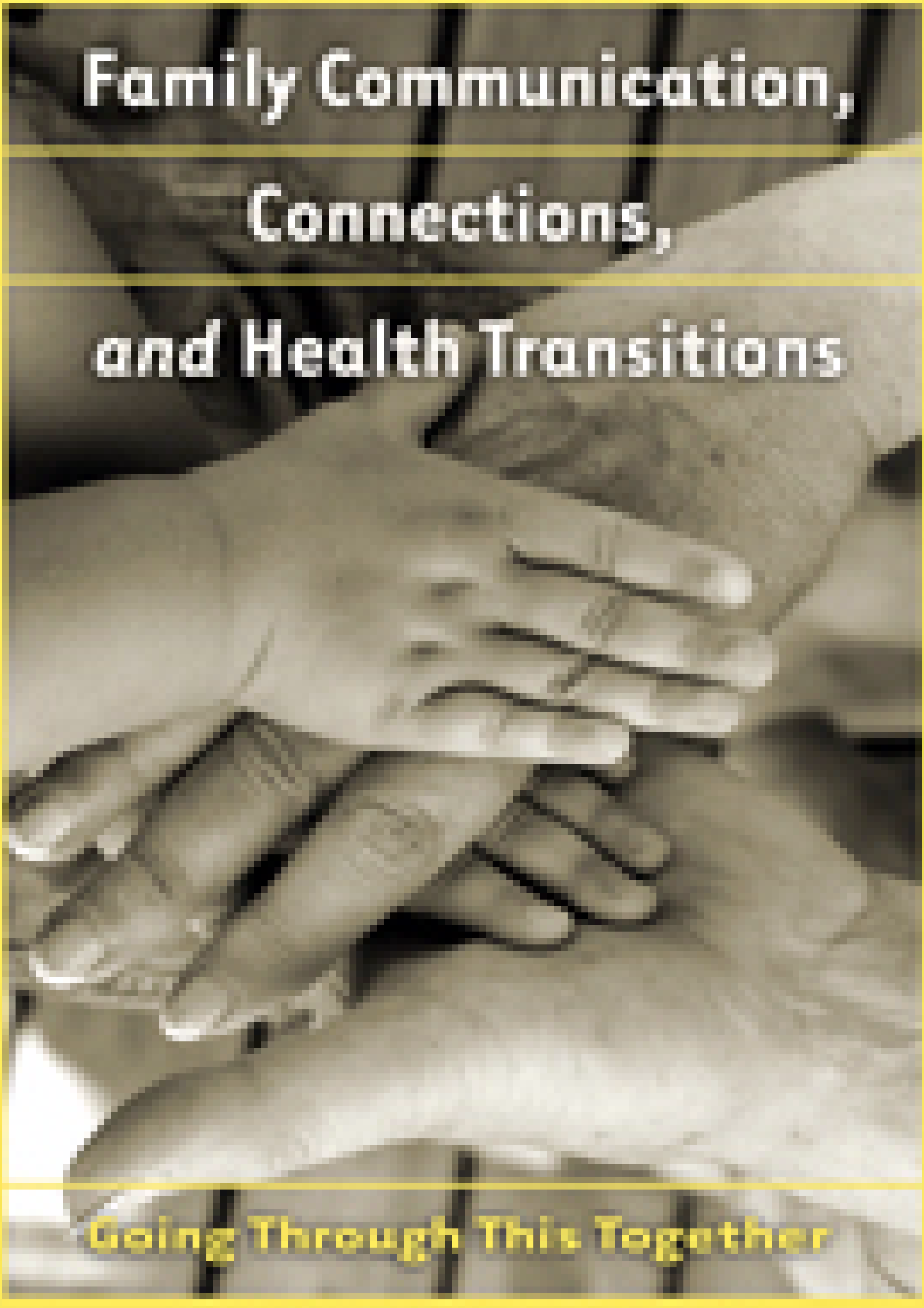

# Family Communication, Connections, and Health Transitions

## Going Through This Together

EDITED BY Michelle Miller-Day

# Health Transitions and Family Communication: An Introduction

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> I drove Annie to [the hospital] this morning and we got bad news. Her white cell counts and hemoglobin fell dramatically over the last week, indicating that the cancer has not been eradicated sufficiently from her bone marrow to start consolidation therapy. She has to go back to the hospital Wed. morning for a more aggressive round of induction therapy, followed immediately by a stem cell or marrow transplant. He told us the chemo will be worse than last time and there is significant risk with the transplant, even if a suitable donor is found. We will have HLA tissue typing done before admission on Wed. so that there is time to find a donor. Her brothers are the most likely candidates…It has been a really bad Monday. She will likely be inpatient *another* 4-6 weeks and is crushed by this prognosis. I'm mostly scared and really, really angry. This is not the news we went up there to get, and she has been really well and energetic these last few days. I hate this fucking disease. The rest of today and tomorrow we will take care of loose ends, pack for her stay, and eat cookies till we throw up (it's a bonding ritual for us).

This is the text of an e-mail message sent to me while in the process of editing this volume. I share this message with you because it embodies what this book is about—health, families, connection, communication, heartbreak, and eating cookies together as a display of solidarity. The book is about individuals like my friend Annie[1] who seek and need support during times of ill health. But, it is also about family members who not only provide—but require their own—support, comfort, information and hope.

When family members experience a diagnosis of a chronic disease (e.g., cancer) or a health crisis (e.g., postpartum depression), not only the diagnosed individuals, but entire families experience immediate and long-term stress as a consequence (Rolland, 1994a; Roy, 2006). Health conditions can introduce dramatic changes in a family mem-

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[1] Her name was changed to protect her identity.

ber's behavior or in a family's daily routine. Family members may be uncertain about what to do, how to help, or how the health condition will affect their family life. Indeed, most families enter the world of illness and disability without a psychosocial map.

Families with members dealing with serious health conditions may be confronted with significant challenges posed by treatment regimes, impacts on day-to-day activities, disruption of family roles, possible threat of death, creating meaning of the illness experience, and a host of psychosocial challenges (Roy, 2006). Sociological and psychological research exists that suggests these kinds of challenges affect general family functioning (Martire, Lustig, Schulz, Miller, & Helgeson, 2004) and the health outcomes of patients (Liu & Gallagher-Thompson, 2009). However, there is very little research that examines the ways in which health transitions shape day-to-day communication within families or what the consequences of communication adaptation might have on physical and psychological functioning of all family members. The remainder of this chapter defines health transitions, provides a brief review of the research literature on families and health, and offers a preview of the forthcoming chapters.

## Health Transitions

In family life there are developmental transitions that may be expected or even planned for (e.g., such as the birth of a new child) which require all members to adapt to increased stress. For many families, however, there are *unexpected* transitions, such as a member's diagnosis of a serious health condition. Transitions highlight change and adjustment. By definition, a transition is a passage—or change—from one state to another (dictionary.com, n.d). Families confront a variety of transition periods when a member suffers from a serious health condition. There is not one single transition from relative health to ill heath, but countless changes and adjustments that may include the onset of symptoms, diagnosis, prognoses, course of treatment, post-treatment and possibly incapacitation and the transition to end-of-life. During these transition periods, families are sometimes at their most vulnerable because certain health transitions (e.g., intensive treatment regimes) can introduce dramatic changes into the family system that require substantive adaptation and reassessment rather than minor alterations to a family's daily routine (Roy, 2006; Sidhu, Passmore, & Baker, 2005). Health transitions are not navigated by the afflicted individual alone. As people cope with and adjust to myriad health transitions, so too do their family members.

## The Interdependence of Families and Health: A Brief Overview

The link between health and family is reciprocal in nature. That is, just as family relationships and processes affect physical and mental health, health conditions influence family relationships and processes. To provide a foundation for understanding this interdependence, I begin by providing some working definitions of family and health.

### Families and Health

What is family? In the 21st century defining family is a complex endeavor. As Baxter and colleagues (2009) point out, family is a hotly contested term among scholars. Definitions of this sort ultimately determine who counts as a "family" and who does not, and this may have implications for policy and treatment of family systems. For this reason, a structural definition of family is often employed in scholarly research and by government agencies. Structural definitions such as, "a group of two people or more related by birth, marriage, or adoption and residing together" (U.S. Census Bureau, 2001, p. 4) highlight the role of blood and legal ties as well as co-residence. This book, however, places communication at the core of defining family; therefore, it reflects a constitutive definition of family—privileging the role of communication (Baxter et al.). From a constitutive perspective, family is defined as a group of persons who interact and through their interactions constitute a family identity. The research presented here argues that family is constructed and maintained through communication.

What about health? The World Health Organization defines health as a state of physical and mental well-being, not simply the absence of disease (World Health Organization, 1946). This broad definition of health focuses on the physical and emotional quality of people's lives. As numerous studies have pointed out, physical and mental health correlate highly; they share common causes and they affect each other.

The interdependence of family and health provides the foundation of this volume. When an individual is coping with a health condition, he or she is not just loosely linked to family members who can be of assistance. I, and the authors of the chapters in this book, argue that typically an afflicted individual is embedded within a family system and this has implications for health care (see chapters 11, 13) and family adaptation (see chapters 2, 3, 4, 5, 6, 8, 14). An illness can become a powerful member of the family. Individuals within a family system may be impatient to move past a health crisis so that life can go back to normal. But for many families experiencing health crises, daily life will need to be recalibrated and adjusted to accommodate the illness. Communication is the mechanism through which adjustment occurs. As the information, examples, and personal narratives presented in this book illustrate, effective communication among and between patients, family members, and care providers is essential for successful navigation of health transitions.

Unfortunately, communication scholars have had surprisingly little to contribute to the conversation on families and health. By its very nature, the study of families and health is interdisciplinary and although we are just beginning to explore these topics in the field of communication, our discipline has much to contribute. The following represents a brief interdisciplinary overview of what is known about the impacts of families on health and the impacts of ill health on families.

## The Impact of Families on Health and Well-Being

Epidemiological research has demonstrated that being married is protective against chronic health conditions (Ross, Mirowsky, & Goldsteen, 1990). Results of the National Longitudinal Mortality Study reveal that, across all causes of mortality and across different nonmarried populations (never married, divorced/ separated, and widowed), nonmarried individuals had elevated rates of mortality compared to married individuals, with higher incidence of coronary heart disease, stroke, pneumonia, and certain kinds of cancer, (Johnson, Backlund, Sorlie, & Loveless, 2000). Additionally, nonmarried individuals have higher levels of psychological distress such as depression and anxiety (Kiecolt-Glaser & Newton, 2001; Mastekaasa, 1994).

In addition to marital status, marital quality appears to impact health. Several studies reveal a relationship between marital satisfaction or strain and women's health. Troxel (2006) revealed that, for middle-aged women, marital dissatisfaction was associated with high blood pressure, LDL cholesterol levels, and aortic calcification. Levenson, Cartensen, and Gottman (1993) found that wives experiencing marital distress reported more mental and physical health problems than their husbands. Specifically for women, marital strain has been associated with increased symptoms of premenstrual symptoms (Coughlin, 1990), ulcers (Levenstein, Ackerman, Kiecolt-Glaser, & Dubois, 1999), coronary events (Coyne, Rohrbaugh, Shoham, Sonnega, Nicklas, & Cranford, 2001), and increased systolic blood pressure (Jacobson, Gottman, Waltz, Rushe, Bobcock, & Holtzworth-Monroe, 1994; Morell & Apple, 1990). Marital satisfaction, on the other hand, has been associated with better overall health for both genders (Ganong & Coleman, 1991) and having caring, supportive spouses can lead to improved immune function (Carrere & Gottman, 1999). Although satisfying marriages generally protect and improve health, they protect men's well-being more so than women's (Johnson et al., 2000; Mayne, O'Leary, McCrady, Contrada, & Labouvie, 1997).

Parental warmth and support appear to be central to children's heath. Wickrama, Lorenz, and Conger (1997), found that parental warmth and support were significant predictors of changes in a child's physical health complaints over a three-month period (e.g., headaches, sore throat, and allergies) and Varni, Wilcox, Hansen and Brik (1988) reported that family support accounted for 22% of variance in depression and anxiety for kids with juvenile arthritis. Moreover, Compas, Slavin, Wagner, and Vannatta (1986) discovered higher levels of anxiety in adolescence for youth whose parents were perceived as nonsupportive.

Support from family members may improve physical health directly or indirectly. Of the many functions served by families, social support is among the most important. Social support involves communication behavior that is responsive to another's needs with the intention of providing assistance (Burleson & MacGeorge, 2002). Emotional support specifically has been found to decrease depression, anxiety, and other psychological problems for receivers of the support (Scwarzer & Leppin, 1991) and, over time, psychological well-being improves subsequent physical well-being (Canary, 2008). By protecting and improving psychological well-being, social support also improves physical health and survival.

Social support from family members also impacts physical health by encouraging and reinforcing preventative behaviors. Parents and relational partners are more likely to encourage family members to quit smoking, to eat diets low in cholesterol and high in fruits and vegetables, and to eat balanced meals (Hayes & Ross, 1987). Women, in particular, often discourage smoking, drug use, or heavy drinking in the house, cook low-cholesterol meals and keep fattening food out of the house, and schedule checkups.

In addition to impacts on general health, there is also much empirical work that has demonstrated how patients and their support systems cope with health conditions to enhance recovery (Broderick, 1993; Minuchin, Rosman, & Baker, 1978; Rolland, 1994ab; 1989). The family-systems approach to recovery posits that the patient and family members are part of a complex integrated system with established patterns of communicating and interacting and that illness poses a significant challenge to these patterns (McDaniel, Hepworth, & Doherty, 1992; Rolland, 1994b). Substantial evidence points to the benefits of family social support for recovery from a variety of conditions such as stroke (Kwakkel, Wagenaar, Kollen, & Lankhorst, 1996), traumatic brain injury (Maitz & Sachs, 1995), breast cancer (Neuling & Winefield, 1988), and depression (McDaniel et al.).

## Impact of Health Challenges on Families

Just as families affect health and well-being, ill health affects families in a variety of ways. Several studies have revealed that patients and their intimate partners experience adverse psychological reactions to the onset of ill health, especially with chronic illness (for a full discussion see Roy, 2006). Illness is typically considered to be a negative life event. Certain health conditions may severely limit the type of activities in which family members can engage, increase family member stress, and increase the "caregiving burden" of families (Cantor, 1980; Zarit, Reever, & Bach-Peterson, 1980). Since family networks are not necessarily trained or prepared to deal with the demands of care for a member suffering from a health condition, this care may create a burden for those providing direct care. Changes in medical practice resulting in shorter inpatient hospital stays and longer survival have substantially increased the numbers of individuals with health conditions being cared for in the home and increased the burdens on carers, as well (Martire et al., 2004).

Health conditions may also affect family members' roles and responsibilities. Family life can become disorganized, household routines upset, and stress increased by uncertainty about how to manage the illness (Zarit et al., 1980). Research finds that family members assume additional responsibilities following the illness of family members, and there is often increased dependency on healthy members of the family (Hummert & Nussbaum, 2001; Vrabec, 1997). Although Michela (1986) demonstrated that patients who increased dependency on spouses initially reported higher levels of marital satisfaction, the spouses reported significantly less marital satisfaction. Since then, a wealth of research has revealed that long-term illness may place a burden on caregivers and adversely affect the quality of their relationships (Adams, 2007). The longer the period of caregiving and dependency, the more ambiguity there may be about role expectations (Scheinkman, 1988). Even the strongest relationships may be strained by role strain and uncertainty in managing illness and other health transitions.

A health condition that is chronic or that lasts for a long period of time can powerfully challenge couples' communication skills. But, sensitive, open, direct communication about a range of issues is essential to living well with chronic disorders (Roy, 2004). Important discussions for couples include understanding the illness and its psychosocial demands over time, beliefs about who or what caused the disorder and what can affect its course; how to live with threatened loss; personal and relationship priorities; the roles of patient and caregiver; how to maintain a balanced, mutual relationship; and wills and advance directives concerning a possible terminal phase (Roy).

While open discussion of these issues is recommended by some, other research suggests that during times of health transitions, privacy and managing boundaries around private information may be important to members with health conditions and their families

(Petronio, 2002). During these transitions family members may need to renegotiate to whom, when, and how much information is shared about the health condition.

To summarize, there is interdependence between health and family relationships. Marital status, marital quality, and family warmth and support appear to impact the health of family members, with supportive relationships linked to, not just general well-being, but recovery from illness. Moreover, health transitions are not navigated by the afflicted individual alone. Patients are embedded within a family system, and as they cope with and adjust to myriad health transitions, so too do their family members.

The research introduced here is elaborated in the forthcoming chapters. The studies reported in this book point to a variety of communication questions that may be pursued when investigating the intersection of family and health. What are the message features of supportive communication? (How are these messages perceived? What are the barriers to messages of support being perceived as supportive?) What communication competencies serve to buffer families from the disabling effects of stressors during health transitions and to promote recovery and successful adaptation? How is information managed and privacy protected during times of transition?

Since there is ample evidence that communication behavior such as providing social support is associated with positive health outcomes for families, perhaps it is time to move to these questions of *how* this communication becomes associated with positive family health outcomes.

This volume seeks to jump into the conversation about families and health in the areas posed above, represent the lived experience of family life during health transitions, and offer an agenda for future studies.

## The Chapters

I firmly believe that science is not achieved by distancing itself from the world. So, in this book I endeavor to capture family life as it is lived for those individuals experiencing health transitions and their families. Bochner (1995) challenged communication scholars to deemphasize studying family in the “largely abstract, cognitive, and objective world" (p. viii) and, instead, seek an understanding of the family in its inherent concreteness, emotionality, and subjectivity. Many of the chapters herein accept this challenge, with the implicit assumption that individuals must be studied in depth to be understood in general. While not all chapters in this book take an interpretivist approach to describing, representing, and interpreting experience; there are a number of chapters that do. As a pragmatist, I agree that, "no perspective of inquiry is privileged over another; all have something to offer in understanding family life" (Stamp, 2004, p. 21). In these pages, surveys are implemented, experiments are conducted, descriptive case studies are presented, and autoethnographic accounts are shared. All these forms of inquiry serve to tell part of the story and provide insight into family communication and family life during times of health transition.

Bringing together veteran communication researchers along with newcomers; and drawing on research, clinical insight, and personal experience to illuminate these issues, this book provides a discussion of communication patterns and processes involved in the day-to-day management of health conditions.

Section one of this volume focuses on *Family interdependence in managing health transitions*. Segrin and Badger (chapter 1) begin the discussion of family interdependence in the context of cancer. This chapter discusses how and why diseases like breast and prostate cancer affect whole family systems. Further, this chapter provides evidence of the profound impacts and communication challenges these diseases pose for the marital subsystem. Readers will learn how social interaction processes such as social support and communal coping can help and hurt the quality of life and adjustment of the patient with breast or prostate cancer and their family members. This chapter also reviews the results of original research conducted by the authors offering stringent tests of emotional contagion in families with cancer, revealing that as patients' physical and psychological condition improved, so too did the emotional state of their partners. This chapter is followed by another look at family interdependence and cancer when Carla Fisher (chapter 2) explores how mothers and daughters partner side-by-side and take on cancer together. Individual life-span interviews with breast cancer patients and their mothers/daughters illuminate how mothers and daughters cope with breast cancer together—how they communicatively share the disease—and, in essence, are each other's strength. Taking a developmental approach, Fisher provides evidence that the communication of social support may be perceived differently at different stages of life development. In chapter 3, Weber and Solomon also examine breast cancer and further hone our understanding of family communication about cancer and coping. Weber and Solomon focus their inquiry on emotional and cognitive reactions to stressors associated with breast cancer and identify unique communication patterns enacted by relational partners. Moving beyond the context of cancer, chapter 4 examines spousal interdependence in managing diabetes. J. Lynne Brown provides a detailed review of the literature available on couple communication patterns and their role in management of type 2 diabetes and reports original findings from a study of couple communication and adjustment during the first year of a type 2 diabetes diagnosis. She reveals patterns of difference among cohesive, enmeshed, and disengaged couples regarding how they manage diabetes in their household. These results suggest that baseline relational cohesion may impact the type and quality of support provided in a marital relationship during the first year of disease management. To conclude this section, Anderson Dearmen (chapter 5) provides an insightful first-hand account of postpartum depression. This chapter is autoethnographic in nature. Autoethnography refers to writing about the personal and its relationship to cultural phenomena. As Ellis (2004) explains, autoethnography is a genre of writing and research that relies on personal narrative, layered within and often in juxtaposition to social scientific evidence. Anderson Dearmen's account provides her readers with a discerning explanation of the barriers women face to diagnosis and treatment of postpartum depression, the ways in which postpartum depression can affect family relationships, and the critical role family members can play in providing support and care for women suffering with postpartum depression.

The second section of this volume addresses *Stigma.* In chapter 6, Rossetto, Smith, and Jones address stigma and taboo. This chapter highlights how politeness and co-ownership of health information provide challenges to families when they discuss taboo or stigmatized health conditions. They explore how people with stigmatized health conditions enact disclosures and examine how these disclosures are interpreted, revealing important findings pertaining to information management. One insight provided by this research is that while disclosure of a health condition provides an access point for obtaining information, support, and treatment, it simultaneously opens the door to potential stigma. Erica Bauer (chapter 7) concludes this section with a discussion of stigma and how it affects disclosure of mental illness within and by families. She offers a model explaining how disclosure of a stigmatized illness is affected by the receiver's orientation to the illness and the receiver's level of intimacy with the person labeled with the stigmatizing condition.

Section three is titled *Living with invisible illness,* and, using techniques of narrative and autoethnography, it uncovers the lived experience of families adapting to members with an invisible illness. Giving voice to the experience of having an invisible illness, Emily Bowlby (chapter 8) provides an autoethnographic examination of invisible illness/disability and the impact of this on her family relationships. The author "layers" alternating voices of herself as a scholar and as a family member living with an invisible disability. Similarly, Pettigrew and Pettigrew (chapter 9) provide a moving autoethnographic account of relationship, transition into marriage, and managing an invisible, unnamed, painful, and sometimes debilitating health condition. This chapter is a love poem; a poem of commitment and endurance. Breanne and Jonathan Pettigrew successfully illustrate how they reframe stress, negotiate privacy rules, and support their relational identity. These authors conclude with a discussion of four communication strategies they implement to cope with Breanne's illness: counseling (informational and emotional guidance), cuddle time (affection and relationship building), crowding (seeking support from others), and confessing commitment (reducing relational uncertainty and reinforcing relational identity). Section four of the book is *Interfacing with others.* This section addresses communication and the interface of patients, families, and other social networks. Petronio and Sweeney-Lewis (chapter 10) begin this section with a comprehensive review of how medical disclosure plays a part in the care of individuals with cancer. Sandra and Shannon explore management of private information across a patient's trajectory of care—from initial diagnosis, discussions of prognosis, and post-treatment, to the end-of-life. This chapter is followed by Steuber and Solomon (chapter 11) who explore how couples disseminate information about infertility to their family and social networks and what the implications are for revealing, or not revealing, this information. The authors report findings from their study of infertile couples and social networks, providing insight into disclosure, negative communication experiences, and privacy management issues related to infertility. This section ends with a chapter by Foster and Cohen-Katz (chapter 12) that offers an applied perspective on medical education, health, and families. A health communication scholar and medical educator (Foster) pairs with a clinical psychologist (Cohen-Katz) to co-author this chapter on ways in which health care professionals can best respond to the complexity of family relationships during times of health transition for a family member. The chapter describes the *family life-cycle model* and the *family meeting*, how these elements fit within the overall philosophy and approach to training physicians, and how the experiences of implementing these elements can inform family and health communication more generally. For health care professionals, this chapter outlines fundamental theory as well as useful practices for working with families.

The final section of the proposed volume—section five—is titled *End-of-Life*. In this last section, Hipper, Catona, and Nussbaum (chapter 13) provide a thorough review of how primary and secondary caregivers in the family manage Alzheimer's disease. This chapter explores how far the "ripple effect" of caregiving changes the familial relational dynamics and argues for the use of the term caregiving networks instead of focusing on a static, singular caregiver. In the next chapter, Pitts (chapter 14) presents an intriguing case study of one family to examine how they co-construct positive end-of-life experiences. Providing rich details about discourse practices in one extended family system, this chapter argues that dying is both an individual and collective experience. Finally, Vande Berg and Trujillo's end-of-life story (chapter 15) is a raw, moving, and incredibly informative account. In this chapter we travel with Leah Vande Berg through her final days, hours, and minutes of her death. We peer over the shoulder of her husband, Nick Trujillo, and struggle along with him as he shares in this communal experience.

Dear reader, I wish for you to be enlightened, moved, and inspired to conduct more communication research at the intersection of family and health. This volume does not provide a definitive conclusion to these matters, but a stepping off point. Happy reading.

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