

REGULAR REFLECTIVE WRITING:  
USING SENSE-MAKING COMMUNICATION STRUCTURES TO IMPROVE  
FAMILY CAREGIVER WELLBEING

BY  
TRISH ZDROIK

THESIS

Submitted in partial fulfillment of the requirements  
For the degree of Master of Communication  
In the Graduate Program of the  
University of Wisconsin at Stevens Point, 2017-18

Stevens Point, Wisconsin

Thesis Committee:

Dr. Cade Spaulding, Chair  
Dr. Timothy Halkowski  
Dr. Tamas Bodor

## Acknowledgements

As I write this last, but very important piece of my Thesis, I am prompted to reflect upon and be grateful for many strong influences.

First, I will thank my committee, who were individually and collectively vital to what and how I was empowered to study. Beginning with my Chairperson, Dr. Cade Spaulding, I am thankful for his true attachment to my growth and my topic. Cade visibly mentored my advancement in the areas of academic writing and organization, helped me create ways of recruiting participants when I felt defeated mentally and physically, and most importantly offered me authentic and inspired encouragement by guiding my focus back to how this study would potentially affect future family caregivers and health professionals. “You had just the right balance between criticism and support, Cade, which made you so very effective as my teacher.”

Next, I will thank Dr. Timothy Halkowski and Dr. Tamas Bodor, who asked questions at my Prospectus defense that formulated a path for me to draw firm conclusions later. These conclusions would have only been based on weak assumptions if these two gentlemen had not challenged me in these specific ways. Tim asked me to define Modernist Mindset and what that had to do with health care; I later found that the difference between Modernist and Post-Modernist mindset provides theoretical and philosophical landscape by which to understand and discuss what communication variables must experience intentional change in order to create empowerment, and therefore wellbeing, with this audience. This understanding provided my deepest epiphany moment. At the same time, Tamas provided my quantitative anchor as he mentored my data analysis thinking and tendering so that I was able to consolidate and tabulate just what effect reflective writing had on wellbeing. I am so thankful for Tamas’s obvious interest in who I needed to recruit, how I would get IRB approval, what questions I should be asking, and what numbers would be most important to report. I learned so much from all of you.

My family also played an unusually vital role in the development of this Thesis. I completed most course work for my Master's Degree twenty-three years ago, while my oldest child was still in my womb. That child, AJ, came to be born two months premature, and I found it necessary to put my research on pause while I nurtured his 4 lb. being. A few years later, I was all set to resume my studies before my seven-year allotment timed out. Though I was with child again, I was certain I would be able to get this thesis written. Again, such was not in the cards for me; I learned 20 weeks into my pregnancy that my child in the womb had only a two-chambered heart vs. the normal four chambers most of us have. At that point, I dedicated all of my research efforts to learning how to help my child survive....and my seven-year clock ran out...and I became a family caregiver.

Several years later, I resumed my second journey through this master's program, having four fairly healthy and beautiful children. I finished my coursework for a second time, and received a final approval from the IRB to proceed with my research on the family caregiver on October 12, 2017. A few hours later that day my heart skipped several beats. I became physically ill, but wouldn't find out until later that evening why my heart acted so strangely. My news was devastating. That child that was born during my first journey through this program was killed that afternoon in a work-related accident. When asked by a colleague, "What would AJ want you to do during this emotional upheaval?", my answer to that question, along with the tool of reflective story-telling, are what got me to the opportunity to write this final piece. I know exactly what AJ would have said: "Don't ever quit when you're busy doing the right thing." Done and done. Thank you to all four of my children for sharing my heart and putting up with my inattention to you so that this thesis, this research, and this degree could finally be accomplished. It is the story about our love and hard-core determination that gave me the energy to succeed!

**Table of Contents**

**Chapter One: Rationale..... 3**

**Chapter Two: Theoretical Background..... 11**

**Study Hypothesis and Research Questions..... 23**

**Chapter Three: Method..... 25**

**Chapter Four: Results..... 27**

**Chapter Five: Discussion..... 34**

**Chapter Six: Conclusion..... 41**

**References..... 42**

**Appendix A: Recruitment Message..... 48**

**Appendix B: Informed Consent Document..... 50**

**Appendix C: Demographic Questions..... 52**

**Appendix D: Wellbeing Inventory (WEMWBS)..... 53**

**Appendix E: Permission to use WEMWBS..... 54**

**Appendix F: Correspondence regarding Qualtrics..... 56**

**Appendix G: Reflective Diary Instructions..... 57**

**Appendix H: Self-Reported Topics of Writing..... 58**

## Chapter One: Rationale

This nation's quality of health care has become dependent upon the 44 million Americans (20% of the US population) who have taken on the role of family caregiving (National Alliance for Caregiving, 2018). Family caregivers are people who provide medical, social, personal, and/or other supportive care for a family member or friend who is chronically ill or disabled (National Alliance for Caregiving, 2009). The Supreme Court's 1999 *Olmstead* decision that gives people the right to reject institutionalized care and receive health care in their own homes (Supreme Court, Argued April 21, 1999–Decided June 22, 1999) has led to a steady increase in the demand for in-home caregiving. According to the U.S. Department of Health and Human Services and the U.S. Department of Labor (2005), the number of Americans requiring some form of supportive caregiving is predicted to double from 13 million in the year 2000 to 27 million by the year 2050. And because most people who need such care prefer to receive it at home, it is their family members who most frequently become the providers (National Alliance for Caregiving, 2009). Special attention is needed to learn how family caregivers cope with the demands of this role while simultaneously navigating the normal stressors of their everyday lives.

Family caregivers are described as family members who become responsible for providing daily functional care for their parent (or grandparent or parent-in-law), spouse (or sibling), or child (or grandchild) because of a physical or mental health diagnosis (Stephens, Franks, & Townsend, March 1994). In the field of health care, *patient* health and wellness has long been the focus, and rightfully so; it is the patient who seeks service and the patient who pays the health care bills. In the past few decades, the field of health care has slowly begun to study the wellbeing of family caregivers (Kurylo, Elliott, & Shewchuk, 2001). Such studies have

focused on the causes and effects of stress due to the increase in trauma known to occur when the family caregiver role is assumed (Lazarus & Folkman, 1984). Research on caregiver stress serendipitously evolved out of a generalized study on the effects of stress due to the prevalence and magnitude of stress consistently found within the caregiver population (Sapolsky, 2008).

### **Multi-dimensional Impact of Caregiver Stress**

Stress has a multi-dimensional effect on the wellbeing of family caregivers. Emotionally, caregivers exhibit symptoms for depression and anxiety two to three times more often than the generalized population (Sheehan, Hiscock, Massie, Jaffe, & Hay, 2014; Seeman & Seeman, 1983), with up to 70% of them describing significant clinical depression (Zarit, 2006) and others receiving a diagnosis for Post-Traumatic Stress Disorder (Jones, et al., 2004; Stukas, et al., 1999; Galovski & Lyons, 2004). Physically, evidence shows that heightened and frequent emissions of adrenaline and cortisol experienced by family caregivers cause biological damage over time (Nelson, Lord, & Ochocka, 2001), including a six-fold acceleration of the aging process for mothers of special needs children (Eppel, et al., 2004). Stress-induced immune system and pro-inflammatory disease, associated with caregiving stress, extends the negative effect on caregiver health for up to three years after caregiving ceases (Glaser & Glaser, June 30, 2003).

The exhaustion and time consumption involved in caregiving for a family member often leads to financial and occupational compromise as well. Because of increased at-home needs, family caregivers often find conflict between work and home projects, and are known to forfeit hundreds of thousands of dollars of income and benefits due to their choice for family care over work (AARP Public Policy Institute, 2011). Furthermore, statistics show that families providing caregiving are 2.5 times more likely to live in poverty than non-caregiving families, and they earn an average income of 15% less than the national average (Census 2000, July 2005). The

stress of the family caregiver role is significant; however, it is the belief of this researcher that there are communication processes that could provide efficacious relief.

### **The Need for Transactional Health Communication**

A significant change in basic assumptions about the administration of health communication occurred in the 80s and 90s. Methods and paradigms regarding communication between providers, patients, and caregivers transformed when the health care field realized the significant impact that the context, feedback, and role equality has on the navigation success and general health outcomes of people experiencing or caring for someone with chronic illness (Glanz, Rimer, & Viswanath, 2008). Health communication and education scholars observed ways in which the health and human service agencies, family members, and greater public community players, message rhetoric and contexts are frequently associated with causes, heightening/lessening negative effects, prevention, and/or the resolution of health care problems (Griffiths, 1972; Green & Kreuter, 2005). Changes in outcomes occur when controlling sender, receiver, context, message rhetoric, and message channel variables and are thought to influence patients and family members ability to manage their roles and outcomes effectively due to their impact on individual and collective perceptions. Highest effect on outcomes is found when involving, analyzing, and measuring: (1) empowerment, (2) social support, and (3) self-efficacy (Nelson, Lord, & Ochocka, 2001; Wallerstein & Bernstein, 1994; Bergsma, 2004).

Progressive disempowerment, social isolation, and the struggle with self-efficacy are compromised by what some authors term in a non-traditional way “modernist mindset”. By this atypical definition, individual thinking is dominated by in-place authority structures. Post-modernism cultures, when focusing on how power and authority are structured, reinforce change and innovative thinking and produce cultures and individuals willing to allow challenges

to the way knowledge, procedures, and authority itself is perceived (Kearns, 1995). Modernist culture tends to evaluate the worth of individuals based on their achieved knowledge of fixed facts and the degree to which individuals are self-sufficient (Fisher, 2008). In a modernist culture, agencies that are in place to aid patient navigation of needed health care and social service resources are honored with unchallenged obedience. By post-modernists, such institutionalized obedience is perceived to undermine patient and caregiver empowerment. Modernist-centered health care systems administer authoritative top-down communication and build services and communication rhetoric around fixed category markers that do nothing but describe the degree of “defectiveness” each patient exhibits (Fisher, 2008). Qualitative research echos the perception of disempowerment as caregivers describe the reasons for their stress:

#1 - perpetual struggles with aspects of ‘the (health and social services) system’ where there is constant negative top-down talk about “what’s wrong” with the care recipient.

The second and third reasons caregivers cited for stress echo themes of “defectiveness”, “exclusion”, and “inadequacy:

#2 – fear provoking narratives about what will become of the family member who is ill, which provoke the perception that there will not be the right resources or enough resources to help the care recipient achieve healing or quality of life.

#3 – progressing narratives about how the rest of the family members are becoming increasingly excluded from “normalcy” standards (Oruche, et.al, 2012).

Such worries bring about anxiety and depression, which lead to powerlessness and isolation behaviors (Benight, 2011; Davidhizar, March-April, 1992) and are believed to cause the multi-dimensional decline of wellbeing for family caregivers (Ryan & Deci, 2000; Prilleltenski, Nelson, & Peirson, 2001; Pearlin, Mullan, Semple, & Skaff, 1990).

Empowering practices emphasizing personal meaningfulness (Giuliano, Mitchell, Clark, Harlow, & Rosenbloom., 1990), inviting caregivers to be part of collective collaboration when decisions of care are made (Bergsma, 2004), and specific consideration for the wellbeing of the caregiver through overt checking-in processes and the extension of resources to and for the caregiver (Noonan & Tennstedt, 1997) can directly counter the perception of powerlessness currently inundating the family caregiver role. Johnson (2011) argues that caregiver empowerment, defined as the overt recognition of caregiver agency and encouragement for active participation in care giving decision-making, will be a key force in the future of health care. Such empowerment will likely lead to improvements in health cost structures, patient treatment plan engagement and commitment, patient advocacy, and overall tolerance for uncertainty. Recognition of caregiver agency and communication models that encourage collective and collaborative participation of caregivers generate opportunities for caregiver self-efficacy and networks of support for both care recipient and caregiver (Bergsma, 2004). Additionally, the fact that the rhetoric of empowerment does not focus on managing symptoms and defectiveness, but instead tends to place dialogue attention on the customization of plans that promote the self/family-described and advocated social, emotional, physical, spiritual, and financial initiatives for each individual patient and family entity serves to have an uplifting quality and effect (Gilbert, Chamberlain, & White, 2012).

These family-centered, holistic, self-advocating models are powerful and inspiring, but are inhibited by the fact that they are presently dependent upon the initiation, rhetoric, and direction of formal health or social service agents (Prilleltenski, Nelson, & Peirson, 2001). This research aims to search and test efficacy for an empirically-sound communication tool that gives opportunity for the ongoing and independent administration of patient and family so that

empowerment and self- and family-sufficiency can be achieved. Patient/family independence seems to be a natural extension of the health empowerment philosophy—so creating a tool that could reasonably be administered by patients, or in this case by family caregivers, would advance the reach of health care and consumer wellness benefits described to be associated with health empowerment. Additional efficiency in performing this research will be achieved if such independent administration is possible--without needing to coordinate through health or social service agencies.

One empirically-sound communication tool proven to initiate health empowerment is the use of medical diary narratives (Combe, 2005; Jones, et al., 2004; Garrouste-Orgeas, et al., 2012). In studies where medical personnel and family members provided daily verbal and photo entries within bedside journals for critically ill care recipients, care recipients and families benefited from the reflective meaning that they interpreted from the narrative product. Specifically, benefits were cited to be achieved from their perceived invitation for collaborative participation because of the specific consideration given to both patient and family wellbeing (Egerod I. , Christensen, Schwartz-Nielsen, & Agard, 2011), and from the medical documentation--written in laymen's terms--which elevated the self-efficacy of patients and families by stimulating collective, practical, and effective reflective dialogue about the illness and ongoing treatment plans (Akerman, Ersson, Fridlund, & Samuelson, 2013). Medical diary narratives empower patients and family members by giving them a shared and explicit channel of communication, and by acknowledging both patient and family as formal players (i.e., senders and receivers) in the health care communication and planning process. Empowerment is achieved as the communication process takes on a more overtly transactional (vs. linear) nature.

The process of narrative journaling also employs reflectivity, which inherently relieves feelings of powerlessness and fosters emotional, social, and physical wellbeing (Ryan & Deci, 2000; Ullrich & Lutgendorf, 2002). Because diary narratives have already been shown to empower and engage family caregivers in reflectivity, and because reflective empowerment has a positive effect on health and wellbeing by reducing isolating perceptions of powerlessness and social exclusion (Tsey, Harvey, Gibson, & Pearson, 2009), the present study tested the efficacy of using diary narratives to empower reflectivity and improve caregiver wellbeing. Additionally, the model for medical diary narratives was chosen for this study because only a small amount of instruction was sufficient to enable family caregivers to independently use this communication tool without dependency on the agency of the “system”.

Overall, studying the impact of reflective writing on the wellbeing of the family caregiver population is robust with potential benefits. To society, such benefits include better knowledge about the family caregiver role and population needs. In fact, in the first and largest meta-analysis performed on the family caregiver role (Reinhard, Fox-Grage, & Feinberg, 2016), findings showed significant benefit when requiring Long-Term Services and Support (LTSS) care policy and care coordinators to include participation of family caregivers as well as to assess and provide resources for family caregiver self-care and wellbeing. This meta-analysis concluded that family caregiver provisions are still rare...”but power exists in standardizing (not just) a person-centered, but family-centered approach...which can lead to better care for (patients) and their families”...and can prevent costly caregiver burnout and institutionalized care and placement for the care recipient. This study was designed to search for “innovative solutions and free-of-charge tools” to be used for this purpose.

## Chapter Two: Theoretical Background

This nation's need for family caregivers is substantial and on the rise (U.S. Department of Health and Human Services, and U.S. Department of Labor, 20 Jan 2005; National Alliance for Caregiving, 2009). The family caregiver population offers significant value to our society's family structure and to the facilitation of health care freedom (Supreme Court, Argued April 21, 1999–Decided June 22, 1999; AARP Public Policy Institute, 2011). At the same time, family caregivers from every category of care encounter multi-dimensional stressors which challenge their own wellbeing (Eppel, et al., 2004; Sapolsky, 2008; MacNeil, et al., 2009; Davidhizar, March-April, 1992). While social and health care agencies rightfully focus on meeting the needs of each client who is ill or disabled, the wellbeing of the family members who voluntarily provide the most care (U.S. Department of Health and Human Services, and U.S. Department of Labor, 20 Jan 2005) is often overlooked (AARP Public Policy Institute, 2011; AARP Public Policy Institute, 2014; Davidhizar, March-April, 1992; Pearlin, Mullan, Semple, & Skaff, 1990). Government agencies highlight the value of the family caregiving role and document the needs of this population in our culture (U.S. Department of Health and Human Services, and U.S. Department of Labor, 20 Jan 2005). Future study of family caregiving will advance our understanding about ways we might prevent and resolve the dramatic decline of caregiver wellbeing.

In this chapter, a conceptualization of who the family caregiver is will be provided and accompanied by a theoretical basis explaining why and how this study productively advanced working knowledge about family caregiver wellbeing. The way communication is compromised within the caregiving phenomena will be explained, showing how regular trauma-producing shifts in the rules and roles of communication affect family caregivers. Sense-making theory

(Weick, 1993) provided the theoretical lens for this study and explains the efficacious effect sense-making has on caregiver wellbeing. Finally, this proposed study will describe how the diary-keeping, narrative-making process institutes both transactional (vs. linear) conversation and reflective story construction, which are essential mechanisms needed for family caregiver wellbeing.

### **Family Caregivers**

The National Alliance for Caregivers (2009) states that family caregivers are this nation's "foundation" for long-term health care. The family caregiver population is made up of people who most often voluntarily accept responsibility for providing daily functional care for their chronically ill or disabled parent, spouse, or child (Stephens, Franks, & Townsend, March 1994) and are said to save this nation an estimated \$375 billion in services annually (National Alliance for Caregiving, 2009). The National Alliance for Caregiving (2009) describes the average caregiver as a woman who is 49 years old, married, employed, and caring for her elderly mother who does not live with her. The alliance also states that most family caregivers are women, with females spending about 50% more time providing care than males. Approximately 73% of caregivers are employed outside of the family caregiving role, with 66% of them stating it was necessary to adjust their work schedule and take occasional leaves of absence up to and including terminating their employment entirely. Statistics regarding who is cared for show that 36% of family caregivers provide care for a parent, 20% care for a spouse (AARP Public Policy Institute, 2014), and 14% care for a child with special care needs (National Alliance for Caregiving, 2009).

**Roles of family caregivers.** The role of the family caregiver is filled with multi-faceted and energy-consuming activity. When surveyed, family caregivers reported that the majority of

their time was spent doing hands-on health care, with much additional time spent managing and scheduling other resources. Many times care recipients also need caregivers to function as surrogate decision-makers and advocates (Navaie-Waliser, et al., 2002). Duty descriptions provided by family caregivers show that 70% of them manage medications, 22% help communicate with physicians, and 90% seek health and social resources. A full 75% of family caregivers agree to take on this role so that they can help a loved-one in need, with the average family caregivers spending 20 hours per week providing supportive care, and 13% of them providing 40 hours or more (National Alliance for Caregiving, 2009).

### **Communication within the Family Caregiver Context**

Quality communication is a complex and transactional process whereby both senders and receivers are main actors that use and convey information by simultaneously playing significant constructional and reactional roles. The actors involved in a communication phenomenon use multiple channels as they create and establish personal and collective meaning where they and the message itself are influenced by the perceived communication context (Barnlund, 1970). If communication is not thought of as transactional, and is instead conceived and facilitated under more linear models where the sender simply decides a message and delivers it to the receivers (Berlo, 1960), the receiver becomes progressively less important and outcomes of shared meaning and receiver empowerment are likely compromised.

Dance (1967) described how communication helps people establish who they are within a larger world, discussing how transactional communication creates what is known as a “personal culture” for individuals. Decisions about (a) when it’s appropriate to talk, (b) what is the best thing to say, and (c) which tone and vocabulary would best be used, are all important to the establishment of personal identity within each unique communication context. These decisions

are based on one's unique background, perceived personal experiences, and the rules that are individually and collectively understood. People make meaning, construct values, and establish perceptions of power each time they become part of a new group. Communication patterns are contingently governed by the culturally perceived rules and roles of each context, and individuals are believed to naturally self-construct comfort zones from understanding their position within the rules and roles of their routine settings.

Sellnow & Seeger (2013) added detail to this thinking. They argued that comfort zones fall apart if the communication context is perceived as traumatic or dynamically new, where the variables of communication actor, message rhetoric, channel, and/or context are changed in any drastic way. During traumatic or crisis situations, people will usually feel vulnerable because the rules and roles of communication are not only unfamiliar, but also are often imposed by the people who are in roles of assumed authority or by the circumstances indicating basic survival is at stake (Davidhizar, March-April, 1992; Grossman, 2008). When placed in settings where crisis communication dominates message content, the rules, roles, and power structures of communication are new and do not fit the norms and patterns that are known and understood by individuals. These unfamiliar rules and roles create anxiety and subsequently provoke an urgent need for new meaning-making systems, values, and frameworks for power (Seeman & Seeman, 1983).

Family caregivers regularly find themselves within traumatic and imposed contexts (Davidhizar, March-April, 1992; Hamel, 2000). The need for constant adjustment to the rules, roles, and power structures often leads to a hijack of caregiver comfort zones. Constant flux dominates the context of family caregiving due to changing care recipient symptoms, care

providers, care strategies, and/or (health care or social service) system rules (Davidhizar, March-April, 1992). Regular processing of traumatic messages and demands for role and rule change can easily cause progressive perceptions of ambiguity, fear, and disorientation that lead to damaging cycles of multi-dimensional stress (Benight, 2011; Grossman, 2008). Qualitative research data collected from the family caregiver population echoes this description of context. Stressor stimuli themes described by caregivers cite perpetual ambiguities and struggles with aspects of “the (health and social services) system”, ever looming “fears” about what will become of the family member who is ill, and other constant worries about the rest of the family members who were progressively becoming deprived of normalcy (Oruche, Gerkenmeyer, Stephan, Wheeler, & Hanna, 2012).

When analyzing how to cope with such stress, Davidhizar (1992) emphasizes the need for communication strategies that give and maintain meaningful personal power for caregivers (i.e., those in crisis). The idea of how transactional communication plays out as powerlessness vs. empowerment in the family caregiving context is further understood through the explanation of the innate human needs for self-efficacy and social support.

**Self-efficacy and social support.** Self-efficacy is defined as the perception of one’s own ability to be effective and is believed to be a foundational concept that leads to personal motivation (Bandura, 2010). Caregiver self-efficacy is compromised when medical and social service agents take over care decision-making and direct care instructions through linear channels. On the other hand, healthy self-efficacy is achieved and associated with perceptions of control and involvement gained through participation in the development of plans for the care recipient’s future; when caregivers can participate within a dependable collaborative context, then empowerment is likely to occur (Benight, 2011). Additionally, perceptions of social

support (i.e., perceiving that one is securely connected to support agents qualified and willing to resolve the problems at hand and provide the resources needed), are necessary for empowerment to ensue. In fact, the perception of social support is argued to be the most significant variable necessary to protect the wellbeing of people who play roles within a chronic health care context (Masters, 2016).

The need to play a significant and efficacious role in communication and be linked to others who will help provide resources and creative thinking about how to handle the often ambiguous and threatening circumstances of caregiving, can facilitate higher cognitive capacity (Dance & Larson, 1976). Empirical evidence supports this theory, showing that a more cognitive discernment and healthy and regulated biological adrenal response from caregivers is found when their self-efficacy and social support needs are met (Masters, 2016). On the other hand, without the ability to play an efficacious role within context where messages of life-threatening and/or perceived quality of life compromises are being communicated by familiar--or worse yet-- unfamiliar actors, then the vulnerabilities which ensue a crisis phenomenon break down caregiver comfort zones and work to create perceptions of uncertainty, fear, and powerlessness (Davidhizar, March-April, 1992).

The role of caregiver is often filled with new and trauma-producing changes in actors, messages, and contexts which create stress. The caregiver must find a way to co-create the rules for and meaning of the dialogue pertaining to their caregiving context so they can maintain an identity encompassed by personal power and significance (Cushman & Whiting, 2006). Such transactional communication structures empower explicit personal efficacy and role belongingness (Garcia-Jimenez, et al., 2014) which in turn initiate calming effects and biological

regulation of otherwise damaging adrenal emitting perceptions of danger, powerlessness, and/or social isolation for the caregiver (Masters, 2016).

### **Reflective Diary Narratives**

**Reflective Writing as a Tool.** The benefits of reflective writing have been studied in the field of health care. Medical diaries have been used to protect and improve patient wellbeing (Backman & Walther, 2001; Combe, 2005) and have had a positive impact on family wellbeing (Jones, et al., 2004; Garrouste-Orgeas, et al., 2012; Engstrom, Andersson, & Soderberg, 2008). The use of reflective writing is also used to teach and encourage empathy and humanistic thought to students in the medical field (Charon, 2001; Dasgupta & Charon, 2009).

Writing itself is used to make sense of things and organize thoughts. It can be used to plot schedules, discern change, comment on emotional reaction, make judgements about people or events, ask and consider questions, explore ideas, or find one's way (Perl, 1979). Writing that integrates reflection offers a highly-respected means for helping people process thoughts, emotions, and experiences (Boyd & Fales, 1983; Boud, Keogh, & Walker, 1985). In combination, reflection and writing are used in academics to rehash learning, initiate voice, personalize descriptive vocabulary, expose higher ideas, or make informed hypotheses about the future (Ryan, 2011).

Intentional reflectivity is a powerful intrapersonal tool. Beck (1992) argues that the ability to act reflectively is what makes us each uniquely human and allows us to develop our own innate and authentic identity. Giddens (1998) takes the argument further with the claim that reflective thinking is the precise process that allows us to cognitively transform challenges into opportunities. Reflective writing settles personal disparity, contributes to critical thinking, and

expands perspective (Jasper, 2005). For therapeutic use, reflective writing provokes imagination and depth of thought, while integrating a full range of emotional introspectiveness (Perl, 1979). Additionally, counselors use reflective writing to generate attitudes of ownership, self-direction, and creative problem solving (Wright & Cheung Chung, 2010). However, no matter what the purpose behind writing is, the outcome is always related to the establishment of personal meaning for the author (Goodman, 1973).

**Medical diaries.** Reflective writing used for medical diaries is of specific interest to this research. I have analyzed why and how such diaries work in efforts to adapt and use them as the independent variable in this proposed study. Medical diaries contain multiple-perspective reflective entries from family and friends, producing narratives that provide opportunities for both patients and their family members to process, “vent”, and record what they are feeling and/or thinking (Backman & Walther, 2001; Egerod I., Christensen, Schwartz-Nielsen, & Agard, 2011).

Medical diaries have offered a springboard for patients and family members to discuss many aspects of the family member’s illness. Severity details, progression timelines, and successful and failed recovery techniques are often documented and lead to more open decision-making and health care planning (Backman & Walther, 2001). The objective detail found within written documentation and photographs boosts the opportunity and likelihood of creative insight and shared dialogue about realistic future health goals and adaptations necessary for the patient and their family (Egerod I. , Christensen, Schwartz-Nielsen, & Agard, 2011).

The experience of socio-emotional support is another central benefit achieved from medical diaries. When patients reviewed their diaries, they could experience the functional support that came from family members during their time of need (Egerod I. , Christensen,

Schwartz-Nielsen, & Agard, 2011). Both patients and families expressed appreciation for the ability to track reflections that showed how they felt about the changing symptoms and components of the relationship between them as illness peaked and valleyed (Garrouste-Orgeas, et al., 2012). Family members also note that diaries helped them cope with emotional trauma by channeling the expression of thoughts and feelings that needed to be shared, processed, and understood by family members and friends (Robson, 2008; Ewens, Chapman, Tulloch, & Hendricks, 2013; Roulin, Hurst, & Spirig, 2007; Gjengedal, Storli, Holme, & Eskerud, 2010; Backman & Walther, 2001). The socio-emotional healing effects of such diary narratives are long-standing for both patients and family members (even in cases of bereavement) because of their ability to explicitly document a collective journey through hope, kindness, great sorrow, and confusion (Engstrom, Andersson, & Soderberg, 2008; Ewens, Chapman, Tulloch, & Hendricks, 2013).

**Best practices.** When reflective writing is used as a tool, specific instructional attributes work best. There are often no subject requirements, but entries serve higher value to the writer when content is personalized and topics contemplate shifts in beliefs, values, perspectives, emotions, decision-making, or relationships (Chretien, Goldman, & Faselis, 2008). Additionally, though there are generally no length of entry parameters, the impact of reflective writing is seen only when the reflective writing effort is repeated across time, with a four-week time frame being a marker of effectiveness (Kyles & Olafson, 2008; Backman & Walther, 2001).

Organization and content have also been studied for best practice considerations. Diary entries kept in chronological order help provide a more accurate recall of events can assist with the production of realistic goals and objectives for the patient and family members (Combe, 2005). Photographs were also very important features and added dimension and tone benefits to

the narrative review process (Backman & Walther, 2001) and improved mental health outcomes for patients and family members (Knowles & Tarrier, 2009). These reported benefits align with theoretical inference regarding the need for collaborative communication and its link to cognition within contexts of ambiguity as cited by Dance & Larson (1976).

### **Sense-making Theory**

Making sense of life experiences is a natural human curiosity and is especially obvious when people find themselves within unfamiliar and threatening circumstances (Weick, 1993). Sense making, sometimes called meaning making, is done through the creation of personal and collective narratives (Czarniawska, 1997) that help a person understand what is happening, assess and elicit necessary resources, decide on personal actions (Feldman, 2004), manage heightened emotions, and organize personal and collective identity within temporally perceived realities (Cooren, 2000; Quinn & Worline, 1996; Gergen, 1994). When within contexts of threat and fear, human motivation to act is based more on perceived and patterned roles and communication rules than on emotional disposition (Aquinas, 2002; Aristotle, 1985; Rachman, 1990; Worline & Steen, 2004). Timely subconscious or overt narratives construct necessary reality checks about context and meaning patterns and help people decide what they should say and do when facing psychological fear (Gergen, 1994; Czarniawska, 1997). Through stories, people can establish new and necessary rules and roles for communication when they find themselves stripped of their familiar contexts and everyday identities (Perrow, 1984; Quinn & Worline, 1996). Whenever contexts and rules are imposed, especially happening when there is danger or dynamically changing actors, channels, contexts, or messages which people are unfamiliar with, people will become disoriented and progressively powerless if they do not have internal or overtly stated narratives (McElheran, 2011).

According to Weick (1993), crisis sensemaking happens in three stages, including: (1) enactment, (2) selection, and (3) retention. First, when in crisis contexts, people tend to begin making sense of things by enacting their personal agency through the act of scrutinizing information for clues about their role within the context they are in; they enact their agency in this manner so that they can figure out what is happening and how to play a part in it. Next, observations of the variables of communication (senders, receivers, channels, contexts) are selected and interpreted for meaning so that these foundational communication variables can be defined in a way that indicates how the problems at hand might best be resolved. This process stems from a basic desire for survival (Grossman, 2008). Finally, as actions are taken (i.e., tried out by actors within the context), mental memories about what communication roles and strategies work most effectively (along with which ones do not work) begin to be retained by actors in order that actors may understand and tell a story to themselves so they can make decisions and perhaps tell others about how they are personally being affected by the present circumstances. This process helps individuals resume personal agency so they may experience a sense of identity and decision-making power within the context.

Reflective diaries can be effective tools for family caregivers to construct narratives that help them make sense of things within traumatic contexts, consuming roles, and imposed power structures. A daily entry, which may include just a few simple, self-reflective words or a seemingly every day photograph of the caregivers choosing, will be “all about” what the *caregiver* feels, thinks, or desires to process each day. The caregiver’s narrative will validate and empower his/her vital and unique role and identity and help the caregiver regulate and manage his/her sense of alterity and stress--therefore increasing opportunity for both empowerment and better health and wellness (Ullrich & Lutgendorf, 2002). The diary becomes

a tool which provides a channel whereby the caregiver can scrutinize and organize unfamiliar, threatening, or other pertinent information and construct the happenings of each day into a meaningful storyline. Additionally, with this chronological log of information, caregivers will be able to review mistakes or vent about problems at hand, and will be able to use the diary as documentation that will help improve the efficacy of decision-making, possibly even producing opportunities for collaboration about plans regarding present and future actions that could benefit both the care recipient and/or the caregiver.

The narrative will document and reflectively explain the caregiver's reality, and will keep the caregiver conscious of his/her role and lead to caregiver empowerment. The narrative process and product will theoretically provoke and organize cognitive and creative thoughts, make sense of rules and roles of communication, especially during times of crisis. These narratives offer a way for caregivers to retain power, role definition, and contribution value while using a tool that naturally leads to resiliency and collaboration (Benight, 2011). Through the self-initiated reflective process, both the self-efficacy and social support that are needed for greater personal empowerment and wellness can be achieved (Tsey, Harvey, Gibson, & Pearson, 2009).

### **Hypothesis and Research Question about Wellbeing**

Using the theoretical basis of sensemaking theory with an understanding of the positive impact diary narratives and reflective writing has on the wellbeing of people, especially as it pertains to critically or chronically ill patients and their families, makes it possible to predict how self-driven reflective diaries will impact the wellness of family caregivers. To investigate this, the following hypothesis was studied:

<p><b>HYPOTHESIS:</b> Reflective diary narratives will increase the wellbeing score of family caregivers, as measured on the WEMWBS.</p>
--

While perusing the literature for information about family caregiver wellbeing, it was found that studies have historically reported results within classifications of the relationship with who is cared for (i.e., child, spouse, or parent) or by care recipient diagnosis (i.e., physical or mental health). To better understand the generalizability of results of studies on family caregivers, this study proposes to analyze the wellbeing of family caregivers as a population entity in its own right, and compare the wellbeing of caregivers across and between “who is cared for” categories and across and between care recipient diagnoses.

This research model began by collecting data about categories of care regarding relationship with and diagnosis of the care recipient. While this information was not of primary concern, the data allowed for quantification of aggregate scores about family caregiver wellbeing within categories of (a) relationship or (b) diagnosis of care recipient, and such scores allowed for the ability to understand more about caregiving population diversity/homogeneity.

RESEARCH QUESTION 1: Will there be a difference between the wellbeing of caregivers based on the population they serve? i.e., (a) service to elder parent, grandparent, or parent-in-law vs. (b) service to spouse vs. (c) service to child or grandchild, vs. (d) other.

RESEARCH QUESTION 2: In each case will there be a difference in wellbeing between caregivers based on the primary diagnosis of their care recipient, specifically: (1) care recipient’s primary diagnosis and care needs are related to *physical* health, vs. (2) care recipient’s primary diagnosis and care needs are related to *emotional and/or behavioral* health.

### Chapter Three: Methods

In the previous chapter, a review of the theoretical literature and research on the positive effect of medical diary narratives on the wellbeing of health care patients and their family members was provided. Additionally, reflective writing itself was explained to have similar positive therapeutic effects. This study tested the effect reflective diary narratives have on the wellbeing of the family caregiver population when the caregivers independently initiated the diaries. In the present chapter, an explanation of the study method and measurement inventory is provided. A controlled experiment was used to test the research hypothesis about the wellbeing of family caregivers before and after the use of reflective diary narratives.

#### Participants

This study consisted of 62 family caregivers total, with two groups of 31 people each who fit the family caregiver role description:

*family members who becomes responsible for providing regular functional care for their parent (or grandparent or parent-in-law), spouse (or sibling), or child (or grandchild) because of a physical or emotional/behavioral health diagnosis (Stephens, Franks, & Townsend, March 1994). Functional care includes such things as looking after medications, taking the care recipient to doctor and health and human services appointments, providing general hygiene, and staying in the hospital with the patient.*

Family caregivers were recruited for this research through snowball sampling and online solicitation through social media, such as Facebook. Additionally, poster announcements were placed at organizations such as Aging and Disability Resource Centers and Health and Human

Service agencies. Recruitment messages used for posters and social media solicitation can be found in Appendix A.

## **Procedures**

Volunteer participants were directed to use an e-mail specifically for this study (FamilyCaregiverWellbeing@gmail.com) through the recruitment message, see Appendix A. After indicating a qualified interest, participants were sent a link to Qualtrics where they first read and completed an Informed Consent Form (see Appendix B).

After confirming their willingness to participate, Qualtrics linked participants into a demographics and basic caregiver role information survey (see Appendix C). Directly following completion of the demographics block, Qualtrics lead participants into the completion of the wellbeing survey, Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) used for both pre- and post-treatment episodes. Next, half of the participants (odd numbered participants: 1st, 3rd, 5th, etc.) were (randomly) assigned to the treatment group where they were prompted to construct daily personal narratives for one month. (Instructions for reflective diaries can be found in Appendix G.) The other half of participants (even numbered participants: 2nd, 4th, 6th, etc.) were assigned to the control group where they took the WEMWBS at the origin and again one month later. The WEMWBS took 5-10 minutes to complete and individual results were kept confidential.

## **Measures**

Participants respond to questions through the online inventory after a request was made for basic demographic information as found in Appendix C (age, gender, education level, and ethnicity) and basic medical information about the care recipient they support (physical or

mental health primary diagnosis), length of time since caregiving for this family member began (less than 12 months, two to five years, six to nine years, 10 years or more), and their relationship to the care recipient (they are the child or grandchild, spouse or committed partner, sibling, or the parent/grandparent/parent-in-law of the care recipient). This section took less than 10 minutes to complete.

The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) consists of 14 positively phrased items where participants were asked questions pertaining to their ability to experience quality of life factors pertaining to physical, emotional, intellectual, and social wellbeing. The WEMWBS originated in the UK and has shown good validity and test-retest reliability (.83) (Stewart-Bown & Jamohamed, 2008). Each question asks for response on a 5-point Likert scale, 1=*None of the time*, 5=*All of the time*, to measure the caregiver's state of wellbeing during the prior two-week period. Comprehensive scores are achieved by adding all items with totals ranging from 14-70 and higher scores translating to better wellbeing. Some items on the inventory include "I've been feeling useful "; "I've been feeling relaxed "; and "I've been feeling interested in other people ". The full WEMBS (2008) can be found in Appendix D. Permission to use the copywritten Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) is displayed in Appendix E.

### **Statistical Analysis**

SPSS was used to analyze the data. Mean and standard deviation were computed for numeric variables whereas frequency and percentages were computed for nominal variables. Comparisons were analyzed using the t test.

Three missing test variable scores were discovered on the original data set. Median scores for each specific variable missing a score were calculated across all survey participants. Specific variable median scores were used to replace each of the three blank variable scores on the data set so score totals would not be skewed falsely low.

Of the sixty-two total participants, eight were discovered to have journaled before beginning the study. The scores of these eight participants were excluded from the data analysis in order to purify the measure of effect the independent variable of writing in a diary had on the wellbeing of the caregiver participants. Further participants were removed from the analysis if they filled out one survey (pre-test or post-test) but not the other. Fortunately, there were seven participants who were removed from each treatment group, so the final sample population size for the control group ( $n = 25$ ) remained equal in size to the experiment group ( $n = 25$ ).

## **Chapter Four: Results**

The culmination of this study is revealed in this chapter. The summer-long investigation into theory, the construction of sound methods and valid instruments of measure, the brooding determination to recruit and gather participants, and the compilation and analysis of data have all come together to teach how the family caregiver responds to reflective writing.

After sorting and analyzing participant demographics, the hypothesis of this study was tested through a paired sample t-test that separated and calculated the mean of pre- and post-total wellbeing scores for the experimental group and for the control group. The hypothesis regarding the ability for reflective writing to positively affect family caregiver well-being and the themes for topics of reflection participants self-reported are illustrated in this chapter.

### **Socio-demographic and Clinical Profiles**

This study included mild diversity within the group of sixty-six family caregiver participants. Though the researcher found it necessary to exclude sixteen participants for either failure to complete both pre- and post-test surveys or for participating in journaling activity before beginning this study, the complete group of sixty-six caregivers (n = 66) was analyzed for demographics of age, gender, ethnicity, and educational level. The mean and mode age of participants was 50 years old (range 18-80). The majority of caregivers were female (72.7%). Ethnicity was represented with a predominance of caucasian participants (83.3%), with participants identifying with some minority groups (three as American-Indian, two as Hispanic, one as Asian-American, and one as African-American). Forty of the participants reported their highest level of education to be graduating from high school (n = 21) or from a two year college

(n = 19), with one reporting no high school diploma, thirteen having a Bachelor's degree, and six reporting receipt of a graduate level degree.

Participants were asked who in their families they provided care for. Well over half of caregivers (62.1%) were assisting either parental figures (n = 21) or children/grandchildren (n = 20). A minor proportion (n = 7 each) cared for siblings or other relatives, and even fewer (n = 6) cared for a spouse.

The clinical profile of the care recipients was evenly distributed, with most participants reporting the family member they provided care for as having physical health needs (45.5%), and a few less having emotional and/or behavioral health needs (37.9%); seven participants (10.1%) chose the option of "other" to answer this question, and four (6.1%) declined to answer. Participants reported varied lengths of service in their caregiver roles, with several (n=11) being new to the role (less than 12 months), most serving for one to nine years (n=37), and a large number serving for over 10 years (n=14). The mode was reporting 3-5 years for service in the family caregiver role (n=21).

### **Wellbeing Scores**

The *Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)* was used to measure overall participant wellbeing. Participants self-reported As shown in Table 1, when analyzing all participants together, scores for pre- and post-tests are fairly close, with a mean total WEMWBS score for the pre-test (46.0; SD = 6.41) calculated to be slightly less than the mean total WEMWBS score for the post-test (47.8; SD = 7.49).

**Table 1. Results of total wellbeing scores for pre- and post-test for all participants**

	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. Deviation</b>
<b>PREtotal WEMWBS</b>	<b>50</b>	<b>29.00</b>	<b>61.00</b>	<b>46.00</b>	<b>6.41</b>
<b>POSTtotal WEMWBS</b>	<b>52</b>	<b>30.00</b>	<b>66.00</b>	<b>47.80</b>	<b>7.49</b>
<b>Valid N (listwise)</b>	<b>50</b>				

*Abbreviation: WEMWBS = Warwick-Edinburgh Mental Well-Being Scale*

See Table 2 for the true contrast of scores which became visible after separating scores for participants (n = 50) when separating the control group (n = 25: those who did not reflectively write between wellbeing tests) from the scores of the experiment group (n = 25: participants who reflectively wrote in diaries between wellbeing tests). Caregivers in the control group reported a total pre-WEMWBS mean score that was nearly identical to their reported post-WEMWBS mean score (46.88; SE = 1.12 vs. 46.68; SE = 1.07).

**Table 2. Results of total wellbeing scores for caregivers separated by treatment group**

<b>TREATMENT GROUP</b>		<b>Mean</b>	<b>N</b>	<b>Std. Deviation</b>	<b>Std. Error Mean</b>
<b>Control</b>	<b>PREtotal_WB</b>	<b>46.88</b>	<b>25</b>	<b>5.62</b>	<b>1.12</b>
	<b>POSTtotal_WB</b>	<b>46.68</b>	<b>25</b>	<b>5.34</b>	<b>1.07</b>
<b>Experiment</b>	<b>PREtotal_WB</b>	<b>45.12</b>	<b>25</b>	<b>7.12</b>	<b>1.42</b>
	<b>POSTtotal_WB</b>	<b>49.12</b>	<b>25</b>	<b>9.33</b>	<b>1.87</b>

*Abbreviation: WB = Wellbeing score as achieved from the Warwick-Edinburgh Mental Well-Being Scale*

*Control Group took pre- and post-WEMWBS, and did not write reflective diaries during the approximate four weeks between tests.*

*Experiment Group took pre- and post-WEMWBS, and wrote reflective diaries for approximately four weeks between tests.*

The change in total wellbeing scores between pre- and post-treatment surveys is explained next. The analyses of the mean difference between the pre- and post-WEMWBS scores (Table 3) for the control group (.20 +/- 6.78), with a range of -2.6 – 3.0, shows no significant change in wellbeing ( $t = 0.15$ ;  $p = 0.88$ ). On the other hand, the analyses of the mean difference between scores for the experiment group (45.12; SE = 1.42 vs. 49.12; SE = 1.87), with a range of -6.95 - -1.05, indicates a significant improvement in overall wellbeing ( $t = -2.80$ ;  $p = 0.01$ ).

**Table 3. Results of difference between pre-and post-WEMWBS scores by treatment group**

TREATMENT GROUP		Paired Differences					T	Df	Sig. 2-tailed
		Mean	Std. Dev.	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Control	PREtotal_WB - POSTtotal_WB	0.20	6.78	1.36	-2.60	3.00	0.15	24	0.88
Experiment	PREtotal_WB - POSTtotal_WB	-4.0	7.15	1.43	-6.95	-1.05	-2.80	24	0.01

*Abbreviation: WB = Wellbeing score as achieved from the Warwick-Edinburgh Mental Well-Being Scale*

*Control Group took pre- and post-WEMWBS, and did not write reflective diaries during the approximate four weeks between tests.*

*Experiment Group took pre- and post-WEMWBS, and wrote reflective diaries for approximately four weeks between tests*

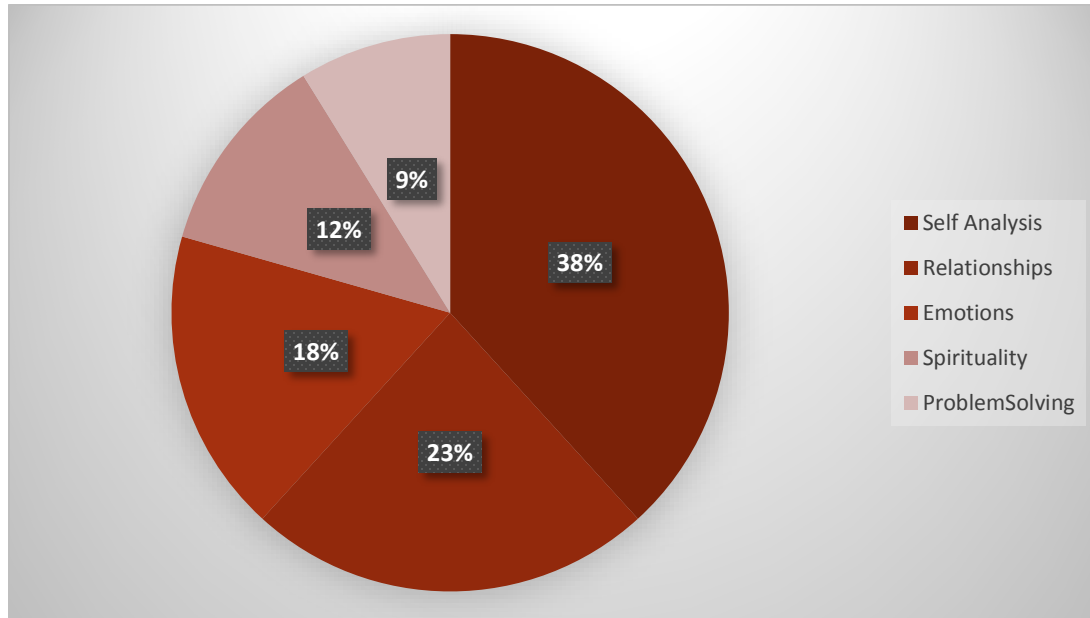
### **Topics of Narratives in Family Caregiver Diaries**

There were five themes discovered within the topic self-reported by the family caregiver participants who wrote in diaries ( $n = 29$ ). Some of the reports came from participants who were later excluded from the data analysis, but there is no easy way or reason to eliminate their topics of writing in this qualitative report. Topics included themes for self-analysis of daily

happenings (n = 13), two of which specifically noted employment related reflections. For example, one participant wrote about “my daily routine for giving care and for caring for me”, suggesting the participant decided to analyze and separate giving care to another from giving care to self. Another participant recognized “what’s been positive and what’s been stressful in a day”. (provide a one sentence summary of what these comments reveal about this theme).

Participants also reflected about family and other relationships (n = 8). Comments found within this theme include, “thankfulness for a loving family...” and “finding strength to let others handle their own affairs”. Generally, when deciding to include content about family in their reflections, they expressed the need to ponder the strength that the love of family provided, but at the same time, articulated the distinct need to operate as a set of interdependent units.

Processing emotions and feelings (n = 6) was the central topic of some participant reflections, with specific comments about working through feelings of failure and of guilt (e.g., “I must re-teach myself to love me again...and not feel guilty”). A total of seven participants reported reflecting on topics about prayer, spirituality, and scripture (n = 4) and others used their reflection journals to work through problems and make decisions (n = 3). Some participants listed topics that clearly belonged in more than one themed category. Please see Appendix H for detailed self-reported topic notes.

**Graph 1. Topics of Reflective Writing from Participant Diaries**

Two of the participants wrote comments through unsolicited email and Facebook that expand on their personal reactions to the reflective writing experience. One family caregiver wrote:

My main concern has switched from care taking for a family member to self survival. I think it's a wake up call for me...I've been learning...that I truly have forgotten how to care for and love myself...At times I really resent being in the caregiver role. I plan to learn to have fun again and not feel guilty...

Another caregiver, who was identified as a pre-writer and had to be excluded from the data analysis, wrote:

...I now understood that I was no longer making progress with the agencies designed to help my son, not because of the reasons I commonly site (like, "I just don't have time for this"), but instead because I didn't want to identify with the family caregiver role anymore...Journaling with this perspective helped me find my way back; this time I designed the role the way I wanted to live it out.

### **Analysis of Answers to Research Questions 1 & 2**

Participant recruitment was projected to reach 100 family caregivers. Because there were only sixty-six participants in this study, and because sixteen of those participants were disqualified for either failing to take both pre- and post-test surveys or for pre-writing, there remains too few participants ( $n = 50$ ), by comparison to the 44 million Americans who live this role (National Alliance for Caregiving, 2018), to draw conclusions about the effect of care recipient diagnosis or relationship. Further, because of the snowball method was used to recruit participants, it's likely participation across these specific variables may have been skewed. For example, the heavy representation of caregivers providing care for a child (30%) is not congruent with national statistics of family caregiver relationships which report only 14% care for a child (National Alliance for Caregiving, 2009). It is likely that participants who cared for a child recruited other family caregiver participants who cared for a child. Additionally, study participants reporting caring for their spouse (9%) is much lower than national statistic (20%) reports (AARP Public Policy Institute, 2014). Again, recruitment seemed to happen along natural family caregiver support networks, and where such networks were not tapped into, participants were not recruited. For these reasons, the two research questions for this study will not be analyzed or reported.

## **Chapter Five: Discussion**

Research indicates that the family caregiver population experiences multi-dimensional damage to their wellbeing. Studies show increased emotional anxiety and depression (Sheehan, Hiscock, Massie, Jaffe, & Hay, 2014; Seeman & Seeman, 1983), physical challenges, age acceleration, and biological deterioration (Nelson, Lord, & Ochocka, 2001; Eppel, et al., 2004; Glaser & Glaser, 2003). This chapter will discuss the reasons why regular reflective writing improved family caregiver wellbeing through the use of transactional and sense-making communication. Limitations of this study and recommendations for future family caregiving research are also discussed.

### **Transactional Communication**

Family caregiver participants who wrote reflectively included topic themes about their daily routines and their relationships the way they decided to see things and process communication. Further, writing reflectively, which is by nature more transactional and therefore empowering, caused well-being improvement. Communication that is linear in pattern, whereby a message is conceived by the sender and dictated to the receiver leads to progressive disempowerment and receiver complacency (Berlo, 1960; Dance, 1967). This is a result of a health care system that is set up around modernist cultural mindset (Kearns, 1995; Johnson, 2011; Fisher, 2008), whereby patients and family caregivers experience ongoing exposure to authoritative and top-down linear communication (Cherlin, et al., 2005; Giuliano, Mitchell, Clark, Harlow, & Rosenbloom, 1990; Oruche, Gerkenmeyer, Stephan, Wheeler, & Hanna, 2012). Barland (1970) describes the need for transactional communication that is open and participative, where all communicators are both senders and receivers of information, in order to create increased well-being and resiliency. Reflective writing gives family caregivers a chance to

intentionally step out of the role of receiving medical directions from doctors, health and human service professionals, and the care recipients about what they need to do to care for their family member. When writing, family caregivers become senders of messages, focusing on the content and shaping the rhetoric used to communicate, cognitively engaging on the roles and messages they want to process, resolving the problems or remembering the joys they want to experience and savor. By writing, family caregivers are able to move out of the decoder's role of obedience and assume an encoder's role of self-advocacy in the communication process. When in the receiver's role, caregivers interpret and act on what they are told by others. By contrast, when in the sender's role, caregivers decide what to say and how to say it--allowing them to take control over the authority role and leadership power involved in encoding messages.

When writing reflectively, family caregivers choose the who, what, where, when, and why of all communicated messages. Reflective writing can be used to process and evaluate daily routines, to plan and decide on courses of action and to contemplate change about the direction of actions considered, to comment on unsettled emotions, to discern about the meaning of people's comments or actions, to ask and consider questions, or to find one's way (Perl, 1979). The act of reflection itself prompts people to process thoughts, emotions, and experiences (Boyd & Fales, 1983; Boud, Keogh, & Walker, 1985). For these reasons, reflective diaries create a window for caregivers to experience their own separate autonomy, which empowers and creates the self-perceptions of worth that are necessary for wellbeing (Ullrich & Lutgendorf, 2002). In all, reflective writing stabilizes a person's self-awareness and sense of agency by creating an overt opportunity to focus on personal thoughts, feelings, roles, and reactions to daily events whereby individuals are empowered to assign their own meaning to events, messages, and other people.

Reflective writing topic themes from family caregivers in this study align with the components described as necessary for empowerment to occur. Self-reported topic themes included the processing of daily routines, the evaluation of how things happened and who was involved, the assignment of emotional and relationship meaning, and the mechanisms involved in personal decision making. During the writing phenomena, the family caregivers were able to step out of the roles of listening to the nurse, pharmacist, financial auditor, or disability advocate about what their care recipient needs and they were able to focus back on the needs of themselves. Family caregivers re-established personal ownership for their daily events, their roles within relationships, their emotions, and their decisions, which seemed to restore their agency of Self (Johnson, 2011).

### **Sense-making through Personal Narratives**

It is natural to cognitively construct conscious and subconscious narratives to make sense of communication phenomena (Czarniawska, 1997; Ulrich & Lutgendorf, 2002). Narratives create meaning-making structures and a basis of purpose (Barnlund, 1970) for people to experience the comfort (versus fear or danger) that is necessary for wellbeing (Davidhizar, March-April, 1992; Tsey, Harvey, Gibson, & Pearson, 2009). People rely on their conscious and subconscious narratives even more heavily when in unpleasant and/or unfamiliar contexts (Gergen, 1994), telling stories to themselves or to others in order to design the rules and roles necessary to navigate new, and often fear-invoking contexts (Perrow, 1984; Quinn & Worline, 1996). Contexts are perceived as dangerous, rather than comfortable, when the rules and roles are new and imposed (McElheran, 2011) and will remain uneasy until internal and overt narratives are constructed. Family caregivers who wrote reflectively did, in fact, construct their narratives about the actors, channels, contexts, and/or content they chose to include during their

writing time. These caregivers were able to claim back their personal power by choosing to write (choosing a channel for communication rather than having one chosen for them), choosing the content about what they wanted to “say” in their writing, choosing who they would (or would not) say it about, and choosing which contexts of communication (e.g., home, work, clinic, community) they wanted to focus on.

The caregiver role is often somewhat circumstantially imposed on individuals rather than sought out by them. Though many love to care for their family members, no one grows up with the life goal of hoping someone in their family becomes ill or disabled just so they can assume the role of family caregiver. Results from this study support previous research (Quinn & Worline, 1996; Perrow, 1984; McElheran, 2011) describing how family caregivers often feel forced into unfamiliar, unpleasant, and even unwanted situations, roles, and negative failure messages. For example, one participant in this study openly expressed “... I really resent being in the caregiver role.” Another said the “...family caregiver role is filled with failure...being told ‘no’ all of the time...”, and concluded “...I didn’t want to identify with the caregiver role anymore.”

Writing reflectively offers a means for caregivers to regularly construct their own narratives and personally assign cognitive and emotional meaning to their interactions and thoughts. By crafting regular diary entries, participants were able to experience growth and improvement in the elements Benight (2011) sites as the critical components of wellbeing: personal power, personal role definition, and individualized contribution value. In addition to seeing a significant self-reported improvement in overall wellbeing for participants who wrote, a clear majority reported writing about topics that facilitate these key elements. The largest group (38% of participants) reported that they evaluated themselves for how their day went—retaining

personal power and individualizing their contribution value. Another 23% of them wrote about their relationships—defining their role within their perceived personal contexts. The concrete cognitive clarity and the chronological order of events produced by regular diary entries adds to the opportunities to overtly and intentionally make sense and self-assign meaning to what first seemed unpleasant, unfamiliar, and imposed.

### **Limitations**

Though grateful for the serendipitous findings, there were roadblocks and limitations in this research journey. Recruitment of family caregivers proved to be very difficult. Many people known to provide care to family members did not identify as such and therefore believed they were not qualified to be in this study; understandably, many others did not believe they had time to participate. In addition, rather than an easy one-time “click here” to participate, participants were asked to provide their email, both for privacy and for some degree of anonymity. This process, though protecting privacy, inhibited some from participation due to forgetting to check their email or because they did not have an email or even a computer. In the end, the researcher put up over 20 posters in strategic health and human services and aging and disability centers, made and posted a video on Facebook that received over 3K views, attended family caregiver support groups, and designed and distributed over 120 invitation-to-participate postcards, and received only 66 participants. Several follow-ups were needed to keep these 66 in the pool, and then 16 of these hard-earned participants were excluded from data analysis because they had either failed to fill out both surveys or because they regularly wrote before the study began. It was notably difficult to recruit family caregivers.

An additional limitation is that the researcher had a personal tragedy occur after starting the first round of eight participants. While handling the tragedy, more than forty-five days went

by from the WEMWBS pre-test of the first group of participants. IRB approved the use of these participants in the data analysis even though the testing time was several days over the 30-day interval between tests.

With the essential knowledge that family caregivers are in part stressed because of the amount of work they have to do, it is the researchers' speculation that regular writing might not be something family caregivers would have the discipline to do long-term. Because this was a thirty-day study, participants were able to manage a regular writing routine. If encouraged to fit in the writing task for a longer period of time, caregivers may perceive writing as a burden instead of a tool.

### **Future Research**

The claim that regular reflective writing improves family caregiver well-being is made, but much is left to study. Future research testing other transactional communication tools for efficacy, like one-on-one or online dialoguing, would add to the repertoire of aids available to family caregivers for improving their well-being. Additionally, it would be fascinating to discover more about the family caregiver role in regards to sense-making theory. Qualitative research which investigates the themes, rhetoric, and very construction process family caregivers use to develop their shifting identity when first initiating, when undergoing specific crisis level transitions, or when no longer finding it necessary to care for a long-term family care-recipient (because of healing or death) would yield both theoretical and practical implications and advancements for the study of health communication.

The recruitment process could also be improved, somehow building in more ease and efficiency than this study allowed; and with more participation, more specific categories of data

could be studied. For example, it would be interesting to compare the effect of reflective writing while separating participants by length of service as caregivers, or by the type of need their care recipient required (emotional-behavioral or physical). It would also be interesting to consider tapping specifically into foster care families who many times care for children and teens who are only transiently in their care. Also, research could uncover whether or not the stigma of having a family member with an often culturally stigmatized mental or social behavioral diagnosis has any effect on how a family caregiver shapes their identity. Finally, adding a category for caring for family members who are addicts would make good sense in contemporary American culture as 20.5 million Americans are recorded as having a substance abuse disorder in 2015 (American Society of Addiction Medicine, 2015). Answering more specific questions about how communication can be used as a tool of empowerment and well-being furthers the value, knowledge, and wisdom of communication as a field of study.

Finally, the idea of using reflective story telling within the context of community and grief is something this researcher is already implementing. The personal tragedy of losing a son was experienced by the researcher in the midst of this study. Hearing, telling, and now recording stories about the researcher's lost loved one has drawn a large and engaged audience. When the researcher started up an interactional story-telling Facebook page in her son's name, there were nearly 100 friends within just one day. This audience serendipitously included at least 10 other mothers who have lost a child. And today, May 14<sup>th</sup>, the day this research will be deposited for final review, an entire community will gather to commemorate the berieved young man for his birthday. Funds were collected and each member of the community will receive a tree to plant in AJ Zdroik's name so that more stories can be told about the beauty of life. Research on how reflective story telling can empower and heal communities would be fascinating.

## **Chapter Six: Conclusion**

This study suggests that the wellbeing of family caregivers is improved when regularly using reflective writing as a tool. Family caregivers in this study reported writing reflectively about themselves; their family and other relationships; and their emotions, spirituality, and problem-solving as they improved their wellbeing. During this month-long study, those caregivers who were in the experimental treatment group showed statistically significant improvement in their overall scores for wellbeing. Because reflective writing enhances the wellbeing of the family caregiver population, both freedom in health care decisions for patients, and the ability of families to support the choice to care for family members at their homes are made easier and with a little less burden. In the end, it is really about finding ways to make it possible to experience how good and important it is to nurture and care for oneself and for one-another, especially when caring for one-another involves those we are blessed to have in our own families.

## References

- AARP Public Policy Institute. (2011). *Valuing the Invaluable*.
- AARP Public Policy Institute. (2014, April 29). *Caregiving Spouses and Partners Often "Go It Alone" with Insufficient Help*. Retrieved from Caregivers:  
<http://www.caregivers.com/blog/2014/04/caregiving-spouses-receive-insufficient-help/>
- Akerman, E., Ersson, A., Fridlund, B., & Samuelson, K. (2013). Preferred content and usefulness of a photojournal as described by ICU patients: A mixed method analysis. *Australian Critical Care, 26*, 29-35.
- American Society of Addiction Medicine. (2015). *Opioid Addictions: 2016 Facts and Figures*. Hyattsville, MD: National Center for Health Statistics.
- Aquinas, T. (2002). *The Essential Aquinas Writings on Philosophy, Religion, and Sociology*. Westport, CT: Praeger.
- Aristotle. (1985). *Nicomachean Ethics*. Indianapolis: Hackett Publishing Co.
- Backman, C., & Walther, S. (2001). Use of personal diary written in the ICU during critical illness. *Intensive Care Medicine, 27*, 426-429.
- Bandura, A. (2010). *Self-Efficacy*. John Wiley & Sons, Inc.: DOI: 10.1002/9780470479216.corpsy0836.
- Barnlund, D. C. (1970). *A transactional model of communication*. In K. K. Sereno and C. D. Mortensen (eds.). New York, NY: Harper and Row.
- Beck, U. (1992). *Risk Society: Towards a New Modernity*. London: Sage.
- Benight, C. (2011). Chapter: Cognitive factors and resilience: How self-efficacy contributes to coping with adversities. In S. M. Southwick, B. T. Litz, D. Charney, & M. J. Friedman, *In Resilience and Mental Health Challenges Across the Lifespan* (pp. 45-55). Cambridge University Press. DOI: 10.1017/CBO9780511994791 .
- Bergsma, L. J. (2004). Empowerment education: The link between media literacy and health promotion. *The American Behavioral Scientist, 152-164*.
- Berlo, D. (1960). *The Process of Communication: An Introduction to Theory and Practice*. New York, NY: Holt, Reinhart, and Winston.
- Boud, D., Keogh, R., & Walker, D. (1985). *Reflection: Turning experience into learning*. London: Kegan Page.
- Boyd, E. M., & Fales, A. W. (1983). Reflective learning: Key to learning from experience. *Journal of Humanistic Psychology, 23*, 99-117.
- Boyd, E. M., & Fales, A. W. (1983). Reflective learning: Key to learning from experience. *Journal of Humanistic Psychology, 23*, 99-117.

- Census 2000. (July 2005). *Disability and American Families*. Washington D.C.: Census 2000 Special Reports.
- Charon, R. (2001). Narrative medicine: A model for empathy, reflection, profession and trust. *JAMA*, 1897-1902.
- Cherlin, E., Fried, T., Prigerson, H. G., Schulman-Green, D., Johnson-Hurzeler, R., & Bradley, E. H. (2005). Communication between physicians and family caregivers about care at the end of life: When do discussions occur and what is said? *Journal of Palliative Medicine*, 8, (6)  
<https://doi.org/10.1089/jpm.2005.8.1176>.
- Chretien, K., Goldman, E., & Faselis, C. (2008). The reflective writing class blog: Using technology to promote reflection and professional development, 23. *Innovations in Education*, 2066: doi:10.1007/s11606-008-0796-5.
- Combe, D. (2005). The use of patient diaries in an intensive care unit. *Nursing Critical Care*, 10, (1), 31-34.
- Cooren, F. (2000). *The Organizing Property of Communication*. Amsterdam/Philadelphia: John Benjamins.
- Cushman, D., & Whiting, G. C. (2006). An approach to communication theory: toward consensus on rules. *Journal of Communication* 22, (3) 217-238.
- Czarniawska, B. (1997). *Narrating the Organization Dramas of Institutional Identity*. Chicago and London: University of Chicago Press.
- Dance, F. E. (1967). Toward theory of human communication: original essays. In F. E. X. Dance (ed.). *Human Communication Theory*, 288-309.
- Dance, F. E., & Larson, C. (1976). *The Functions of Human Communication: A Theoretical Approach*. New York, NY: Holt, Rinehart and Winston.
- Dasgupta, S., & Charon, R. (2009). Personal illness narratives: Using reflective writing to teach empathy. *Academic Medicine*, 79, 351-56.
- Davidhizar, R. (March-April, 1992). Understanding powerlessness in family member caregivers of the chronically ill. *Geriatric Nursing*, 13, (2), pp. 66-69. DOI: [http://dx.doi.org/10.1016/S0197-4572\(05\)80110-7](http://dx.doi.org/10.1016/S0197-4572(05)80110-7).
- Egerod, I., Christensen, D., Schwartz-Nielsen, K. H., & Agard, A. S. (2011). Constructing the illness narrative: A grounded theory exploring patients' and relatives' use of intensive care diaries. *Critical Care Medicine*, 39, 1922-1928.
- Engstrom, A., Anderson, S., & Soderberg, S. (2008). Re-visiting the ICU experience of follow-up visits to ICU after discharge: A qualitative study. *Intensive and Critical Care Nursing*, 24, 233-241.
- Eppel, E. S., Blackburn, E. H., Lin, J., Dhabhar, F. S., Adler, N. E., Morrow, J. D., & Cawthon, R. M. (2004). Accelerated telomere shortening in response to life stress. (pp. 17312-17315). National Academy of Sciences of the United States of America.

- Ewens, B., Chapman, R., Tulloch, A., & Hendricks, J. M. (2013). ICU survivors' utilization of diaries post discharge: a qualitative descriptive study. *Australian Critical Care, 27*, 28-35.
- Feldman, M. S. (2004). Resources in emerging structures and processes of change. *Organizational Science, 15*, (3) 295-309.
- Fisher, P. (2008). Wellbeing and empowerment: the importance of recognition. *Sociology of Health & Illness, 30*, (4) 583-598.
- Galovski, T., & Lyons, J. A. (2004). Psychological sequelae of combat violence: A review of the impact of PTSD on veteran's family and possible interventions. *Aggression and Violent Behavior, 9*, (5) 477-501. DOI: [http://dx.doi.org/10.1016/S1359-1789\(03\)00045-4](http://dx.doi.org/10.1016/S1359-1789(03)00045-4).
- Garcia-Jimenez, M., Santoyo-Olsson, J., Oritiz, C., Lahiff, M., Sokal-Gutierrez, K., & Napoles, A. M. (2014). Acculturation, inner peace, cancer self-efficacy, and self-rated health among Latina breast cancer survivors. *Journal of Health Care of Poor and Underserved, (4)*:1586-602. DOI: 10.1353/hpu.2014.0158.
- Garrouste-Orgeas, M., Coquet, I., Perier, A., Timsit, J., Pochard, F., Philippart, F., . . . Misset, B. (2012). Impact of an intensive care unit diary on psychological distress in patients and relatives. *Critical Care Medicine, 40*, 2033-2040.
- Gergen, K. (1994). *Realities and Relationships Soundings in Social Construction*. Boston: Harvard University Press.
- Giddens, A. (1998). *The Third Way: the Renewal of Social Democracy*. Cambridge: Polity Press.
- Gilbert, M., Chamberlain, J. A., & White, C. R. (2012). Controlled clinical trial of a self-management program for people with mental illness in an adult mental health service - The Optimal Health Program (OHP). *Australian Health Review, 36*, 1-7.
- Giuliano, A. J., Mitchell, R. E., Clark, P. G., Harlow, L. L., & Rosenbloom, D. (1990, June). The meaning on a caregiving scale: Factorial and conceptual dimensions. *Poster session presented at the second annual convention of the American Psychological Society*. Dallas, TX.
- Gjengedal, E., Storli, S., Holme, A., & Eskerud, R. (2010). An act of caring - patient diaries in Norwegian intensive care units. *Nursing i Critical Care, 15*, 176-184.
- Glanz, K., Rimer, B. K., & Viswanath, K. (. (2008). *Health Behavior and Health Education: Theory, Research, and Practice, 4th ed.* San Fransisco: Jossey Bass: A Wiley Imprint.
- Glaser, J., & Glaser, R. (June 30, 2003). *Chronic stress and age-related increases in the proinflammatory cytokine IL-6*. National Academy of Sciences.
- Goodman, K. S. (1973). *Miscue analysis: Applications to reading instruction*. Urbana, IL: NCTE and ERIC.
- Green, L. W., & Kreuter, M. W. (2005). *"Precede-Proceed." Health program planning: an educational and ecological approach. 4th ed.* New York: McGraw-Hill.
- Griffiths, W. (1972). Health education definitions, problems, and philosophies. *Health Education & Behavior, 1*, (3) 7-11. DOI: 10.1177/109019817200103103.

- Grossman, D. L. (2008). *On Combat, 3rd ed.* Warrior Science Publications.
- Hamel, G. (2000). *Leading the Revolution.* Boston: Harvard Business School Press.
- Jasper, M. A. (2005). Using reflective writing within research. *Journal of Research in Nursing, 10*, (3) pp. 247-260 doi: 10.1177/174498710501000303.
- Johnson, M. O. (2011). The shifting landscape of health care: Toward a model of health care empowerment. *American Journal of Public Health, 101*, (2) 265-266.
- Jones, C., Skirrow, P., Griffiths, R. D., Ingleby, S., Eddleston, J., Waldmann, C., & Gager, M. (2004). Post traumatic stress disorder-related symptoms in relatives of patients following intensive care. *Intensive Care Medicine, 30*, 456-460. DOI: 10.1007/s00134-003-2149-5.
- Kearns, R. A. (1995). Medical geography: Making space for difference. *Progress in Human Geography, 19*, 2, 251-259.
- Knowles, R., & TARRIER, N. (2009). Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: a randomised controlled trial. *Critical Care Medicine, 37*, 184-191.
- Kurylo, M. F., Elliott, T. R., & Shewchuk, R. M. (2001). Focus on the family caregiver: A problem solving training intervention. *Journal of Counseling and Development, 275-281.*
- Kyles, C. R., & Olafson, L. (2008). Uncovering preservice teachers' beliefs about diversity through reflective writing. *Education & Educational Research.*
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.
- MacNeil, G., Kosberg, J., Durkin, D., Dooley, W. K., Decoster, J., & Williamson, G. (2009). Caregiver mental health and potentially harmful caregiving behavior: The central role of caregiver anger. *Gerontologist*, DOI: 10.1093/geront/gnp099.
- Masters, R. (2016). Preventing invisible wounds. *EMS World, 45*, (8), 50-52.
- McElheran, M. (2011, April 20). *Trauma Change Resilience.* Retrieved from TEDx: <https://www.youtube.com/watch?v=P8nMgY5dkTs>
- National Alliance for Caregiving. (2018). *Advancing Family Caregiving Through Research, Innovation, and Advocacy.* Bethesda, MD : National Alliance for Caregiving.
- National Alliance for Caregiving. (2009). *Caregiving in the U.S.* National Alliance for Caregiving. Washington D.C.: AARP.
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C. L., Kuerbis, A. N., & Donelan, K. (2002). When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health, 92*, (3), 409-413.
- Nelson, G., Lord, J., & Ochocka, J. (2001). Empowerment and mental health in community: Narratives of psychiatric consumer/survivors. *Journal of Community & Applied Social Psychology, 11*, 125-142.

- Noonan, A. E., & Tennstedt, S. L. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist, 37*, (6) 785-794.
- Oruche, U. M., Gerkenmeyer, J., Stephan, L., Wheeler, C. A., & Hanna, K. M. (2012). The Described Experience of Primary Caregivers of Children With Mental Health Needs. *Archives of Psychiatric Nursing, 382-391*.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 583-594*.
- Perl, S. (1979). The Composing Processes of Unskilled College Writers. *Research in the teaching of English, 13*, (4), pp. 317-336.
- Perrow, C. (1984). *Normal Accidents*. New York: Basic Books.
- Prilleltenski, I., Nelson, G., & Peirson, L. (2001). The role of power and control in children's lives: An ecological analysis of pathways toward wellness, resilience and problems. *Journal of Community & Applied Social Psychology, 11*, 143-158.
- Quinn, R. E., & Worline. (1996). Enabling courageous collective action. *Organization Science 19*, (4) 497-516.
- Rachman, S. J. (1990). *Fear and Courage*. New York: W. H. Freeman and Company.
- Robson, W. P. (2008). An evaluation of patient diaries in intensive care. *The World of Critical Care Nursing, 6*, 34-37.
- Roulin, M., Hurst, S., & Spirig, R. (2007). Diaries written for ICU patients. *Qualitative Health Research, 17*, 893-901.
- Ryan, M. (2011). Improving reflective writing in higher education: A social semiotic perspective. *Teaching in Higher Education, 99-111*. DOI: <http://dx.doi.org/10.1080/13562517.2010.507311>.
- Ryan, M., & Deci, E. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*, 68-78.
- Sapolsky (Director). (2008). *Stress, Portrait of a Killer* [Motion Picture].
- Seeman, M., & Seeman, T. (1983). Health behavior and personal autonomy: A longitudinal study of the sense of control in illness. *Journal of Health and Social Behavior, 24*, 144-160.
- Sellnow, T. L., & Seeger, M. W. (2013). Chapter 1: Introduction to Crisis Communication Theory. In T. L. Sellnow, & M. W. Seeger, *Theorizing Crisis Communication* (pp. 2-22). West Sussex, UK: Wiley-Blackwell.
- Sheehan, J., Hiscock, H., Massie, J., Jaffe, A., & Hay, M. (2014). Caregiver coping, mental health and child problem behaviours in cystic fibrosis: a cross-sectional study. *International Journal of Behavioral Medicine, (2)* DOI: 10.1007/s1259-013-9289-y.
- Stephens, M. A., Franks, M. M., & Townsend, L. (March 1994). Stress and rewards in women's multiple roles: The case of women in the middle. *Psychology and Aging, 9*, (1) 45-52.

- Stewart-Bown, S., & Jamohamed, K. (2008). The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes, 5*, (63) 12.
- Stukas, A. A., Dew, M. A., Switzer, G. E., Dimartini, A., Kormos, R. L., & Griffith, B. P. (1999). PTSD in heart transplant recipients and their primary family caregivers. *Psychosomatics Journal, (3)* 212-221. DOI: [http://dx.doi.org/10.1016/S0033-3182\(99\)71237-5](http://dx.doi.org/10.1016/S0033-3182(99)71237-5).
- Supreme Court. (Argued April 21, 1999–Decided June 22, 1999). *OLMSTEAD V. L. C. (98-536) 527 U.S. 581*. Washington, D.C.: CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE ELEVENTH CIRCUIT. Retrieved from ADA.gov: [https://www.ada.gov/olmstead/olmstead\\_about.htm](https://www.ada.gov/olmstead/olmstead_about.htm)
- Tsey, K., Harvey, D., Gibson, T., & Pearson, L. (2009). The role of empowerment in setting a foundation for social and emotional wellbeing. *Australian e-Journal for the Advancement of Mental Health, 8*, (1) 6-15.
- U.S. Department of Health and Human Services, and U.S. Department of Labor. (20 Jan 2005). *The future supply of long-term care workers in relation to the aging baby boom generation*. Washington, D.C.: Office of the Assistant Secretary for Planning and Evaluation: Report of Congress.
- Ullrich, P. M., & Lutgendorf, S. K. (2002). Journaling about stressful events: Effects of cognitive processing and emotional expression. *Annals of Behavioral Medicine, 24*, (3), 244-250.
- Wallerstein, N., & Bernstein, E. (. (1994). Community empowerment, participatory education and health: Part I and II {Special Issue}. *Health Education Quarterly, 21*(2/3), 141-419.
- Weick, K. E. (1993). The collapse of sensemaking in organization: the Mann Gulch disaster. *Administrative Science Quarterly 38*, (4), 628-652.
- Worline, M. C., & Steen, T. A. (2004). Bravery (Valor). In M. C. Peterson, & e. Seligman, *Character Strengths and Virtues: A Handbook and Classification*. Washington D.C., New York: American Psychological Association and Oxford University Press.
- Wright, J., & Cheung Chung, M. (2010). Mastery or mystery? Therapeutic writing: A review of the literature. *British Journal of Guidance & Counselling*, pp. 277-291.
- Zarit, S. (2006). *Assessment of Family Caregivers: A Research Perspective*. Center on Aging Society.

**Appendix A: Recruitment Message**

# Are you a FAMILY CAREGIVER?



## Seeking FAMILY CAREGIVERS for a study on the caregiver role

Family caregivers offer significant value to our society's family structure and to the facilitation of health care freedom. Researchers from the Division of Communication at the University of Wisconsin-Stevens Point are conducting research about the role of family caregivers.

Participation involves completing a voluntary short online questionnaire at the beginning of the study and again after one month. Some participants will also be prompted to complete very simple communication tasks over the duration of one month.

To participate, you must be at least 18 years old and responsible for the day to day functional care of a parent, grandparent, spouse, sibling, child, grandchild, or foster child who is chronically ill or disabled.

If you would like to participate in this study or would like to learn more, please use the following contact information to indicate your interest:

[FamilyCaregiverWellbeing@gmail.com](mailto:FamilyCaregiverWellbeing@gmail.com)

**Please consider participating in this research!**

**The VOICE of Family Caregivers (FCGs) – Please participate!**

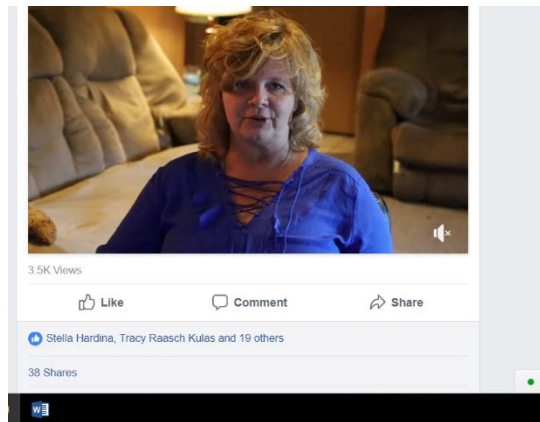
**Who?** To participate, you must be 18, and caring for a parent, child, spouse, grandchild, or foster child who has emotional or physical health concerns.

**What?** (1) Get us your email. (2) Take a brief survey. (3) You may or may not be asked to perform some simple tasks we are studying. (4) After 30 days, take a second survey.



**Why?** FCGs encounter many stressors that jeopardize their physical, emotional, and social wellbeing. We wish to measure some simple ways to correct such effects.

**Contact us: [familycaregiverwellbeing@gmail.com](mailto:familycaregiverwellbeing@gmail.com)**



## Appendix B: Informed Consent Document

### Family Caregiver Wellbeing

**Who is conducting this research study?** This research is being conducted by Trish Zdroik, a master's degree student in the Division of Communication at the University of Wisconsin-Stevens Point. This study is being supervised by Dr. Cade Spaulding, an associate professor in the Division of Communication at the University of Wisconsin-Stevens Point.

**What is this study about?** The purpose of this study is to learn more about the role of the family caregiver over a one-month period.

**What will I be asked to do if I choose to participate?** If you agree to participate, you will be asked to complete a short online questionnaire. The questionnaire will ask you a little bit about your family caregiving role and then ask you to rate your physical, emotional, and social wellbeing through a series of a few brief questions. The questionnaire should take approximately 15-20 minutes. Some, but not all, of the participants will be asked to complete some small but regular communication tasks that will involve writing or drawing each day. At the end of a one month period, all participants will be asked to take another small online questionnaire on general wellbeing that will take between 5-10 minutes to complete.

**Your participation in this study is voluntary.** You may choose whether you want to participate in this study. If you begin, you may choose to stop participating at any time, which means that you may choose to stop the questionnaire at any time and you may choose not to answer any question you do not want to answer. If you have been asked to complete any communication tasks, you may stop this activity at any point in time. Your decision to participate or not to participate will have no effect on any future relations you may have with the University of Wisconsin-Stevens Point. You must be at least 18 years old and you must be a current family caregiver in order to participate.

**Your participation in this study is confidential.** Your individual information will be kept confidential. Your completed questionnaire will be stored on a password-protected computer. Your personal information will be kept separate from your responses so that nobody can connect your identity to your responses. I will collect responses from a larger number of people and calculate scores for the group; your individual responses will not be analyzed on their own or identifiable. The data collected from this study will be presented to other researchers and written up for publication.

**Are there any risks to being part of this study?** The risks of participating in this study are likely to be minimal, but you may experience some discomfort when thinking about your role as a caregiver makes you uncomfortable or causes you distress, free assistance is available to you through the National Alliance on Mental Illness (1-866-615-6464) or by accessing other health resources through the online MedlinePlus directory found at <https://medlineplus.gov/directories.html>.

**Are there any benefits to being part of this study?** You may or may not benefit from this study as it explores some components of the family caregiver role with you. Either way, the study will most definitely benefit the scholarly health communication community by helping us to better

understand the role of family caregivers. The information collected could lead to recommendations to family caregivers, health and human service providers, and to the medical community regarding the role of family caregiver in and of itself.

**Who do I contact if I have questions or concerns?** Upon the completion of this study, I will be glad to share results with you. If at any time during the study you have any questions, you may contact me, Trish Zdroik at

[Trisha.Zdroik@uwsp.edu](mailto:Trisha.Zdroik@uwsp.edu)

or my advisor, Dr. Cade Spaulding, at

[Cade.Spaulding@uwsp.edu](mailto:Cade.Spaulding@uwsp.edu).

If you have questions or complaints about the rights or treatment of research participants, you may contact the university's Institutional Review Board Chairperson, Dr. Debbie Palmer:

Dr. Debbie Palmer, Chair  
Institutional Review Board for the Protection of Human Subjects  
Department of Psychology  
Science Building, D240  
University of Wisconsin-Stevens Point  
Stevens Point, WI 54481  
(715) 346-3953  
[dpalmer@uwsp.edu](mailto:dpalmer@uwsp.edu)

**Agreement:** I understand this consent form and the meaning of this information. I understand what I am being asked to do and my rights as a study participant. I understand that I may stop my participation at any time. By clicking on the red arrow below and continuing with the questionnaire, I express my consent to participate.



**You may print a copy of this consent form for your records.**



This research project has been approved by the UWSP Institutional Review Board for the Protection of Human Subjects.

### Appendix C: Demographic Questions

Please provide the following information about yourself.

Your age is: \_\_\_\_\_

Your gender (please check one):  Female  Male

Your highest level of education (please check one):

Have not graduated from high school  Graduated from high school

Graduated from a two-year college or technical institute  Graduated with a bachelor's degree

Graduated with a master's degree  Graduated with a doctoral degree

Your ethnicity (please check one):  African-American  American-Indian  Asian-American

Caucasian  Hispanic  Other

The primary diagnosis of the family member for whom you provide care (please check one):

Physical  Mental Health  Other

The relationship description between you and the care recipient for whom you provide care (please check one):

I care for my parent, grandparent, or parent-in-law

I care for my spouse or "committed partner"

I care for my sibling

I care for my child or grandchild

Other

Please check the category, from those listed below, which marks the length of time for which you've been providing care for your family member:

Less than 12 months  1 - 2 years  2 - 5 years  6- 9 years  10 years or more

**Pre- and Post-test QUESTION: Please indicate the answer that best describes your current level of participation with journaling, blogging, reflective writing, diary keeping, and/or scrapbooking.**

Hardly ever  Less than once per month  A few times per month

Once per week  A few times each week  Daily

If you have regularly practiced writing (as described above) within the previous month, please describe the general topic(s) you write about: \_\_\_\_\_

### Appendix D: Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

*This is a short 14 item questionnaire that asks you to consider how well you believe yourself to be regarding your emotional, physical, and social health. This survey has been used many times before to measure the wellbeing of participants as they see themselves. The questions are validated and results are reliable for this purpose. Please read the directions below to proceed with the survey.*

**Below are some statements about feelings and thoughts.**

**Please check the box that best describes your experience of each over the last 2 weeks.**

Statements	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

**Appendix E: Permission to use WEBWBS****From: no-reply@warwick.ac.uk**

Submission (ID: 328520114) receipt for the submission of  
</fac/med/research/platform/wemwbs/researchers/register>

Thank you for completing this registration. You now have permission to use WEMWBS in the manner detailed in your submission.

Question: Name:

Answer:

TrishAnn Zdroik

Question: Email address:

Answer:

Trisha.Zdroik@uwsp.edu

Question: Institution/Organisation

Answer:

University of WI-Stevens Point (USA)

Question: Type of Study

Answer:

Controlled Study

Question: Description of proposed project:

(For translations, please state the language concerned)

Answer:

I will be using a controlled experimental design to test the efficacy of using Reflective Writing (treatment) to positively affect the well-being of the family caregiver population. I will use the WEMWBS pre- and post- treatment and at the origin and completion of one month for the control group.

Question: Description of participants

Answer:

I will be recruiting adults who are working in the role of family caregiver: providing daily functional care for their parent/grandparent, spouse, sibling, or child/grandchild.

Question: Location

Answer:

I will be hosting the study online, but will collect data via the University of WI - Stevens Point (USA)

Question: Gender

Answer:

mixed, with an expected dominance of females as females hold 66% of the family caregiver population

Question: Ages

Answer:

Adult, varied ages with an expected mean of 49 years old

Question: Approximate Start Date

Answer:

01/02/2017

Question: WEMWBS version

Answer:

14 items

Question: Expected number of people to be studied

Answer:

80-200

Question: Other information as relevant

Answer:

Question: Are you willing for us to share top level details of your research

Answer:

Yes

## Appendix F: Correspondence Regarding Assistance & Capabilities with Qualtrics

In efforts to sure-up the use of Qualtrics for this study, I contacted our campus expert, Sean Ruppert. You will find my questions and his answers below:

*Will Qualtrics allow me to distribute and accept Informed Consent?*

Yes. We just did this with another survey. Informed consent was offered in a block by itself, with notification that continuing to the next question was acknowledgement.

*Will Qualtrics allow me to distribute instructions for participants entering the study? I am also hoping that I will be allowed to distribute every other participant (odd numbered) into treatment group instructions, and the other half (even numbered participants) into control group instructions.*

It looks like you can, though I don't have any experience with it. I'd be happy to help figure this out when the time comes.

<https://www.qualtrics.com/support/survey-platform/survey-module/survey-flow/standard-elements/randomizer/>

*Will Qualtrics give each participant an id so that they may come back in for the post-treatment survey in a way that I will be able to measure the difference in score from the pre-treatment survey?*

*If not, perhaps I'll need to set up an encrypted email or website to administer these functions...*

It looks like you can do this too. Again, I don't have experience with it, but we can figure it out.

<https://ithelp.brown.edu/kb/articles/728-use-qualtrics-for-human-subject-research-using-a-screener-survey>

Sean

Sean Ruppert

CITL

Center for Inclusive Teaching and Learning

Albertson Hall (formerly LRC) 403

University of Wisconsin Stevens Point

[sruppert@uwsp.edu](mailto:sruppert@uwsp.edu)

715.346.2375

## Appendix G: Instructions for Completing Reflective Diary



As a participant in this study, we would like you to keep a daily diary for yourself. Your writing will be entirely confidential and for your eyes only. We will not review, collect, nor ask to hear about what you wrote at any time. If you wish, you can share your entries with others, but we will not ask you to share your diary entries with us.

**How long should each entry be?** Your entries do not need to be long. They can be as simple as one little phrase, a meaningful sketch, or even a special photograph you took that day. Of course, if you prefer to write longer pieces, that is all right.

**What should I include in my daily entry?** There are no subject or length requirements. We hope that you will use a small bit of your time each day to rehash the day's events, process unsettled emotions, consider changes you hope will occur, think about your personal beliefs or values, or just write, draw, or place a photo in your diary about something that caught your attention. You are free to use words, draw pictures, or include photos.

**How should I organize my entries?** The entries should be kept in chronological order, meaning that each day's entry will be placed just beneath or on the next page from the entry the day before.

**How long should I expect to keep this diary?** We ask that you make small daily entries for twenty-eight days (or one full month) in a row. Of course, if you enjoy the process of diary keeping, then you can carry on after the study at your discretion. We will ask you to take another online questionnaire after twenty-eight days have gone by.

**\*\*Please use a specific notebook or sketchpad for this diary.**

## Appendix H: Qualitative Research

### Participant Self-Reported Topics of Reflective Writing

S-self reactions to daily happenings or needs = 13

F-family and relationships=8

E-emotions and feelings = 6

P-spiritual, prayer, scripture = 4

D-problem solving and decision making=3

(n= 29)

- S Happenings of a day and how I feel about it
- E Emotions and mood
- P Prayer
- F Letters to a friend who committed suicide
- S What's been positive and what's been stressful in a day
- S Daily encounters
- F Resolving when I'm overwhelmed by trying to make everyone happy
- S Physical and mental things that affect me
- S My daily routine for giving care and for caring for me
- F Scrapbooking
- F Thankfulness for a loving family and solving problems
- S-work Daily life, especially work
- D Problem solving in relationships and staying positive with medical problems
- S Every day – what happened and how I felt about it
- D Frustration with government health care and bad attitudes of careworkers. Mean things my daughter did that hurt me
- S-work Work lessons and how people react to me, how to get better
- F My son and other relationships, work, future, life themes about beginnings and endings
- E,D Feelings/emotions, future plans
- E,P Mood and feeling of the day. Spiritual reflections. Journaling has boosted my mood; I'll continue
- D,S Daily thoughts, struggles and successes, goals

P Prayer

S,F How to find to care for myself. Find strength to let others manage their own affairs. Allowing others to experience their own failure

S,E-guilt Switching from caring for others to self survival. Read a book that spoke of a caregiver who forgot how to take care of self. Journaling must become a habit. I must reteach myself to love me again. I've given everything away.

"My main concern has switched from care taking for a family member to self survival. I think it's a wake up call for me...I am currently in chronic pain myself and I know that it is not just physical but also emotional pain that is making me hurt. I found a website ... As a medical doctor/neurologist he was a caregiver for all of his patients. He discovered that he did not understand how to take care of himself. His book is excellent and worked with the me self journaling for the care taking study. Hanscom stressed that the journaling had to become a habit and so I write both morning and evening... What I've been learning is that I truly have gotten how to care for and love myself. I cried during my counseling session when my therapist said, do you love yourself? I couldn't even answer the question. Caretaking for a family member is draining and I've found that I now am broken spiritually, emotionally, and physically...And during the times I stumble I will get up and forgive myself and get going. I'm going to work on forgiving myself too. At times I really recent being in the caregiver role. I plan to learn to have fun again and not feel guilty. I am thankful I can be there for my grandson but I am coming to terms with who I am, where I want to go, and find the path to get there."

D Life in general

E-failure Feelings of failure

S,E Life, personal feelings/thoughts

S,F My general mental and physical health; perceived mental health of partner and what to do about it

P Gratitude, scripture/prayer

F Reflections about family

From a Facebook private message, the following was said, and is reported here but not part of the formal data analysis:

"My husband knew I was involved in this study and discussed the caregiver role with me as a result. He told me something about myself and my relationship with my adult son that I didn't realize before. He said that he now understood that I was no longer making progress with the agencies designed to help my son, not because of the reasons I commonly site (like, "I just don't have time for this"), but was instead because I didn't want to identify with the family caregiver role anymore. He told me, and I think he was profoundly correct, that the caregiver role was filled with failure, getting told "no" time after time, and that is why I no longer pursue advocating and helping him like I used to. Because of this study, I have become aware of my state of mind and forced myself back into the caregiver role. Journaling with this perspective helped me find my way back; this time I designed the role the way I wanted to live it out."