

University of Nevada, Reno

**An Examination of Preparedness for Family Members of Individuals with a
Life Limiting Illness: A Possible Protective Factor for Pre-Loss Grief**

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Psychology

by

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May 2021



THE GRADUATE SCHOOL

We recommend that the dissertation
prepared under our supervision by

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entitled

**An Examination of Preparedness for Family Members of
Individuals with a Life Limiting Illness: A Possible
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be accepted in partial fulfillment of
the requirements for the degree of

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Abstract

Pre-loss grief (PLG) has been defined as the presence of grief symptoms (e.g., longing/yearning for the person) while a family member with a life limiting illness is still alive. “Preparedness” has been consistently found to strongly predict PLG yet a consensus has not yet been reached about how best to assess for preparedness. The purpose of this study was to develop a preliminary theoretical framework of preparedness through conducting prospective semi- structured interviews with family members of Stage 4 Cancer (N=16) and Advanced Dementia (N=24) patients. A codebook was created, as blind coders were asked to identify themes based on the answers to the questions from five separate transcriptions. Next, two other coders, coded all forty transcriptions. Nodes were identified for each transcription and summed. Also, the number of times the node appeared throughout the forty transcriptions were summed. The main overarching theme related to preparedness for the loss was the issue of the need to reduce uncertainty, both before the person passes away (i.e., present certainty) and after the person passes away (i.e., future certainty). Present Certainty included, religiosity and spirituality, good relationship quality with the person who has the life limiting illness, having access to family, friends and community support, good communication with person with life limiting illness, and acceptance of the impending death. Future Certainty was reflected in statements pertaining to religious and spiritual, knowing what to expect due to past experience of loss, having plans for life without the person, making pragmatic preparedness for the event of the death, and having social support. This study provides a preliminary framework of preparedness for family members of individuals with life limiting illness. After validation of this framework, a

measure of preparedness should be developed and tested. This measure would provide the field with the ability to identify family members' preparedness for the death of their loved one.

Dedication

I have several people who have helped me get to where I am today. First, I want to thank my entire committee. Dr. Tung, I appreciate you agreeing to sit on my committee and providing me with some valuable ideas for my dissertation. Dr. Duckworth, I would like to thank you for being on ALL of my committees including comps, master's thesis and now my dissertation. Dr. Davis I want to thank you for always pushing me to be a better researcher and critical thinker. I might have hated it at the time, but I sure appreciate it now. Also, thank you for always including me as part of your lab and family. You have the biggest heart and I will always be grateful to you. Dr. Hughes Lansing, thank you for being there for me when I needed advice about literally everything. Your knowledge of the field and dedication to your students is remarkable. Most of all, thank you for always being there for Caroline and supporting her when she was at her lowest. I will never forget what you have done for both myself and Caroline. Lastly, thank you to my advisor and mentor, Dr. Papa. Yes, I have spent late nights cursing at my computer because of your comments to "expand," or "start over" on papers but I am extremely grateful for how hard you have pushed me both as a clinician and a researcher. I know that for the rest of my life I will have your voice in my head when writing a manuscript and for that I am extremely grateful.

To my closest UNR friends, Tyler (I put you first; credit) and Peter. I am beyond grateful for both of you. I would not have been able to accomplish everything I did without our 5 am gym schedule, late nights working on Markus's messy data homework and our Chipotle Thursdays. I appreciate you two listening to my rants and laughing at my "manic" moments. You two are more than friends, you are family.

There have been a lot of ups and downs at UNR and without my family I would not be writing this dedication. To my future father and mother in law, Lisa and Kevin. You have both been there for me and supported me from the moment Caroline and I started dating. Your genuine love for me and your family is one of a kind. Mostly importantly, you have kept me fed with the best fried rice and wings. To my sister Monica. Monica, you are one of the most remarkable people I have ever met. You have broken the ceiling for women in your field and you have always taught me to work hard, and good things will happen. To my mother and father. Mom there are no words to describe what you have meant to me and my success. You have been there at every critical moment, from tears of sadness to the happiest days. You are the nicest and most caring person in the entire world, and I am the luckiest person to have you as my mother. Popi, I appreciate you editing my essays in high school and college and pushing me to be a better writer and scholar. More importantly, thank you for pushing me to be a better man and to always give back. You have dedicated your life to your clients, and I am proud to call you my father. To my cat Thai, who has always been at the door after a late night in the office and woken up with me at the earliest hours with a cold nose. To my fiancé Caroline. I don't think you will ever truly know what you mean to my life. Mostly importantly, you gave me three years with Whiskers who did not make it to see us graduate but will forever be in our hearts. You have been my support system and pushed me to be a better researcher and person. I am the luckiest man alive because I not only get to call you my wife soon, but I get to call you my best friend. I am so glad we get to play the game of life together.

Lastly, I want to thank the participants in my study. There is no worst time in a person's life than when their loved one has a terminal illness, yet these individuals discuss their current situation and answer my hard-hitting questions. We cried together and we laughed together, and I am extremely grateful to all of you. I hope that one day my research and clinical work can impact someone's life as much as you impacted mine.

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- I. Preliminary Framework of Family Members' Preparedness

An Examination of Preparedness for Family Members of Individuals with a Life Limiting Illness

Pre-loss grief (PLG) has been defined as the presence of grief symptoms (e.g., longing/yearning for the person) while a family member with a life limiting illness is still alive (Nielsen et al., 2016a). The prevalence of this phenomenon is unknown due to the scarcity of research examining PLG. However, with the number of people affected by life limiting illnesses (e.g., dementia) increasing (Larson, & Langa, 2017), an increase in PLG can be predicted as well. Despite the potential impact that PLG may have on family members, relatively little is known about the etiology and protective factors that influence the presentation of PLG. This is problematic, as issues related to coping with grief post-loss are known to have a significant impact on an individual's functioning (e.g., Shear et al., 2011; Strobe & Schut, 2015). However, a few studies have examined PLG as a risk factors for PGD, finding that higher rates of PLG are linked to Prolonged Grief Disorder (PGD; e.g., Nanni et al., 2014; Nielsen et al., 2016), which will be added to the ICD-11 criteria in 2021 (Singer et al., in prep.). Therefore, PLG might be an early indicator of negative outcomes following the loss of a loved one, which warrants an identification of risk and protective factors for PLG in order to create interventions to reduce PLG and possibly PGD.

Across the studies that have examined PLG, "preparedness" has been consistently found to strongly predict PLG (Nielsen et al., 2016a). The work is nascent in this area and a consensus has not yet been reached about how best to assess for preparedness, and, to our knowledge, no reliable measure of this construct exists. Thus, given the general paucity of research on the construct of preparedness, the lack of reliable measures of preparedness, and preparedness as a potential target for preventative interventions aimed at decreasing the impact of PLG, an investigation into preparedness is prudent at this time.

However, before examining the relationship between preparedness and PLG, an in depth understanding of how family members define preparedness is warranted. The current study aims to assess preparedness using a qualitative design that would aid in the development of a future assessment instrument to test preparedness. The gained understanding of preparedness will be utilized to guide efforts towards improving the assessment and intervention for family members, thereby improving the well-being and quality of care in this at-risk population.

Qualitative Descriptions of Preparedness

To date, three qualitative studies have investigated end of life preparedness of bereaved family members, bereaved friends, and healthcare providers. These three studies provide a preliminary understanding of preparedness and have considerable overlap. However, these studies have significant limitations, including the use of retrospective reporting, which might limit the utility of findings.

The first study by Steinhauer and colleagues (2001) used mixed qualitative and quantitative methods to investigate preparation for end of life care. They assessed patients with life limiting illnesses, family members who were recently bereaved, and health care providers, with regard to what constituted preparation for the death of a loved one. The study used two methods of data collection, focus groups (n=72) and a nationwide survey (n=1885). Focus group participants were asked to discuss their experiences with the deaths with their family members, friends, or patients and to reflect upon what made those deaths “good” or “bad.” In the survey, they asked respondents to rate the importance of 44 attributes of experiences at the end of life derived from the focus groups (e.g., name someone to make decisions; know what to expect about one’s physical conditions). The study identified five domains of preparedness that were consistent across informants: (1) the ability to designate a single individual to make decisions,

(2) knowing what to expect from the medical condition, (3) having financial affairs in order, (4) having treatment preferences in writing, and (5) knowing that one's physician is comfortable discussing death and dying.

Building on Steinhäuser and colleagues (2001)'s domains of preparedness, Hebert and colleagues (2006) conducted a secondary analysis of open-ended questions from the Resources for Enhancing Alzheimer's Caregiver Health study, which examined the association between PLG and preparedness with two hundred and twenty-two recently bereaved caregivers. Their analysis suggested preparedness was characterized by four distinct but related categories, medical, psychosocial, spiritual and practical preparedness, each of which was theorized to directly impact caregivers' presentation of PLG. Medical preparedness was defined as knowing what signs and symptoms to expect, as well as treatment and disease progression during the terminal phase of the illness. Psychosocial preparedness was defined as the ability to discuss grief and emotions while being able to maintain relationships with friends and family. Spiritual preparedness was defined as the use of prayer and/or talking about the meaning of the death to the family caregiver. Practical preparedness was defined as planning the funeral arrangements and estate planning.

Hebert and colleagues (2009) then revised this model using focus groups and ethnographic interviews, and asked questions regarding the participant's relationship with their loved one, their loved one's illness, and preparation for their future. Participants were recruited from a palliative care consult service and community-based hospice. The sample consisted of mostly bereaved caregivers (82%) of terminally ill patients who had died in the last year. Four primary themes were found: "life experiences," "uncertainty," "communication," and "preparedness" (Hebert et al., 2009). "Life experiences" included the duration of the illness, the

amount of time the family member served as a caregiver, previous planning regarding death/advance directives, and previous experience with caregiving or death. “Uncertainty” encompassed the same four categories found in Hebert and colleagues’ (2006) study (i.e., medical, psychosocial, spiritual and practical). “Communication” referred to clear, consistent, and reliable communication between health care providers, the patient, and other family members who were involved at the end of life. Specifically, participants indicated that ambiguous messages by these groups made preparation difficult. Finally, “preparedness” was separated into three dimensions: cognitive (the caregivers need for information to reduce uncertainty surrounding the illness and death of a loved one), affective (mentally and emotionally preparing for the death of a loved one), and behavioral (tasks that reduced the impending burden of the loss of a loved one, including estate planning, planning funeral arrangements, rearranging work schedules, and generally “keeping busy”). Despite the retrospective design, this study offers a more nuanced understanding of preparedness than Hebert and colleagues’ original model (2006) and offers a more well-developed basis in understanding preparedness for informal caregivers.

The results of the three studies overlap to a high degree. Aspects of Steinhauser and colleagues (2001) model might fit under the behavioral, medical and communication aspects outlined in Hebert and colleagues (2006) model. For example, “knowing what to expect from the medical condition” might be best categorized as medical preparedness and “knowing that one’s physician is comfortable discussing death and dying” might be categorized as communication preparedness. However, not all aspects of Steinhauser and colleagues (2001)’s model fits (e.g., having financial affairs in order), which may be due to their utilization of a diverse sample comprised of patients, families (all participants were bereaved), and health care providers. In

addition, all of the studies relied on samples in which retrospective reporting bias may have affected the results (the limitations of which are described in detail below). Nonetheless, these studies provide a preliminary understanding to build upon for future studies aimed at clarifying the definition of preparedness in family members of terminally ill patients.

Across the three studies, three major themes of preparedness were found: behavioral, medical and communication. Behavioral aspects of preparedness included having financial affairs in order (Steinhauser, 2001), designation of a single individual to make decisions (Steinhauser, 2001), and being involved in tasks that reduce the impending burden of the loss (Hebert et al., 2009). Medical preparedness involved knowing what to expect from the medical condition including what signs and symptoms often emerge (Steinhauser, 2001; Hebert et al., 2006; 2009). Lastly, communication patterns of preparedness entailed knowledge/confidence that one's physician is comfortable discussing death and dying (Steinhauser, 2001) and the family member's ability to discuss grief and emotions (Hebert et al., 2006; 2009).

Quantitative Studies of PLG and Preparedness

A recent systematic review of twenty quantitative studies that examined the associated constructs of PLG in informal caregivers found that preparedness was a consistent predictive factor related to PLG (Nielsen et al., 2016a). The quantitative studies included in the review were primarily cross-sectional surveys (70%) and prospective (60%). They operationalized preparedness in three different ways; (1) preparedness for ongoing caregiving (35%), (2) preparedness for the impending death of a loved one (5%), and, (3) retrospectively, how prepared they were for the death of a loved one (60%). A subsequent literature search conducted by this author revealed that no new studies have been published on this topic since the review was completed, thus the study of preparedness as a predictor of PLG remains quite limited.

Despite the variation in methods and operationalizations, across the twenty studies published on PLG, there was a strong negative association between preparedness and PLG, such that endorsement of lower preparedness was associated with higher PLG (i.e., grief symptoms before the family member's death), post-loss depression, and post-loss pathological grief symptoms. While this systematic review provided evidence of the relationship between preparedness and PLG, the brief review below of the twenty previously published studies on this topic provide evidence of significant limitations in the studies on preparedness to date, mainly revolving around two measurement issues; (1) problems defining preparedness (i.e., low construct validity) in the quantitative work, and (2) the reliance on retrospective recall for data collection in both the quantitative and qualitative work.

Problems Defining/Operationalizing Preparedness

Across the twenty purely quantitative studies, three different definitions were used to investigate preparedness and each method addresses a distinct aspect of a much broader construct; however, together they have little intersection. Twelve of the twenty studies identified in Neilsen and colleagues' (2016a) systematic review defined preparedness as caregivers' perceptions of how prepared they were for caregiving an individual with a life limiting illness, including the family member's physical needs (e.g., pushing them in a wheel chair), emotional needs (e.g., increased depression) and how prepared they were to make caregiving activities pleasant for the dyad. The twelve studies used the Preparedness for Caregiving Scale (PCS) to measure preparedness.

The PCS currently represents the most comprehensive and highly utilized assessment tool for examining preparedness for family members or friends, but there are limitations to this measure. First, the PCS (e.g., "how well prepared do you think you are to take care of your

family member's physical needs?) was derived from the Family Caregiving Inventory, which was designed to assess role strain (difficulty in fulfilling the role obligations of family caregiver; Archbold et al., 1990), in caregivers whose family member had recently been discharged from the hospital. Although role strain and preparedness for caregiving are related concepts, they are distinct in that role strain revolves around burden, regarding not being able to complete all responsibilities of being a caregiver for a family member, whereas lack of preparedness for caregiving (i.e., not having the necessary skills or resources to help someone with cognitive decline) can lead to role strain. Also, role strain does not assess for preparedness in relation to losing a loved one, a major aspect identified in the theoretical models above.

Thus, it is unclear the extent to which the items on the PCS thoroughly assess preparedness for loss, casting doubt onto the construct validity of the measurement of preparedness in this context. For example, Archbold and colleagues (1990) found high correlations between caregiver worry and the PCS ($r = .88-.93$), suggesting that the PCS may instead tap into caregiver's worry (and thus strain) rather than caregiver's preparedness. Taken together, the PCS appears to measure other constructs (e.g., role strain; caregiver worry) rather than caregiver's preparedness for the death of their loved one. Further, it falls short of measuring all aspects of Steinhauser's (2001) and Hebert's (2006; 2009) frameworks.

The remaining eight studies examined preparedness using single item face valid questions, "to what extent were you prepared for the care recipient's death," and, "how prepared were you for the death of a loved one," suggesting preparedness may be a simplistic construct. The single-item approach may tap into a unitary aspect of preparedness but there are several limitations of using a single item to assess a complex construct. The first is low construct validity. The point was made long ago that a single item cannot fully represent a complex

theoretical concept (McIver & Carmines, 1981). As the qualitative work described above ascertained, preparedness is potentially a multifaceted theoretical concept found to have numerous sub-factors (e.g., medical; behavioral; communication; see Hebert et al., 2006). Single item measurements limit the knowledge of the effects of these factors as potential intervention targets. Finally, single item measurements have problems with sensitivity and reliability because they are limited in their capability to provide enough variability or points of discrimination while also requiring a larger sample size (Sarstedt & Wilczynski, 2009).

Limitations of Retrospective Studies

In addition to problems with operationalization, the investigation of preparedness is often conducted retrospectively after an individual has already lost their loved one. Retrospective measurements are problematic as they are subject to memory and social interaction biases (Tofhagen, 2012), especially when coping is being reported retrospectively. In evaluating individuals' retrospective reporting of coping, numerous studies have found low to moderate accuracy in retrospectively reporting the coping mechanism utilized (e.g., Ptacek et al., 1997; Smith et al., 1999; Todd et al., 2004). One particular study compared daily diary data of coping reports seven days prior to an exam and retrospective recall data of coping five days post-exam (Ptacek et al., 1997). Analyses demonstrated that participants were only 58% accurate at the 5-day follow-up, suggesting that memory biases emerged at least five days post-event, if not earlier. Nonetheless, in the systematic review of preparedness, reported above, eight of twenty studies asked family members to recall their perceived level of preparedness upon learning of their loved one's death, where data collection occurred on average 4-5 *years* post-loss. Needless to say, participants in these eight studies might not have accurately reported their preparedness due to memory bias.

One type of memory bias that is particularly salient to bereaved individuals is the halo effect, which is defined as “the tendency to let one characteristic of an individual positively influence the appraisal of other characteristics” (Smith, 2006, p. 233). For example, a person may state, “she was my wife”, and so it stands to reason that “she was a good person and treated me well.” The family member might report retrospectively that they were prepared for the death of a loved one, in part due to a positive view of the individual who is no longer alive, and an unwillingness to speak poorly about them or a less than desirable situation related to them. Yet, if this individual’s evaluation of their preparedness was assessed prospectively (when the individual with the terminal illness was alive), they might instead state that they are not prepared, due to being presently in the situation and thus able to better self-report their current state of being.

Social interaction threat is when social norms and/or interactions with others influence outcomes (Tofhagen, 2012). There is a strong social expectancy that loss of a loved one is associated with acute functional disruption and emotional turmoil (despite empirical evidence to the contrary; Wortman & Silver, 1989; Kahler et al., 2019). Belief in this expectancy may have an effect on reported preparedness as well as levels of PLG. This may be magnified when asked to evaluate preparedness for the loss of a loved one retrospectively. After the death of a close friend/family member, a bereaved individual usually has an increase in their social interaction (e.g., funeral; sitting Shiva), during which the expectancies of grieving are often communicated (Wortman & Silver, 1989). This increase in social interaction may influence a bereaved individual’s current experience of loss as well as previous related experiences, thus interfering with measuring this construct at a later timepoint.

While the literature reviewed suggests a relationship between preparedness and PLG exists, the studies identified used three distinct definitions of preparedness and utilized three different measures, which had low construct validity, poor operationalization, and often used retrospective reporting. The problems in retrospective reporting with recall, along with the potential for bias, can negatively influence our understanding of preparedness, but can be mitigated with the use of a prospective rather than retrospective design. Therefore, there is a need to examine family members' sense of preparedness while the individual with the life limiting illness is alive.

The Current Study

Gaining a greater understanding and framework of preparedness will allow for the ability to create a measurement tool to identify preparedness in family members of individuals with life limiting illnesses. The studies above set the groundwork for future research of preparedness in this population. However, the flaws of those studies (e.g., retrospective reporting; measuring different construct) limit the ability to use the extant models to build a scale for preparedness. Therefore, a deeper, prospective exploration of preparedness using a sample of family members of individuals with a life limiting illness is warranted. Further, this study is the first to directly examine preparedness for the death of a loved one as the other three qualitative studies aimed to examine many aspects of preparedness (e.g., preparedness for caregiving/end of life care). The purpose of this study was to conduct prospective semi-structured interviews with family members of individuals with a life limiting illness, in order to develop a theoretical framework of preparedness.

Method

Participants

Participants were recruited from Reno Oncology Consultants (Urban Setting), Nevada Neurology & Vascular Center (Rural Setting) and the Carson Cancer Center (Rural Setting). Individuals were English speaking and endorsed having a relationship with an individual who had either Stage 4 Cancer or Advanced Dementia that started prior to the diagnosis. Participants were enrolled concurrently until saturation was met in each group (i.e., when similar responses were repeatedly being endorsed by participants in each respective group). More specifically, in the cancer group the same answers were being endorsed by participants by the time the 12th participant was enrolled. In the dementia group, the same answers were being endorsed by participants by the time the 20th participant was enrolled. Given the lack of statistical analysis guiding the threshold of saturation, four additional participants were included in each group after saturation was purported to be met. Therefore, sixteen family members of cancer patients and twenty-four family members of advanced dementia patients were included in the final sample. The racial distribution of family members was predominantly Caucasian (97.5%). The same racial distribution was found for the individuals with a life limiting illness (97.5%). Participants ranged in age from 29 to 91, with a mean age of 69.20 (12.74). Individuals with life limiting illnesses ranged in age from 53 to 98, with a mean age of 75.08 (10.58).

Twenty-nine of the participants in the study identified as being female (72.5%) and eleven (28.5%) were males. Twenty-three of the participants' family members with a life limiting illness were males (57.5%) and seventeen (42.5%) were females. Regarding relationship to the individual with the life limiting illness, twenty-five (62.5%) were spouses, twelve (30%) were parents and three (7.5%) were siblings. The number of years that the participant has known the person with the life limiting illness ranged from 4 years to 76 years, with a mean of 47.78

years (19.29). Time since diagnosis ranged from 2 months to 12 years from the time of the interview, with a mean of almost 5 years since the diagnosis.

The average length of diagnosis for participants with a family member who had advanced dementia was more than 5.06 years ($SD=3.01$) compared to cancer patients who were diagnosed a little over four years from the time of the interview ($M=4.30$; $SD=3.02$). There was a wide range of cancer and dementia diagnoses enrolled in this study (Table 1). The most common dementia diagnoses were Alzheimer's (40%) and Frontal Temporal Dementia (10%). The most common cancer diagnoses were Stage 4 Lung (10%) and Esophageal (10%) cancer.

Interestingly, two of the family members of cancer patients also endorsed that they currently had terminal cancer.

Materials

Qualitative materials. Semi-structured interviews began with three inductive questions (e.g., "Have you done anything to prepare for the loss of your loved one?" "If so, what have you done?"). An additional eight questions were included and derived from past research (e.g., "What will be the biggest change in your life when your loved one passes away?"; "How do you prepare for that?"). Two new questions were generated during enrollment (see procedures for details). First, the research team added, "If you have lost someone in the past has experiencing that loss made preparing for your family member's loss worse or better?" Second, the research team added, "Do you believe it is possible to still have hope and be prepared for someone's death at the same time?"

Quantitative Materials. Quantitative materials were only used to gain a greater understanding of participants characteristics and to identify if there were any differences in psychological profiles between family members of individuals with dementia and cancer.

Demographics, pre-loss grief, anxiety, depression and role centrality were all measured quantitatively. The PG-12 is a 12-item self-report questionnaire for pre-loss grief. Respondents are asked to rate, on a 5-point Likert-type scale (1=almost never, 5=always), how often they have experienced distressing grief symptoms in the previous month. The first eleven questions assess eleven grief symptoms. The eleven items are summed (range of 11 to 55) in order to gain a severity of pre-loss grief. Previous studies showed the measure had good internal consistency (Cronbach's $\alpha = 0.88$) and a monofactorial structure (Chiambretto et al., 2008). The final question asks if the person has had a reduction in social, occupational or other important areas of functioning.

The Patient Health Questionnaire 9 (PHQ-9) is a 9-item self-report scale used to assess and monitor depression severity. The PHQ-9 sums the score for each of the nine questions and ranges from 0 to 27. It was developed as a screening tool for depressive symptomatology (Kroenke et al., 2001; Kroenke and Spitzer, 2002). The scale is shown to have high internal consistency ($\alpha = .86$ to $.88$; Kroenke et al., 2001) and high test-retest reliability ($\alpha = .84$ to $.95$; Kroenke et al., 2001; Löwe et al., 2004).

The Generalized Anxiety Disorder-7 (GAD-7) is a 7-item self-report scale used to measure the severity of anxiety symptoms, which has been shown to be a reliable screening tool for panic, social anxiety and post-traumatic stress disorder (Kroenke et al., 2007; Kroenke et al., 2010). The GAD-7 exhibits excellent internal consistency ($\alpha = .89$ to $.92$; Löwe et al., 2008; Kertz et al., 2012; Spitzer et al., 2006), and good convergent validity when compared to the Beck Anxiety Inventory ($r = .72$), Symptom Checklist 90 anxiety subscale ($r = .74$; Spitzer et al., 2006), Penn-State Worry Questionnaire (PSWQA worry; $r = .64$), Depression Anxiety Stress Scale (DASS-anxiety ($r = .77$) and DASS-stress ($r = .79$; Kertz et al., 2012).

Procedure

All study procedures were approved by the University of Nevada, Reno Institutional Review Board. In order to gain a greater understanding of family members' perspective on end of life issues, family members of individuals who had been diagnosed with Stage 4 Cancer or advanced dementia were asked to take part in a 30-minute qualitative interview and answer fifteen minutes of quantitative questions. All participants' doctors confirmed their family members' diagnosis.

Moderator guide. After participants were informed about the study, and provided informed consent information, they were brought into a private room to answer all questions. Appendix A lists the questions that participants were asked. The first three questions asked participants to independently generate how they define preparedness. The other eight questions were developed based on research that has examined preparedness. Through including these additional questions, we aimed to replicate previous findings and examine the constructs in more depth using a prospective design. These questions asked about possible definitions of preparedness (e.g., religion), which have been endorsed in studies that examine preparedness retrospectively. There were two questions that were added during the data collection based on the responses that participants were providing. The first explored how experiencing a previous loss has made them feel more prepared for their present circumstances. Therefore, participants 9 through 40 were asked, "If you have lost someone in the past, has experiencing that loss made preparing for your family member's loss worse or better?" A second question was added to assess the effect of maintaining hope as a mean of promoting positive outcomes in the treatment of cancer patients on preparedness for death. A consistent theme arose in the interviews with the family members of cancer patients in which many verbalized the need to maintain hope for

positive outcomes in the present and not focus on negative outcomes in the future as a means to promote well-being in their loved one. As a result the following question was added, “Do you believe it is possible to still have hope and be prepared for someone’s death at the same time?,” which was added for participants 28 through 40.

Data collection and management. All participants were enrolled and interviewed by the first author. After each interview was complete, participants were asked to fill out the demographics sheet, PG-12, role centrality questionnaire, and mental health questionnaires. A member of the research team transcribed the transcripts verbatim after the participant completed the semi-structured in-depth interview. Following their completion, the first author cleaned all transcriptions, correcting typos and going back to recordings where transcriptions did not make sense. Another research team member cleaned the transcriptions that the first author had transcribed. Individual interviews ranged from 12.5 minutes to 50.87 minutes with a mean of 25.7 minutes ($SD=6.75$ minutes).

Data Analysis

A formal coding scheme was developed iteratively following the cleaning of the transcriptions. Two graduate students (referred to as coders 1 and 2), who were not familiar with the research area (e.g., end of life) and had no prior knowledge of the research questions or proposal, created a codebook. In creating the codebook, all transcripts were analyzed for thematic content using the principles of thematic and content analysis (Miles & Huberman, 1994). Each blind coder was asked to identify themes based on the answers to the questions from five separate transcriptions, three transcriptions of family members of individuals with dementia and two transcriptions of family members of individuals with cancer. To ensure as many themes as possible were found, the coders were not provided the same five transcripts. The two coders

were instructed to identify any themes that the participant described as preparedness and label them as nodes into the NVivo 12 system (Castleberry, 2014). No other details were provided to coders as the research team aimed to limit bias. After the two coders finished going through each of the five transcriptions, their nodes were combined and reworded for clarity by the first author to make a codebook (Appendix B). With this approach, reliability of coding between raters was not assessed as the coders had five separate transcriptions. However, 81% of the codes (see Table 2) were identified by both coders, which indicates consistency between coders. Also, having 81% of codes identified by both coders indicates saturation was met as coders had different transcriptions and similar codes still emerged.

After the codebook was developed, two post-baccalaureate research assistants coded all forty transcriptions. The first author provided the two research assistants (Coder 3 and 4) with the forty transcriptions and the nodes from the codebook in an NVivo 12 file. Coder 3 and 4 were instructed to code anything that the participant described as preparedness into one of the nodes from the codebook. After all transcriptions were coded, we summed the number of files and references that were coded in each node (Table 2).

Results

Participants Psychological Profile

We ran descriptive statistics and *t*-tests in order to evaluate the psychological profiles of the participants and evaluate any differences between family members of individuals with cancer or dementia. First, the PG-12 was analyzed. The mean PG-12 score was 23.05 (*SD* = 9.24) with a range of 11 to 49. We examined differences between the two groups. There was no significant difference based on diagnosis type, $t(38) = .757, p = .454$, despite family members of individuals

with dementia ($M = 23.96$, $SD = 7.83$) attaining higher scores than family members of cancer patients ($M = 21.69$, $SD = 11.17$).

Second, the PHQ-9 was analyzed. The PHQ-9 mean score was 2.13 (2.94) with a range of 0 to 11. We examined differences between the two groups. There was no significant difference based on diagnosis type, $t(38) = -.88$, $p = .156$, despite family members of individuals with cancer ($M = 2.63$, $SD = 3.48$) attaining higher scores than family members of dementia patients ($M = 1.79$, $SD = 2.54$).

Third, the GAD-7 was analyzed. The GAD-7 mean score was 2.88 ($SD = 4.06$) with a range of 0 to 18. We examined differences between the two groups. There was no significant difference based on diagnosis type, $t(38) = -1.43$, $p = .155$, despite family members of individuals with cancer ($M = 4.00$, $SD = 5.28$) attaining higher scores than family members of dementia patients ($M = 2.13$, $SD = 2.89$).

Inductive Coding

The inductive coding included 25% (N=10) of the participants in the study. The two coders came up with sixteen themes, both coders independently provided the same themes for thirteen of the sixteen themes identified (81%). Coder 1 came up with two additional themes and coder 2 came up with one additional theme. The themes coders 1 and 2 both identified were, “acceptance regarding the diagnosis,” “friend, family and community support,” “sense of meaning about the diagnosis,” “relationship quality with the person with the life limiting illness,” “communicating with the person with the life limiting illness,” “talking about their eventual death,” “religion and spirituality,” “past experience of loss,” “having identities outside of caregiving,” “planning for life without the person,” “medical planning (e.g., funeral/financial arrangements; medical directives),” “prognosis of the disease,” and “talking about their eventual

death and learning about the disease.” Coder 1 added “support from employer” and “making future plans (e.g., moving to be closer to family).” Coder 2 added “individuals with life limiting illnesses making plans for themselves after they pass away (e.g., their own funeral arrangement).” These codes comprised the codebook (Appendix B) that was used for deductive coding of all participants.

Deductive Coding

After the codebook was developed, Coder 3 and 4 coded all forty transcriptions. Nodes (i.e., a code theme or idea regarding the definition of preparedness) were identified for each transcription and summed (referred to as *files* in the results section) and the number of times the node appeared throughout the forty transcriptions were summed (referred to as *references* in the results section). For example, Coder 3 indicated religiosity and spirituality (node) was endorsed in thirty-eight out of forty files and referenced one hundred forty-three times throughout the entire forty transcriptions. Also, we calculated the average amount of times each node was endorsed across the entire sample. The main overarching theme that participants discussed related to preparedness for loss was that they wanted to reduce their uncertainty related to their loved one’s death and the uncertainty of what will happen to their life following their loved one’s death. Many of the subthemes described below were related to increasing their certainty through preparing. Several participants discussed the feeling of uncertainty being related to some of the subthemes (e.g., religiosity). For example, one of the participants stated that knowing g-d had a plan assuaged her uncertainty and made her feel prepared for whatever happened to her loved one. Establishing certainty about what will happen seemed to be related to a sense of control and a sense that participants would be able to cope with the loss better. In discussing this need to promote certainty, two themes emerged as the focus in efforts to increase preparedness for the

death: Present Certainty (i.e., wanting to reduce uncertainty before their loved one passes away) and Future Certainty (i.e., wanting to reduce uncertainty after their loved one passes away).

Some of the themes identified regarding preparedness fit under both Present Certainty and Future Certainty (see Figure 1).

Present certainty. Present Certainty was related to the need to address how the impending death was affecting participants in the present as they continue to deal with the emotional aspects and day to day demands of having a loved one with a life limiting illness. This was reflected in statements pertaining to religiosity and spirituality (e.g., God had a plan), good relationship quality with the person who has the life limiting illness, having access to family, friends and community support, good communication with person with life limiting illness, and acceptance of the impending death.

Coders 3 and 4 identified statements of religiosity and spirituality in most files (coder 3 = 38; coder 4 = 36) and noted that it was referenced numerous times per transcript (coder 3 = 143; coder 4 = 106). This resulted in an average of 3.76 times (coder 3) and 2.94 times (coder 4) per interview. During the interview, the first author asked participants to expand upon how religion and spirituality play a role in preparing the person for the death of their loved one and a few common concepts surfaced. First, participants identified feeling prepared knowing that God had a plan for them and their family. Second, they felt supported no matter what happens because they have their minister, which makes them feel like there is no uncertainty. Lastly, participants stated they felt that having religion provides them meaning in what is happening to their loved one. Many participants stated that having meaning in what is happening to their loved one provides them a current sense of certainty that God knows what he is doing. “So, my life is in

God's hands. John's (changed for confidentiality purposes) life is in God's hands. So knowing that, knowing those facts, just gives me a ton of peace and makes me feel prepared."

References to the quality of the relationship with the person who has the life limiting illness was coded in numerous files (coder 3 = 12; coder 4 = 18) and had many references (coder 3 = 8; coder 4 = 11). This resulted in an average of 1.50 times (coder 3) and 1.64 times (coder 4) per interview. Participants endorsed that having a good relationship with the person with the life limiting illness made them feel more prepared for their loved one's death, because they knew these feelings of closeness would continue after the death despite their loved one no longer being physically present. Therefore, they were not worried about feeling lonely after the death because they did not perceive it as a loss of a relationship post-death. Moreover, participants felt this closeness with their loved one allowed them to discuss other aspects related to preparedness (e.g., end of life wishes). On the other hand, some participants stated that their poor relationship quality hindered their ability to prepare for their loved one's death because their loved one is negative all the time and they feel resentful towards the person. "Sometimes I fell a little resentful, that doesn't help. So, that's kind of has gotten in the way as far as communicating and preparing."

Support, including family, friend, community and healthcare support, were endorsed in many of the interviews (coder 3 = 12; coder 4 = 18) and referenced many times (coder 3 = 20; coder 4 = 32). This resulted in an average of 1.67 times (coder 3) and 1.67 times (coder 4) per interview. Family support included having all their family members in agreement regarding treatment, consistent communication between family members, and agreeing with pragmatic decisions (e.g., power of attorney; the family members will; funeral arrangements). Friend support consisted of talking to friends about their experiences with individuals with life limiting

illnesses. Participants stated that having their friends' support helped them feel more prepared for their loved one's death because it provided them with an awareness that other people are going through the same experience while gaining knowledge about what to expect. Community support included attending support groups, which participants reported helped them feel connected to people with similar experiences. Also, participants endorsed feeling more prepared because they were around individuals who understand their situation and how to handle the decline. Last, healthcare professionals were included under support. This included educational support (e.g., providing participants about prognosis) and informational support (e.g., when does the family member call hospice; what resources are available to the family member). "I have turned to my support groups because they are walking in the same shoes. I have close friends there and we have talked a lot."

Many participants discussed how communicating with the person with life limiting illness about their illness, their wishes (e.g., cremation; burial), and dying helped them feel more prepared. These were identified by both coders in numerous files (coder 3 = 39; coder 4 = 29) and had multiple references (coder 3 = 187; coder 4 = 112). This resulted in an average of 4.79 times (coder 3) and 3.86 times (coder 4) per interview. The three aspects of communicating with the person with the life limiting illness that participants identified as preparing them for the death of a loved one were: (1) communicating and laying out steps of what needs to be done before the loved one passes away and after they pass away (e.g., learning how to take care of household tasks before the person passes away); (2) communicating with the individual who has the life-limiting illness about their wishes (e.g., do they want them to remarry); (3) a lack of communication regarding how the loved one feels about dying (e.g., fear around dying). "As far as actual mortality, what has been hard for me is getting her to talk about it, because she has been

very unclear about what she wants, as far as, you know, burial process and end of life care, it's something she does not want to talk about and doesn't want to think about, and doesn't want to be reminded about. That makes it hard for me to prepare.”

In discussing acceptance, three common themes were identified by both coders in numerous interviews (coder 3 = 35; coder 4 = 20), and were referenced many times (coder 3 = 80; coder 4 = 37). This resulted in an average of 2.28 times (coder 3) and 1.85 times (coder 4) per interview. First, participants who stated that they were able to accept the diagnosis also reported that they felt they were prepared for the loss whereas those who could not accept the diagnosis felt they were unprepared. Second, participants also endorsed that accepting that their loved one would die from the illness helped the family member feel more prepared for the death. Last, almost all participants stated that the biggest change in their life following the loss would be feeling lonely. They identified that the only way to prepare for that was to accept the loss and be prepared for life without the person. “I am very at peace, and comfortable with it. I know my mom's gone, I know that she's no longer able to travel in the motor home like she did for years, and I know that there is just no real quality in the life that she's leading now. I can prepare for life without her because I have accepted it.”

Finally, when the participants were asked what, if anything, hinders their ability to prepare for the death of their loved one, many participants discussed how they were hopeful their loved one would get better. These were identified by both coders in numerous files (coder 3 = 11; coder 4 = 9) and referenced many times (coder 3 = 34; coder 4 = 27). This resulted in an average of 3.09 times (coder 3) and 3.00 times (coder 4) per interview. It should be noted that participants who reported being hopeful as an aspect of preparedness were only family members of terminally ill cancer patient. They stated that they could not prepare either in the present or for

the future, because preparing for their loved one's death meant they had lost hope that they would get better. "If I start to prepare for the loss of my husband, I can no longer be hopeful he will beat the cancer."

Future certainty. Future Certainty was related to the need to address what would happen when their loved one died. Preparing for the death by addressing issues to establish Future Certainty was reflected in statements pertaining to religious and spiritual beliefs (e.g., there is an afterlife; we will be together again), knowing what to expect due to past experience of loss, having plans for life without the person, making pragmatic preparedness for the event of the death (e.g., funeral/financial arrangements; medical directives), and having social support.

Themes related to religiosity/spirituality came up related to both establishing certainty in present and future due to the complexity of the construct and wide breadth of answers describing how religion and spirituality prepared participants. In regard to Future certainty, participants stated that knowing there is an afterlife helped them feel more certain about where the person with the life limiting illness is going when they pass away. Also, participants endorsed feeling prepared for the death of the individual with the life limiting illness because they will be together again when they pass away and can still communicate with them after they pass away. Similarly, many participants stated that they believed in reincarnation and that made them feel there was certainty that they would meet their loved one again. "We were raised Catholic, and believe in after-life and that whatever form we're gonna be in, whatever that is, everything will be ok... And I really do believe, just my personal spiritual sort of belief, that the only thing that separates us is the physical body and nothing else. So it makes it easy to know that I'll always have communication with my mom, no matter who goes first, me or her."

Increased sense of preparedness due to past experience of loss was discussed by

numerous participants (coder 3 = 37; coder 4 = 26) and had multiple references (coder 3 = 63; coder 4 = 33) throughout the transcriptions. This resulted in an average of 1.70 times (coder 3) and 1.26 times (coder 4) per interview. Based on the high number of endorsements by the first seven participants, participants eight through forty were asked if past losses helped them feel more prepared for the loss of their loved one. Participants stated that experiencing a past loss helps them feel more prepared for the death of their loved one because they know what to expect. When asked to expand on how it reduces their uncertainty, several participants endorsed knowing there will be good days and bad days, but their “grief” would mitigate over time. “So yeah, going through all that (referring to past loss), I know what it personally feels like to lose someone. So I can say that is helping me to prepare for the day John (changed for confidentiality) isn’t here anymore.”

Planning for life without the person was endorsed in several interviews (coder 3 = 37; coder 4 = 36) and referenced (coder 3 = 94; coder 4 = 59) numerous times. This resulted in an average of 1.70 times (coder 3) and 1.26 times (coder 4) per interview. A major aspect of planning for life without the person was making sure to have other roles outside of the relationship with their loved one. Many participants described being able to move closer to their family, play a more prominent role as a parent or grandparent, and focus on other identities (e.g., play more golf with friends). When the interviewer asked how this made them feel more prepared, participants stated that they would be able to focus on these new roles rather than dwelling on the loss. Further, they stated that not focusing on the burden related to caregiving and having a new purpose to look forward to made them feel more prepared for the loss. “I learned to knit, I’m learning to play the guitar, I’ve joined a unitarian fellowship and made

friends there. It's a small group of people and I've gotten on committees there and, um, yeah, made new friends there.”

Pragmatic preparedness was endorsed by all participants (coder 3 = 40; coder 4 = 40) and had the most references (coder 3 = 330; coder 4 = 245). This resulted in an average of 8.25 times (coder 3) and 6.13 times (coder 4) per interview. Statements related to pragmatic preparedness fell into four subcategories: financial, funeral, housing, and medical directives. Financial preparedness included: having a will completed, knowing what bills and mortgage need to be paid, and gaining financial power of attorney. Funeral preparedness involved knowing the wishes of the person with the life-limiting illness, in regard to burial or cremation, where they wanted to be buried/where they wanted their ashes spread, and what kind of funeral they wanted. Some participants stated they felt really prepared because the individual with the life limiting illness was planning their own funeral. Housing included downsizing their house to an apartment or townhouse where it was easier to manage, both physically and financially. Some participants endorsed feeling they were not prepared for their loved one's death because they were unable to afford their house payments without their loved one's salary but did not have time to sell the house or downsize due to their caregiving role. Issues around medical directives included having power of attorney (i.e., medical), guardianship, having “do not resuscitate” (if necessary) or having a Physician Order for Life-Sustaining Treatment (POLST) form completed. “I have an attorney, we have a will, we have all the things that we need to have in place. I have his power of attorney, and my attorney has gotten two letters from physicians saying that John (changed for confidentiality) is no longer able to handle his affairs.”

When coding the transcripts, support, including, family, friend, and community support was complex and endorsed at such a high rate that it not only fit under Present Certainty, but also

under Future Certainty. Support in relation to establishing certainty about the future was related to knowing that they would have friends, family, and community support after the person passed away. Participants stated that they will feel they are not alone when the person passes, they will have a life without the person, and they have emotional support from these individuals.

“Emotional support. I will handle it fine, but you still need to know that you are not alone.”

Discussion

This study examined the description of preparedness by family members of individuals with a life limiting illness, in order to gain a greater understanding of the themes associated with this construct. The results of this study highlight the complexity of preparedness and the necessity for examining this construct using a grounded approach. Through inductive and deductive coding, the main overarching theme identified as a precursor to having a sense of preparedness for loss was the issue of the need to reduce uncertainty in terms of increasing Present Certainty and Future Certainty. Present Certainty included religion and spirituality; relationship quality with the person with the life limiting illness; family, friends and community support; communicating with person with life limiting illness; and, acceptance. Future Certainty included religion and spirituality; past experience of loss; planning for life without the person; pragmatic preparedness; and future family, friends and community support.

Supporting Past Findings

All participants regarded religion and spirituality as aspects of preparedness. This is consistent with prior research (Hebert et al., 2006; Hebert et al., 2009; Steinhauer et al., 2001) that showed that religion and spirituality are facets of preparedness, but past studies have failed to describe how the practice of religion and spirituality help individuals feel more prepared. Due to the complexity of this construct, aspects of religion/spirituality were important for establishing

both Present and Future Certainty. Under Present Certainty, the effects of religion and spirituality on feeling prepared revolved around knowing that God had a plan for their family, feeling close to God through their minister, and feeling there is meaning in what is happening to their loved one. Under Future Certainty, the effects revolved around knowing there is an after- life, knowing they will be reunited with their loved ones, and believing in reincarnation for some. These three subthemes of Future Certainty are closely related to the phenomenon of “continued bonds” in the post-loss literature, in which a bereaved individual does not sever the bonds with the person who has died, but rather continues the attachment within the new circumstance through having an inner relationship with the deceased person (Klass & Steffen, 2017; Stroebe & Schut, 2005).

The current study also supported past research that found preparedness includes knowing what to expect as the medical condition progresses (Hebert et al., 2006; Hebert et al., 2009; Steihauser et al., 2001). This study went a step further than previous studies and found that participants wanted to know the negative effects of the current illness (e.g., when family member’s ADLs; IADLs will decline) and specifics on the prognosis. Providing family members with a timeline would allow them to prepare for when the loss will happen and prepare for the decline of ADLs and IADLs, which might reduce uncertainty leading up to the death of their loved one. Also, understanding the prognosis and timeline for the decline of ADLs and IADLs can affect the other themes identified in this study. For example, if a family member knows their loved one with the life limiting illness has a month until they will no longer be cognitively able to sign financial documents, they might start the process to achieve financial preparedness.

Pragmatic preparedness, which included funeral arrangements, financial arrangements (e.g., will), housing, and medical directives (e.g., power of attorney) has been identified in all of

the past studies and also endorsed in this study as a major facet of preparedness. Hebert and colleagues (2009) categorized pragmatic preparedness under “behavioral” where they explained that family members are more prepared when they accomplish these tasks because it reduces the burden of the loss of a loved one. Even though this study found similar results in describing pragmatic preparedness, participants in the current study explained that it was not just that completing pragmatic tasks is expected to reduce the burden when their loved one passes away, but the certainty that they are following the wishes of the individual with the life-limiting illness adds a level of comfort. Particularly, they did not want to be faced with presuming what the individual who has the life limiting illness would have wanted. One participant even mentioned that their family member with the life limiting illness planned their entire funeral, highlighting the importance of this aspect of preparedness in improving both Present and Future Certainty.

Interestingly, social support was only discussed in one of the previous studies examining preparedness. Hebert and colleagues (2006) described one aspect of preparedness as the ability to discuss grief and emotions while being able to maintain relationships with friends and family. However, participants in this study described how support from their social network affected their sense of preparedness in relation to both Present and Future Certainty. In the current study, participants expressed that support, whether that be family, friend, community or healthcare professional support, is a major aspect of preparedness. There were four themes that fit under support regarding Present Certainty. First, family support was described as family members being on the same page. Second, participants endorsed that support from friends, included gaining information about the life limiting illness from their friends who experienced a similar situation. Third, community support included family members joining support groups, which made them feel they were not alone (e.g., support group). Last, health professionals provided

them with educational and informational support. Participants' description of support provided considerably more depth than past studies. Even though past studies have identified support as an aspect of preparedness, there were aspects of support that have not been discussed in past literature. Support that fit under Future Certainty has not been discussed in past literature but was endorsed by participants at a high rate. Support regarding Future certainty included participants feeling they are not alone when the person passes, they will have a life without the person, and they have emotional support from friends, family and the community.

Novel Findings

There were many themes under Present Certainty and Future Certainty that were not identified in past studies. The quality of the relationship with their ill family member, having good communication with their ill family member, as well as the many aspects of accepting the impending death were new themes that fit under Present Certainty. Planning for life without the person and information from past experiences of loss were new themes related to increased sense of preparedness that fit under addressing Future Certainty.

This study is the first to our knowledge that specifically identifies relationship quality as an aspect of pre-loss preparedness. This finding supports studies that have found that relationship quality is important for family members of individuals with a life limiting illness both before and after the loss of their loved one. For example, Reblin and colleagues (2016) found that family members with high-quality relationships experienced a less subjective burden. Similar research has found that individuals with high quality relationships have lower anxiety and depression (Grumfeld et al., 2004). Research examining post-loss grief (e.g., Mancini, Robinaugh, Shear, & Bonanno, 2009) also suggest that family members who reported better relationship quality prior

to their family member's death had lower rates of prolonged grief and negative outcomes following the loss.

While research in other fields (e.g., palliative care) have identified that poor communication leads to poor mental health for both patients and their family member, this study goes a step further suggesting that a mechanism linking communication and mental health in these the family system is preparedness, suggesting a possible target for intervention. Communication between the family member and the individual with the life limiting illness involved three distinct features: talking about the illness, communicating about the person's wishes, and talking about the family member dying – all of which could be easily promoted in prevention programs. In the palliative care literature, increased communication at the end of life between family members, patients, and healthcare professionals has been linked to improved psychological outcomes for all parties (e.g., Curtis et al., 2012). In fact, a recent randomized control trial found that using communication facilitators to increase communication (i.e., discussing the disease; healthcare wishes; and end of life care) between the dyad in the intensive care unit resulted in lower rates of depression for both individuals.

Acceptance related to being diagnosed with a life limiting illness has been studied extensively; however, this study is the first to our knowledge to explicitly provide evidence that family members' acceptance of the life limiting illness is a part of preparedness. Acceptance was described by family members as accepting the family member's diagnosis, accepting their family member would pass away and accepting that they would be lonely when their loved one passed away. This is consistent with past literature that examines acceptance in individuals with the life limiting illness. For example, Sachs and colleagues (2012) found that patients suggested that acceptance allowed them to enjoy other aspects of life, such as time with loved ones, as well as

provide an improved quality of life in regard to personal and family relationships. Family members in our study who stated that they have accepted that the person is going to pass away, endorse being able to cherish their limited time with the individual with the life limiting illness. The third aspect of acceptance identified by family members, accepting they would be lonely after the loss, is unique to family members. Family members describe that by accepting they will be lonely following the death of their loved one, they can prepare by creating new relationships and adding other roles in their life (e.g., finding a group of people to golf with). This is related to another subtheme, planning for life without the person, as family members can start creating friendships in the present moment before the loss rather than planning for the future without the person.

Planning for life following the loss included having other roles outside of the relationship with the loved one. Even though planning for life following the loss has not been identified as an aspect of preparedness, these results are not surprising as past research has identified that bereaved individuals who endorse additional roles and identities not affected by a loss report fewer grief and depressive symptoms (Papa & Lancaster, 2015). Similarly, Maccllum and Bryant (2013) found that a bereaved individual with an independent self-identity endorsed lower rates of prolonged grief than bereaved individuals with a codependent self-identity.

In previous studies, previous loss has not been identified as an aspect of preparedness for family members of individuals who have a life-limiting illness. However, in the current study it was endorsed by almost all of participants as an aspect of preparedness. Participants endorsed that experiencing a previous loss makes them feel increased certainty regarding life without the person and how they will handle and cope with the change. The bereavement literature has been

equivocal regarding previous loss as a risk or protective factor for increased grief symptoms (e.g., Lobb et al., 2010; McSepedden et al., 2017).

Hope has been identified in numerous studies as a protective factor for negative psychological outcomes (e.g., post-traumatic stress disorder; worry; depression; Long et al., 2018; Peh et al., 2017) in both cancer patients and their family members. Contrary to these findings, participants in this study reported that they were unable to prepare for the loss of a loved one as that would mean they lost hope that their family member would get better. There has been a quantitative study (Shirado et al., 2013) that has examined hope and preparedness. Results differed from the current study as Shirado and colleagues' (2013) found that 73% of family members reported they were able to maintain hope and also prepare for the loved one's death, whereas our sample endorsed that they were unable to maintain hope and prepare for the loved one's death. There might be several reasons why participants in the current study contradicted findings from Shirado and colleagues (2013) study. First, Shirado and colleagues' (2013) study is retrospective and measures participants preparedness as well as hope using a single question after the loved one passed away whereas our findings are prospective and the loved one is still alive. Past research in combination with the current research highlight the complexity of preparedness and hope as constructs.

Limitations

This study had some limitations. First, due to the low rates of a minority population in Northern Nevada, participants were predominantly Caucasian. However, the large variability between the amount of time since diagnosis (2 months to 12 years) improves generalizability of the results. Second, given the recruitment method there is a distinct possibility that those

participants that volunteer for this, and studies like it, might not be representative of the general population.

Conclusion

Family members face tremendous challenges due to a family member's life limiting illness. Research has found that preparedness for the loss of a loved one is a robust protective factor for negative psychological outcomes (e.g., Pre-Loss Grief; Prolonged Grief Disorder). However, the current understanding of preparedness and the measurement tools for preparedness have significant weaknesses, which stand in the way of understanding the relationship between preparedness and mental health symptoms, as well as creating interventions to increase preparedness. Therefore, this preliminary study utilized mixed method design in order to create a framework for preparedness. In order to gain a greater understanding of preparedness, this study asked family members of advanced dementia and stage 4 cancer patients their view of what prepares them for the loss of their loved ones. Some findings (e.g., religion/spirituality) supported past studies of preparedness, and additional novel factors (e.g., previous loss) were identified as aspects of preparedness for family members.

Future Directions

This study provides a preliminary framework of preparedness for family members of individuals with life limiting illness, which needs to be validated using a larger and more generalizable sample. After validation of this framework, a measure of preparedness should be developed and tested. This measure would provide the field with the ability to identify family members' preparedness for the death of their loved one. Also, it would provide the field a greater understanding of the relationship between preparedness and negative psychological outcomes, both prior to and following the death of their loved one.

There were two findings that were not originally proposed but are important to the field of preparedness. Future research should prospectively examine the relationship between hope

and preparedness using valid measures of both constructs. This relationship is important to examine as preparedness appear to be a protective factor for psychological symptoms following the death of a loved one, but the relationship of maintaining a sense of hopefulness and being more prepared for an impending death appears to be complex.

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Table 1. Participants' Psychological Characteristics

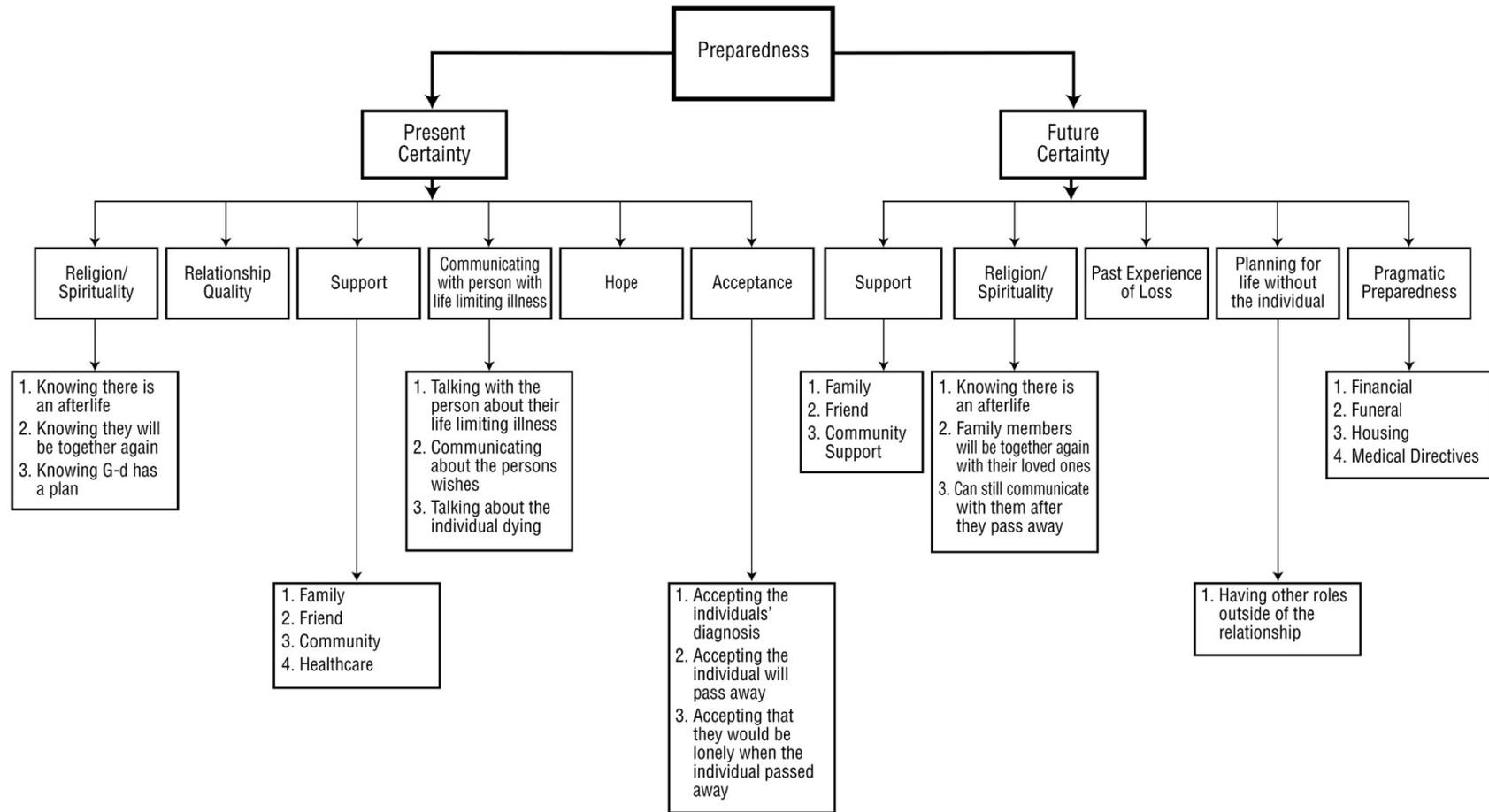
	# of Participants	<i>PG-12 Mean</i>	<i>PHQ-9 Mean</i>	<i>GAD-7 Mean</i>
Overall	40	23.05 (9.24)	2.13 (2.94)	2.88 (4.06)
Cancer	16(40%)	21.69 (11.17)	2.63 (3.48)	4.00 (5.28)
Lung	4 (10%)			
Esophageal	4 (10%)			
Breast	3 (7.5%)			
Lymphoma	1 (2.5%)			
Leukemia	1 (2.5%)			
Prostate	1 (2.5%)			
Colon	1 (2.5%)			
Liver	1 (2.5%)			
Dementia	24 (60%)	23.96 (7.83)	1.79 (2.54)	2.13 (2.89)
Alzheimer's	16 (40%)			
Frontal	4 (10%)			
Temporal				
Lewy Body	2 (5%)			
Vascular	1 (2.5%)			
Parkinson's Dementia	1 (2.5%)			

Table 2. Codes, Files and References

	Coder 1: Files	Coder 1: References	Coder 2: Files	Coder 2: References
<i>Present Certainty</i>				
Religion/Spirituality	38	143	36	106
Knowing there is an afterlife				
Knowing they will be together again				
Knowing God has a plan				
Relationship Quality	12	18	8	11
Support	37	277	35	123
Family				
Friend				
Community				
Healthcare				
Communicating with person with life limiting illness	39	187	29	112
Talking with the person about their life limiting illness				
Communicating about the persons wishes (e.g., cremation; burial)				
Talking about the individual dying				
Acceptance	35	80	20	37
Accepting the individuals' diagnosis				
Accepting the individual will pass away				
Accepting that they would be lonely when the individual passed away				
<i>Future Certainty</i>				
Religion/Spirituality	38	143	36	106
Knowing there is an afterlife				
Family members will be together again with their loved one				

Can still communicate with them after they pass away				
Past experience of loss	37	63	26	33
Planning for life without the individual	37	94	36	59
Having other roles outside of the relationship				
Pragmatic preparedness	40	330	40	245
Financial				
Funeral				
Housing				
Medical Directives				
Support	37	277	35	123
Family				
Friend				
Community Support				

Figure 1
Preliminary Framework of Family Members' Preparedness



Appendix A

Activity	Question
Interviewer Introduction	N/A
Question 2	Have you done anything to prepare for the loss of your loved one? If so, what have you done?
Question 3	Have you turned to anyone to help you prepare for the death of your loved one? How have they helped you or made it worse?
Question 4	What problems have you encountered that have hindered your ability to prepare yourself for your loved one's death?
Question 5	What (if anything) are healthcare professionals doing to help you prepare for losing your loved one? Or what would you like them to do?
Question 6	Does talking about the imminent death of your loved one help prepare you for the loss? If so, with whom? What is most helpful to talk about?
Question 7	Do you think your roles/commitments affect your ability to help you handle your loved one's life limiting (other than caregiving)? What have you done (if anything) to ensure you will have other roles/commitments after their death?
Question 8	Have you focused on pragmatic issues to address before the loss (including estate planning, planning funeral arrangements, rearranging work schedules)? Has it been a part of preparing for the death? Does it help or make it worse?
Question 9	Do you think it helps or would help if you could find some kind of meaning in what is happening to your loved one?
Question 10	What will be the biggest change in your life when your loved one passes away? and how do you prepare for that?
Question 11	Has religion/spirituality played a role in preparing you for the death of your loved one? If so, how?
Question 12	Is there anything else we have not discussed that has prepared you for the loss of your loved one?
Added Questions During Interview	
Question 13	If you have lost someone in the pass, has experiencing that loss made preparing for your family members loss worse or better?
Question 14	Do you believe it is possible to still have hope and be prepared for someone's death at the same time?

Appendix B

Code book

- Acceptance
- Future Plans/New identity Following Death
- Support
 - Family
 - Friend
 - Community (e.g., employer)
- Conversation about the Death with Family Member
- Past Experience with Loss
- Pragmatic
 - Funeral
 - Medical direction
 - Legal
 - Financial
 - Housing
- Religion/Spirituality
 - Knowing there is an afterlife
 - Knowing they will be together again
- Role in the family/sense of identity
- Want Healthcare professions to help prepare
- Don't want healthcare professionals (e.g., oncologist) to help prepare
- Disease Prognosis
- Learning about Disease (e.g., how to prepare for it)
- Relationship Quality