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## Older Women's Stories of COVID-19 Loss: Communicated Narrative Sense-Making Through Photography

### Abstract

The diverse array of challenges associated with the COVID-19 pandemic make it difficult to assess the full impact of this global health crisis. More than 300,000 older Americans died, leaving a nation of grieving survivors in their absence. This profound loss of life will undoubtedly inform the field's understanding of grief and grieving for many years to come. Pre-pandemic, older women in the United States understood grief to be part of their life stage; COVID-19 amplified the grief experience through both cumulative losses and the isolation particular to the novel coronavirus response. However, few qualitative studies explore older women's grief, and even fewer capture pandemic grief. The present study illuminated ways in which older women made sense of their losses during the pandemic. Through photography and qualitative interviews, I uncovered the stories behind the mortality statistics. Eleven themes emerged that offer insight into the grieving experience of older women in the United States: social isolation, fear of the virus, efficacy of support, efficacy of the healthcare system (HCS), multiple simultaneous losses/stressors, interpersonal conflict, political divide, delayed grief/rituals, gradual loss, responses to loss(es), and the presence of deceased. Findings offer important recommendations for theory and practice.

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Through Photography

A Dissertation

Presented to

the Faculty of the College of Arts, Humanities and Social Sciences

University of Denver

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

by

Anne Walker

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Advisor: Dr. Erin Willer

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#### ABSTRACT

The diverse array of challenges associated with the COVID-19 pandemic make it difficult to assess the full impact of this global health crisis. More than 300,000 older Americans died, leaving a nation of grieving survivors in their absence. This profound loss of life will undoubtedly inform the field's understanding of grief and grieving for many years to come. Pre-pandemic, older women in the United States understood grief to be part of their life stage; COVID-19 amplified the grief experience through both cumulative losses and the isolation particular to the novel coronavirus response. However, few qualitative studies explore older women's grief, and even fewer capture pandemic grief. The present study illuminated ways in which older women made sense of their losses during the pandemic. Through photography and qualitative interviews, I uncovered the stories behind the mortality statistics. Eleven themes emerged that offer insight into the grieving experience of older women in the United States: social isolation, fear of the virus, efficacy of support, efficacy of the healthcare system (HCS), multiple simultaneous losses/stressors, interpersonal conflict, political divide, delayed grief/rituals, gradual loss, responses to loss(es), and the presence of deceased. Findings offer important recommendations for theory and practice.

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#### **Chapter One: Introduction and Review of the Literature**

Every week, I call my 86-year-old mother who lives alone in Central Illinois. She tells me about her tennis game and her early morning walks along the Constitution Trail. For me, these chats are a welcome respite from my hectic life, juggling graduate school and raising three teenagers. Many of my friends struggle to take care of their ailing parents, but I am one of the lucky ones. Mom is exceptionally healthy at her age, both physically and cognitively.

When the pandemic hit, Mom was vacationing with friends in Arizona. Like most of us, she had no idea what to do. Should she stay in place in her rental home or drive herself all the way back home to Illinois. At that time, even staying in hotels seemed dangerous, especially for older people, who were most vulnerable to the novel coronavirus. Mom's independent streak led her to pack her car with Clorox wipes and masks and drive all the way home by herself. Being in a familiar locale was worth the risk, she decided. I was terrified for her, but she was lucky and made it home safely. Her luck continued as she managed through the 2020 lockdown all by herself, staying connected to family and friends through her landline, FaceTime, and Zoom. She got vaccinated and boosted as soon as shots were available, and she and her friends miraculously avoided the virus.

But things changed during the fall 2021 surge. After a mostly mask-free summer, the virus came back with new variants. I was afraid for her health all over again. And fate had other plans for her friends. In December of 2021, Mom learned that her dear friend of 60 years died in hospice care after years of suffering from cancer. A few weeks later, she emailed her college roommate to arrange a visit in Chicago—something they'd been doing for 50 years. After several days of no response, a Google search revealed that her friend had died suddenly. A few days after those two deaths, Mom learned that her bridge club friend unexpectedly died from surgery complications. The worst news came a week later: my mother's brother got out of bed in the middle of the night and walked outside in the Minnesota December snow. He had been living with dementia for years and somehow unlocked the back door and fell down the wooden stairs. His wife discovered his body the next morning, his face flat on the ground. He had frozen to death.

A few days later, my sister sent Mom a text saying, "Mom, you will outlive us all." I think she meant it as a compliment, but the reality is that the longer she lives, the more people Mom loses. Even though her losses were not caused by COVID-19, the pandemic made it harder for her to grieve. There were no memorials to attend, no social gatherings to grieve and remember all of the people she lost in rapid succession.

#### \*\*\*

The number of people who have died from the COVID-19 pandemic is staggering. Like a tidal wave, this virus hit the U.S. hard (Yong, 2022). From the beginning, COVID-19 has impacted older adults significantly, with 95.5% of deaths among those aged 50 and older (CDC, 2022). Despite the wide availability of vaccines, 952,223 Americans had died from the virus with more than 8.5 million Americans grieving a loved one lost to the virus as of March 2, 2022 (CDC, 2022). Each death leaves an average of nine people grieving the loss (Verderi et al., 2020).

In January 2021, the U.S. death toll reached 500,000. It was only then—nearly a year after the onset of the pandemic—that the federal government formally acknowledged the lives lost. A somber candle-lighting ceremony led by President Biden and Vice President Harris recognized people who died from the virus (Wise, 2021). President Biden ordered the Washington National Cathedral to ring bells 500 times, each representing a thousand COVID deaths ("Biden holds candle lighting ceremony," 2021). Although this acknowledgement was affirming for some people, others were disheartened that it took a new president and half a million deaths for the national government to formally recognize our collective suffering. This "too little, too late" response from the country's leaders sent the message to grievers across the country that their losses didn't really matter (Global Strategy Group, 2020). Perhaps these deaths did not register as important because a majority of them were among the elderly, revealing rampant ageism in response to the virus (Ng et al., 2021). In addition, women experience more deaths in their lifetimes than men (Lekalakala-Mokgele, 2018). The intersection of gender and age made older women's experiences with grief especially profound during the pandemic (Lekalakala-Mokgele, 2018; CDC, 2022).

Hidden behind COVID-19 death counts are stories of older women suffering. Yet, this gendered grief is both underdiscussed and underexamined. Thus, further research is needed to capture older women's experiences of pandemic loss in order to broaden our understanding of grief. New insights will likewise benefit the friends and family members who support older women, as well as those who provide social, psychological, and community-based support to older adults. As such, the purpose of the present study is to discover the common themes in the stories of older women who lost someone meaningful to them during the COVID-19 pandemic.

#### **Review of the Literature**

#### **COVID-19** Context

The context of COVID-19 created a high number of common stressors including cascading collective traumas, collective uncertainty, political dissonance, and social unrest. Each of these stressors is explained in the following section.

#### Cascading Collective Traumas

In addition to grief caused by the deaths of so many people to COVID-19, many Americans experienced "cascading collective traumas" across 2020 and 2021 (Silver et al., 2020, p. 4). These traumas included destructive weather events, economic losses, and a racial reckoning that led to mass street protests (Silver et al., 2020, p. 4). Destructive wildfires burned through Boulder County, Colorado, leaving more than a thousand residential structures destroyed (Boulder County News Archive, 2022). Increases in job loss, homelessness, and domestic violence were also prominent during the pandemic (Giebel et al., 2021; Katz et al., 2020; Maddrell, 2020). Research suggested that one single COVID-19 death results in an average of nine people losing a close family member, resulting in historically high levels of collective grief (Verderi et al., 2021).

Smaller losses like cancelled appointments and theater shows added to a sense of collective anxiety. Katz et al. (2020) describe "heightened emotions" emerging due to the anxiety and fear of people's health and security (p. 433). Similarly, Goveias and Shear (2020) describe the numerous stressors people faced during the first year of the pandemic:

COVID-19 mitigation policies are associated with other forms of loss that are also stressful. There are high rates of unemployment, furloughs, salary reductions, and an increase in homelessness. Many are experiencing disruptions in living arrangements and painful physical separation from close friends and family. There is widespread fear of contamination, possibly increased by frequent reminders of death rates and exposure to distressing stories and other emotionally activating media coverage. (p. 1122)

Even as recent as the Omicron surge in December 2021, the pandemic compounded many traumatic events in a matter of a few years. Together, they created unprecedented and simultaneous collective stressors that include multiple deaths, collective uncertainty, unpreparedness and political dissonance. These stressors came as people were ordered to stay home, resulting in a "void of support when [they] need[ed] it most" (Murphy, 2020, p. 246).

#### Collective Uncertainty

The periodic waves of confusing information about the virus created a heightened experience collective uncertainty (Goveias & Shear, 2020). However, the flood of confusing and inaccurate news surrounding the pandemic also added to people's stressors, especially in early 2020, when very little was known about the virus (Rocha, 2021). Although it is well known now that surface transmission poses a relatively low risk, an early pandemic study showed that the COVID-19 virus could live up to 72 hours on surfaces, leading to the panic purchasing of wipes and sprays in stores across the country (CDC, 2021). People felt an immediate shock of unanticipated deaths mixed with fear and dread of what no one quite understood (Maddrell, 2020).

#### **Political Dissonance**

Political dissonance was omnipresent under the leadership of President Trump whose COVID-19 task force ignored a prepared pandemic playbook created by the Obama administration specifically for a situation like COVID-19 (Knight, 2021). The chaos in Washington translated into various contrasting messages about what to do to stay safe (Comancho & Glickman, 2021). The combination of mixed messages, disinformation, and the politicization surrounding public health orders was on full display during a press conference at the White House. President Trump instructed the American people to inject themselves with disinfectant while Anthony Fauci (the director of the National Institute for Allergy and Infectious Disease) covered his face with his hands (LeBlanc, 2021). The high levels of political dissonance heightened the collective anxiety in the United States.

#### Social Unrest

Amid this global health crisis, 2020 saw an increase in social unrest after the public murder of George Floyd by a police officer in Minnesota, followed by 140 city protests led by the Black Lives Matter social movement (Taylor, 2021). This added additional stress on grievers, especially Black Americans, who were disproportionately impacted by COVID-19 death (CDC, 2020; Fowers & Wan, 2020). During protests, depression increased by 7%, "regardless of personal involvement [suggesting] community spillover effects" (Ni et al., 2020, p. 232). Being elderly, female, Black, and lacking social support are significant risk factors for mental health challenges during times of social unrest (Ni et al., 2020, p. 232). Additionally, Black and Asian survey

respondents reported experiencing higher levels of discrimination during the pandemic than before, adding even more stress to an already difficult time (Ruiz et al., 2020).

#### **Older Women at Risk**

Older women were at a particularly high risk for stress due to grief before and especially during the pandemic. Extant research on pre-pandemic grief among older women shows that the loss of a spouse is one of the most stressful life events, and women have more "cumulative exposures to family members' deaths" (Lekalakala-Mokgele, 2018, p. 52). In another pre-pandemic study, researchers tracked bereavement for 30 months, revealing that women suffered more losses including "any loss, non-spousal family loss, spousal loss, as well as loss of a friend" (Williams et al., 2006, p. 11). Additionally, a 2014 CDC report specified that 54% of women aged 75 and older identified as widows, in contrast to only 20% of men (CDC, 2014). Due to their longevity, older women are also more likely to be caregivers, adding yet another burden to their already challenging life stage (Williams et al., 2006). Furthermore, women tend to have larger social networks than men, and therefore lose more friends to death (Wang et al., 2021).

The pandemic worsened these conditions for older women. Although pandemic stress impacted everyone, older women were particularly vulnerable to mental health risks (Treml et al., 2020; Wang et al., 2021; CDC, 2022). Bereavement researchers report that "[n]ot only are older women subject to the stresses of caring for loved ones, but by virtue of their longevity advantage over men, women are more likely to experience the loss of loved ones as part of the aging process" (Williams et al., 2006, p. 5). Furthermore, research has shown that among other factors, "[g]rief severity was associated with female

gender" (Treml et al., 2020, p. 7). For example, while men were more likely to die from the virus, surviving women were at a higher risk for grief disorders due to experiencing a large number of losses over a short period of time (Nguyen et al., 2021; Treml, et al., 2020; Wang et al., 2021). Furthering this connection between gender and mental health, in a study on loneliness and COVID-19, Savage et al. (2021) reported that "several characteristics—such as being female and living alone—increased the odds of loneliness" (p. 1) Women are also more likely to contract COVID-19, but men are more likely to die from it (CDC, 2021). Older women are therefore at a higher risk of losing a spouse or a loved one to this virus. Despite their high number of losses, current research indicates that older women's experience with grief provides no discernable advantage (Lekalakala-Mokgele, 2018).

#### Impact of Social Isolation

One of the greatest pandemic disruptions resulted from the various stay-at-home orders and advisories. Social isolation contributed to an increase in depression, anxiety, and other psychological symptoms (Pera, 2020). Nursing homes were highly susceptible to outbreaks due to congregate living conditions (Barnett & Grabowski, 2020). Due to this vulnerability, nursing homes restricted residents to their rooms with virtually no human contact (Frieden, 2020). Hospitals also experienced lack of human contact, as medical staff scrambled to accommodate many patients who were dying (Young et al., 2020; Wakam et al., 2020). Furthermore, social distance safety measures (staying 6 feet apart, wearing masks) along with an overwhelmed healthcare system had a profound impact on those who were dying (Galviria & Smith, 2020; Myers & Liu, 2022). COVID

patients as well as others died alone without friends and family and sometimes without even a caregiver present (Galviria & Smith, 2020).

The Frontline documentary *The Last Call* illustrates a common scene in the early days of the pandemic (Galviria & Smith, 2020). The film tells the story of Jessica Caro's experience with COVID, beginning with her teenaged daughter and then her aunt catching the virus. In March 2020, Caro called 911 for her aunt, only to be told that they did not have enough ambulances to transport her to the hospital. Four days later, her aunt died. A few days later, Caro's 79-year-old mother landed in the hospital with COVID. A healthcare worker outfitted in full personal protective equipment arranged a FaceTime call with Caro. As her mother lay in the hospital dying, Caro begged her to stay alive, to fight this virus. "I love you so much," she cried to her unconscious mother on an iPhone screen (Gaviria & Smith, 2020).

Caro's experience mirrors Mayland et al.'s (2020) research on previous pandemics and their profound impact on grief. One of the central experiences outlined in the study is the experience of the survivors being away from their loved ones at the time of their death:

[P]revious pandemics appear to cause multiple losses both directly related to death itself and also in terms of disruptions to social norms, rituals, and mourning practices. This disruption affecting an individual's ability to connect with the deceased both before and after the death may potentially impact on grief. In particular, the usual societal and cultural rituals can seem rushed, altered, or absent. (Mayland et al., 2020, p. e36).

Caro's gut-wrenching experience illustrates the nature of many deaths during the COVID-19 pandemic. Carr et al. (2020) explain how experiences like Caro's pandemic experience put many people at risk of elevated mental health risks:

Bereaved family members have heightened psychological symptoms when they did not have an opportunity to say 'goodbye' to the decedent, when the decedent was in pain, when the death was unexpected, when they perceive that the death was unjust and could have been prevented, when the death occurred in an ICU or hospital rather than at home, and the treatments received were intrusive or discordant with the patient's preferences (e.g. Carr, 2003; Chi & Demiris, 2017; Wright et al., 2010). (pp. 427–428)

Pre-pandemic, healthcare workers aimed for a "good death" for terminal patients (Gawande, 2014). A good death means that the patient feels a sense of "comfort, emotional and spiritual well-being ... surrounded by loved ones in a peaceful environment" (Carr et al., p. 426). COVID-19 patients experienced particularly "bad deaths," with difficulty breathing and without loved ones present (Krikorian et al., 2020). These tragic deaths resulted in a higher risk of trauma for the bereaved (Carr et al., 2020; Verderi et al., 2020). In a troubled U.S. healthcare system, some traumatized family members reported not receiving the help they needed for their high bereavement needs (Stone, 2021).

An absence of closure and proper goodbyes severely impacts an individual's "ability to connect with the deceased both before and after the death," placing grievers at greater mental health risk (Mayland et al., 2020, p. e36; Goveias & Shear, 2020; Testoni et al., 2021; Murphy, 2020). This moment of being with the body is important because

having physical contact with a loved one "facilitate[s] the work of mourning" (Testoni, 2021, p. 7). The absence of being in the physical presence of the body led to mourners' "continuous rumination, which oscillate[s] between anger and disbelief" (Testoni et al., 2021, p. 7). This could lead to an extension of the bereavement process (Testoni, 2021). Thus, COVID-19 deaths have been "both traumatic and delegitimized … and comparable to the effects of ambiguous loss" (Testoni et al., 2021, p. 7). Ambiguous loss is the kind of loss that is missing something important, oftentimes a lack of information surrounding a death, something that many people experienced in COVID-19 due to a lack of being able to be in the presence with their loved one(s) (Testoni et al., 2021). Therefore, a death experienced during the COVID-19 pandemic may lead grievers to feel an uncertainty, confusion, or lack of finality surrounding their loved one's death. This can be uniquely painful for the bereaved due to "the human need for finality" (Boss, 2007, p. 106).

The isolating circumstances surrounding a COVID-19 death could also result in a longer period of mourning, putting the bereaved at greater risk of abnormally persistent grief and significant impairment associated with prolonged grief disorder (Testoni et al., 2021, p. 7; Wang et al., 2021; Lundorff et al., 2017; Pedrosa et al. 2020). Furthermore, with a disproportionately high amount of grief during a time of little social support, older women have been particularly vulnerable to excessive grief and grief disorders during the COVID-19 pandemic (Testoni et al., 2021).

As this review suggests, older women's experiences with loss during the COVID-19 pandemic has been unique, significant, and pervasive. However, research to date has typically been quantitative and has lacked the voices of the women themselves, as well as an understanding of their rich and nuanced experiences of grief and loss during the

pandemic (e.g., citations). Knowing more of how this particular group of grievers has experienced death during a pandemic has the potential to broaden our understanding of grief and loss during a challenging time in history. As a result of this need, the present dissertation draws on a narrative theorizing and communication narrative sense-making theory (CNSM) in order to unveil older women's experiences of loss.

#### Narrative Theorizing

Narrative theorists name storytelling the framework for how we see ourselves (Koenig Kellas, 2015). In this way, narrative theory is ontological in that it is "our way of being in the world and is conceived as knowledge set against social and historical backgrounds" (Koenig Kellas, 2015, p. 256). The narrative paradigm of Fisher (1989) argues that "people are inherently storytelling beings," shaping and assessing their lives through narrative; people understand their experiences in terms of narrative (Koenig Kellas, 2015, p. 257).

In addition to the perception of narrative as ontological, it is also seen as epistemological as the majority of interpersonal communication is stories. When we talk to one another, we naturally organize our experiences into a story form (Fisher, 1989). People tell stories with plots, timing, heroes, and villains in order to make sense of their experiences (Koenig Kellas, 2015). Stories are more than just a way to frame conversations. In an article on end-of-life care, Pangborn and Harter (2020) claim that storytelling is "a legitimate form of reasoning: a knowledge producing resource enabling individuals to make sense of disruption and envision otherwise" (p. 3).

Storytelling helps people make sense of difficult events and experiences (Kellas, 2015; Pangborn, & Harter, 2020). Well-told stories also evoke strong feelings in both the

listener as well as the storyteller (see Bochner & Ellis, 2016). Life is "messy, multi-vocal, [and] complicated" which can lead to confusion and suffering (Koenig Kellas, 2015, p. 254). Therefore, the structure of a story—characters, plot, setting and motivations—help contain the confusion and messiness central to the human experience. This adaptive quality of narratives becomes particularly important during times of "fast, unforeseen changes in the cultural niche" such as natural disasters and global events (Bietti, 2019, p. 711). COVID-19 presented such an event, creating a collective experience of multiple traumas, stressors and widespread uncertainty across the globe (Maddrell, 2020). Stories on a collective level then become the "social glue" that help people to adapt to unexpected events (Bietti et al., 2019, p. 711). With conflict as a necessary element of narrative, a global crisis provides fertile ground for storytelling (Harter et al., 2005; Bietti, 2019).

Narrative theories are applied in various contexts, including narrative therapy and coping with loss and trauma (Koenig Kellas, 2015). Storytelling allows individuals to rethink and reimagine identities and new interpretations of life experiences as well as help people cope with loss associated with trauma. Harter's (2013) research on health narratives notes the connection to stories and health:

Stories do things for people, institutions, and cultures. Stories can reinvent selves, create identification across locations, and warrant and legitimate decision-making. Much of the time, life is harder than we'd like, and we are a vulnerable species.

Artfully pursued storytelling offers opportunities to imagine new normal. (p. 339) Personal narratives' cathartic nature help people feel more in control and have the potential for healing from painful life events through (Koenig Kellas, 2015).

#### **Communicated Sense-making Theory (CNSM)**

This functional and adaptive quality of storytelling is at the heart of Koenig Kellas's (2018) communicated narrative sense-making theory (CNSM)—the theoretical foundation of the present study. This theory assumes a strong relationship between storytelling and wellbeing and "seeks to illuminate those connections" (Koenig Kellas, 2018, p. 64). The foundation of this theory rests on the adaptive and functional nature of storytelling, previously explained. People tell stories to "cope with difficulty, complexity, trauma, and risk" (Koenig Kellas, 2018, p. 64). This theory is divided into three separate heuristics: retrospective, interactional, and translational.

#### **Retrospective, Interactional, and Translational Heuristics**

The *retrospective* storytelling heuristic, which is applied in the present study, focuses on the content of narratives and how they reflect the values, beliefs, and sensemaking of individuals and families. The themes of the stories that people hear and tell provide a window into what matters most to them. Additionally, using a retrospective lens can reveal patterns surrounding characters, timing, setting and other storytelling characteristics (Koenig Kellas, 2018). The stories that we hear as well as those we tell are at the heart of the process of sense-making (Koenig Kellas, 2018, p. 65). The retrospective heuristic proposes that the content of people's stories reveals what matters most to them. It also claims that positively-framed stories are positively related to individual's overall well-being (Koenig Kellas, 2018, p. 65). In other words, this lens helps researchers better understand the motivations and inner beliefs of participants. It also explains that positively-framed stories are directly connected to individual well-being and health (Koenig Kellas, 2018, p. 65).

The *interactional* storytelling heuristic focuses on the way that stories are told. Studies that use the interactional heuristic examine certain behaviors such as level of engagement, turn-taking, and perspective-taking. Researchers exploring these storytelling behaviors often investigate how the communication processes are related to participants' individual and relational well-being. Additionally, understanding the way a story is told can reveal how people make meaning together. In one interactional CNSM study, researchers analyzed the role of perspective-taking between friends sharing stories of difficulty with one another (Koenig Kellas et al., 2021). Another interactional study examined the ways in which families discuss risk in their stories of cancer (Campbell-Salome & Rauscher, 2020).

The third heuristic is *translational* storytelling, which centers on the creation and development of storytelling interventions. Translational studies focus on the impact of storytelling in order to improve policies and programs that benefit the public good (Koenig Kellas, 2018). This heuristic is especially helpful in policymaking that maximizes positive outcomes for communities in need. In a study that measured the impact of a storytelling support group for parents, researchers measured how parents' participation impacted their well-being (Koenig Kellas et al., 2020). Another CNSM study measured the impact of communicated perspective taking (CPT) on millennials under stress, showing a positive relationship between perspective taking and mental and physical health (Maliski, 2017). Another example of this intervention approach had participants gather to share stories of their experiences as parents (Koenig Kellas, 2020). Researchers were able to measure the effects of writing and sharing stories on participants, leading them to identifying results such as feeling more understood and

understanding themselves better after telling and sharing stories (Koenig Kellas, 2020). Furthermore, a study on social aggression in adolescent girls asked them to tell their stories of experiences through drawings and narrative (Koenig Kellas & Willer, 2020). The translational heuristic was used to identify the impact of their storytelling on their well-being (Koenig Kellas & Willer, 2020). The results indicated a significant reduction in negative mental health symptoms of the participants, demonstrating the effectiveness of the translational heuristic for evaluation of interventions (Koenig Kellas & Willer, 2020).

In sum, retrospective storytelling centers the content of stories in order to understand their connection to people's beliefs and values. Interactional storytelling researchers study the process of sharing stories together, and translational studies examine the practical applications of storytelling interventions (Kellas et al., 2020). Each of these heuristics has the potential to serve as a useful lens for exploring older women's experiences of COVID-19-related loss. However, the retrospective storytelling heuristic provides a meaning framework for beginning to understand their stories.

Although CNSM has often been used for post-positivist research, this theory has more recently been the center of interpretive studies using the first proposition of the retrospective heuristic of CNSM. This proposition states that the content of stories reflect how people make meaning, what they care about, and what they believe (Koenig Kellas, 2018, p. 65).

For example, CNSM was a useful theoretical foundation in a study that examined coming out stories from the parents' perspectives through a retrospective lens (Butowski, 2020). Parents were asked to tell the stories of when their child(ren) came out to them in order to uncover the themes of casual acceptance, supporting, acknowledging their struggle, and learning (Butowski, 2020, p. 350). Another study used CNSM in order to understand pregnant women's experiences of support during the pandemic (Charvat et al., 2021). In this study, participants were asked, "What is the story of your pregnancy during a global pandemic?" (Charvat et al., 2021, p. 171). Through the examination of the themes that emerged from their stories, researchers identified how participants made sense of their experiences surrounding support.

One compelling retrospective bereavement study focused on participant stories surrounding the common ritual of cleaning out closets of deceased loved ones (Barney & Yoshimura, 2021). Participant stories revealed themes of motivations, communication and outcomes that reflected values and beliefs of the bereaved (Barney & Yoshimura, 2021). Stories of the bereaved were also analyzed in another study to illuminate the experiences of people experiencing end-of-life care (Taladay, 2021). This research used the retrospective heuristic to uncover the ways that the bereaved coped during their loved one's terminal illness (Taladay, 2021).

Along with studies surrounding grief and loss, other sensitive topics that might be difficult to study have adopted this narrative approach including living with autoimmune disease (Gunning, 2021), caregiving (Cooper, 2021), and mental illness (Flood-Grady & Koenig Kellas, 2019). More recently, retrospective narrative studies have illuminated people's various experiences during the pandemic including pregnancy (Charvat et al., 2021), coping during lockdown (Bruning, 2021) as well as anxiety during the COVID-19 pandemic (Koy, 2021). Therefore, using CNSM as a theoretical framework and the lens of retrospective storytelling has the potential to illuminate the values, beliefs and needs of

hard-to-reach populations, such as older women experiencing COVID-19-related loss (Bruning, 2021; Charvat et al., 2021; Cooper, 2021; Flood-Grady & Koenig Kellas, 2019; Horstman et al., 2021; Taladay, 2021).

Given the usefulness of the retrospective heuristic in previous studies on bereavement (Barney & Yoshimura, 2021), health (Campbell-Salome & Rauscher, 2020), and mental illness (Koy, 2021), the present study engages it as a framework for understanding older women's experiences of loss during COVID-19. Choosing the retrospective heuristic for the proposed study is meaningful due to its usefulness in interpretive research examining grief and loss.

Whereas research to date on COVID-19 continues to broaden our understanding of the outcomes and associations surrounding grief during the pandemic, our understanding is still unfolding about what it has been like for older women to lose a loved one during the pandemic. Though emerging research suggests that older women struggled greatly during a socially isolating global pandemic, their voices are largely absent in these studies. Thus, this study narrows this gap by offering a grasp of the fullness and complexity of older women's losses and grief experiences (Nguyen et al., 2021; Ni et al., 2020). Hearing directly from the women themselves results in a more nuanced understanding of older women's COVID-related grief.

As a way to amplify the voices of participants, this study employs CNSM's first proposition of the retrospective heuristic lens to guide inquiry into older women's grief experiences during the COVID-19 pandemic. Specifically, the study seeks to answer the following research question: What common themes emerge in older women's stories of losing loved ones through death during the COVID-19 pandemic?

At her age, grief is not new to my mother. She was alone on the afternoon of August 13<sup>th</sup>, 2015, when she discovered her husband of 57 years (my father) dead on the rug in her front hallway. She called 911. Then she called Donna, her best friend of 50 years, who helped her call the family. Within days, Mom's house was packed full of friends and family. Photos of Dad scattered on the dining room table served as catalysts for tears and shared memories. Mom's favorite people showed up for the funeral to witness her pain—something she says was crucial to moving through those early days of grief.

Mom sold her house to a young family and downsized to a two-bedroom condo on the edge of town. "In all my life, I've never lived alone," she said to me at the time. Even though she has always had an independent streak, I worried about her feeling lonely without my father by her side; I knew the negative health effects of loneliness included heart disease and cognitive decline, and that losing a spouse makes one particularly vulnerable. But I hadn't realized that the death of my father was just the beginning of her losses. In addition to saying goodbye to her home, she had to rebuild her life without her life partner and the person who knew her best. Mom began the arduous journey of learning how to be alone, how to navigate social events by herself, how to reconstruct a life without Dad. The days were long with too much time and space to fill. But Mom's support system kicked into gear following Dad's death. Friends called her frequently, inviting her to social events and vacations. Her good friend Sandy helped to arrange an estate sale of her house of 50 years. It was hard, but Mom let go of a lifetime of personal objects, holding on to just a few of her favorite things. One of her most prized possessions

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currently hangs on the wall above her upright piano. It was a painting my father commissioned for their 40<sup>th</sup> anniversary: a landscape of her childhood backyard.

As difficult as Mom's 2015 grief was, there were no limits on social gatherings. Friends could come over in a moment's notice if she got lonely. Mom could hop in her car and lose herself in a game of tennis. She could play bridge at the country club and share a glass of wine with her friends. She could spread her husband's ashes at his favorite lake in Ontario with her grandchildren. Freedom and social connections helped her get through the emptiness.

The pandemic changed everything. Even though many restrictions were lifted in the fall of 2021, people were hesitant to go back to life before the pandemic. The swarm of friends and family wasn't automatic. Before the pandemic, I would have seen her at my uncle's funeral. I would have sat next to her as she grieved. Instead, on the day her brother died in the midst of the pandemic, she sent me a text sharing the sad news with a request: "I'm too upset to talk. Please don't call me," she typed, alone in her grief.

#### **Chapter Two: Methods and Procedures**

For the present study, I used a combination of narrative and photovoice methodologies to answer a research question exploring themes in older women's stories about their experiences of loss during the U.S. COVID-19 pandemic. In the following sections, I explain the benefits of both approaches and how the two of them worked together for this type of thematic inquiry.

#### **Overview and Benefits of Narrative Inquiry**

Narrative theory is considered ontological in that "people are inherently storytelling beings," and that "all human communication and knowledge is interpretable and should be theorized as narrative" (Koenig Kellas, 2015, p. 257). The goals of narrative theories are "to better understand the content, process, functions, and outcomes of interpersonal narratives, stories, and storytelling" (Koenig Kellas, 2015, p. 255). Narrative theories are used to examine the content of stories as well as their structure (Koenig Kellas, 2015). How a story is constructed and the elements involved can be helpful in inquiries on individual experiences (Koenig Kellas, 2015). Narrative inquiries are also useful for studies examining relationships. For example, narrative theorists look at the way that families tell stories. Using a narrative lens, stories can reflect what families are doing (performance) as well as how the family's construction (performative) (Koenig Kellas, 2015, p. 259). Narrative methods help with meaning-making through examination of "human depictions of life events" (Yamasaki et al., 2014, p. 101). Including story elements such as character, setting, plot, and turning points in an interview can provide structure to data collection and analysis on a topic that may be difficult to piece together, which often results in a rich data collection (Yamasaki et al., 2014). Through these elements, people piece together meaning about their experiences (Koenig Kellas, 2015).

Difficult experiences are sometimes more easily expressed through stories. For instance, grief is often experienced as a nonlinear process, and so the story structure tends to work well for studies regarding bereavement, loss, and illness (Corr, 2015; Devine, 2017). A narrative approach also "acknowledges the 'unfinalizability' of persons and events," which was particularly needed for the unprecedented and complex landscape of the COVID-19 pandemic (Yamasaki et al., 2014, p. 115).

Various studies using the CNSM lens have effectively explored sensitive themes. In one such study on bereavement, researchers examined stories about cleaning out the closet of loved ones (Barney & Yoshimura, 2021). They drew themes from the content of the stories, examining the stories of that revealed themes of how families communicated their reasons for making changes after the death of a loved one (Barney & Yoshimura, 2021). Another illustration of this method is a study on miscarriage and how fathers narrate memorable messages said to them after a pregnancy loss, which revealed themes reflecting the beliefs and values of the fathers (Horstman et al., 2021).

The benefits of narrative methods are exemplified in various studies on health and well-being. The stories people tell and the stories that they hear reflect their values, beliefs and perspectives through the lens of the CNSM retrospective framework. CNSM helped deepen an understanding of COVID-19 grief by illuminating the values, beliefs and sense-making of the participants through their individual stories. Given the various benefits of narrative methods, using this approach for the present study resulted in a better understanding of older women's pandemic grief.

#### **Overview and Benefits of Photovoice**

Photovoice is a participatory action research (PAR) method that centers the voices of the participants, placing their voices at the heart of the research process (Hergenrather et al., 2009; Jongeling et al., 2016). Photovoice is considered a "radical departure" from traditional qualitative data collection methods because it empowers participants through visual expression (Mitchell, 2011, p. 52). Put simply, a photovoice study has participants answer questions that help to illuminate issues through the taking of original photographs. The participant prompts are designed in service of answering a broader research question. For example, one photovoice study inquired about gender equity from the perspective of adolescent girls. They were prompted to take photos of "objects, symbols, scenarios and/or situations they felt depicted what gender equity meant for them (personally or socially) (Simmonds et al., 2015, p. 37).

One of the main benefits of this visual approach is that the voices and perspectives of the participants are placed at the heart of the research (Jongeling et al., 2016). This bridges the gap between researcher and the topic studied by sharing power with the participants themselves. For instance, a photovoice project may include a dialogue in which participants discuss the construction of the research question. Similarly, participants may participate in a dialogue about the commonalities between photos, thereby engaging in data analysis (Hergenrather et al., 2009). This approach

flattens the hierarchical relationship that frequently exists between researcher and participants. The collaborative nature of this approach also broadens the understanding of the subject being studied by bringing in multiple voices.

These multiple voices from marginalized populations come together to creatively express their unique perspectives on their own terms (Jongeling et al., 2016). For example, in one study, researchers gave children digital cameras to take pictures that describe how they feel in Pittsburgh, PA. The purpose was twofold: to offer a creative healing tool for participants who suffered from trauma and secondly, to identify possible root causes of the issues prominent in their neighborhood. This method placed the children's perspectives at the center of the study (Gupta et al., 2019). Similarly, photovoice researchers Baker and Wang (2006) worked with a vulnerable population when they gave cameras to older adults experiencing chronic pain. Their assignment was to take pictures that represented life with pain and life without pain. They shared their best photos with researchers with titles and brief narratives explaining the meaning behind each photo (Baker & Wang, 2006). Photos have the ability to provide a visual metaphor that participants can use to express experiences that may be hard to access otherwise (Moon, 2007). In this way, the photograph becomes a catalyst to a more indepth understanding of participant experiences that may not have been accessible without a camera.

Another example comes from Desyllas's (2014) photovoice study of sex workers whose purpose was "to understand what their world was like, from their point of view" (p. 482). This method allowed the participants to tell their stories with the help of the photographs. Thus, inviting participants to express themselves through visuals including

photos helps researchers dig even deeper into the "layers of meaning" that exist beyond words (Steger et al., 2013, p. 1; Willer, 2012; Willer et al., 2018; Harter, 2013; Pangborn & Harter, 2019).

#### Benefits of Combining Narrative and Photovoice as Methods of Inquiry

As useful as a narrative approach is, it can have limitations. For many people, it may be difficult to put their experiences into words, either spoken or written (Frank, 2013). Harter & Hayward (2010) found visual approaches in narrative research especially useful in a study of pediatric cancer patients and their families when they included the participants as partners in the filming process (Harter & Hayward, 2010). Allowing the participants as partners in the creation of the documentary added richness and complexity by including the voices of those most impacted by cancer: the patients and their families (Harter & Hayward, 2010). Including a visual with narrative spotlighted the "sounds and spaces of vulnerability that could not be captured in only writing" (Harter & Hayward, 2010, p. 328). Along with previous grief studies (Willer, 2012; Willer et al., 2018), Harter and Hayward's (2010) visual approach made participant experiences "seeable" if not "sayable" (Riessman, 2008, cited in Harter, 2013, p. 33).

This interplay between narrative and visual data collection is also demonstrated in Willer's (2012) study of adolescent social aggression. Instead of photos, participants drew pictures and engaged in an interview centered on their drawings, which broadened the understanding of the topic through two separate but overlapping forms of data (Willer, 2012). Indeed, Barbatsis (2005) argues that by "expanding the notion of narrative to include all symbolic forms of expression, visual communication scholars gain a valuable set of critical tools" (p. 330).

Narrative and photovoice approaches blend well together as further exemplified in Simmonds et al.'s (2015) study on gender (in)equity. This study is a prime example of how a study on COVID-19 grief could benefit from a narrative and photovoice approach. Simmonds et al.'s (2015) study blended both approaches in their study on gender in South Africa. This combined approach "capture[d] participants' lived experiences in the photographs they take and their reflections in their accompanying narratives" (p. 38). This study asked participants to take photographs in response to prompts and to choose their best 5-10 photos. They were also instructed to include a "title, a phrase, a statement or even a question" along with each chosen photo. The process also included a storytelling interview with the understanding that a photograph "cannot speak for itself; it needs to be accompanied by a narrative" (Simmonds et al., 2015, p. 38).

Integrating a visual component also has the added benefit of making the narrative interview process "less confrontational and threatening" to participants, which allows them to express their experiences more freely (Moon, 2007). Centering the needs of the participants is particularly important when interviewing on topics such as grief and loss during the pandemic, because of the multitudes of stressors present during an historic time of loss.

Since the purpose of the study was to identify common themes from older women's stories of pandemic grief and loss, a combined and complementary narrative and photovoice approach maximized the benefits of both methodologies. The following is an overview of the participants, recruitment, procedures of this blended methodology, as well as data collection and analysis methods.

#### **Participants**

#### **Participation Criteria**

To qualify for the study, participants had to be U.S. residents who identified as women aged 65 or older; and have experienced the death of a spouse, family member, friend, and/or other person meaningful to them between March 2020 and January 2023. The death could have been due to COVID-19 or any other cause, but participants needed to have felt as though the pandemic impacted their experience of grief and loss in some way. Participants additionally qualified for the study if they had access to a smartphone or digital camera and had the ability to take photos and share them via email or text. With 83% of women ages 50 and older owning a smart phone, the process of taking and sharing photos was a simple process for the participants (Pew Research Center, 2021).

Given that there has not been a clear end point to the pandemic and that it continued to impact the experience of grief at the time of data collection (November 2022 to March 2023, anyone whose loved one died between mid-March 2020 and January 2023 qualified for the study (The British Academy, 2021). Age 65 and older was chosen as a limit, as the federal government identifies 65 as the age to qualify for Social Security benefits (Social Security, 2022). Additionally, given that the focus of the study is on older women's experiences of loss during the pandemic, deaths could be the result of COVID-19 or otherwise.

Eighteen women participated in the study. Theoretical saturation is considered complete when no new themes are identified through the collection of additional data. Therefore, this study concluded recruitment at 18 participants as this was the number at which theoretical saturation was reached (Charvat et al., 2021). In December 2022, I

identified more than a dozen fraudulent international participants. I conducted three fraudulent interviews that were excluded from the data set. In response, I amended the criteria to qualify for the study to include a U.S. resident requirement as well as mandatory Zoom cameras that illuminated participants faces<sup>1</sup>.

Participant ages ranged from 65 to 86, with an average age of 73.1. Eighty-three percent of participants resided in the Metro Denver/Boulder area, with four from Denver (22%), one from Boulder (5%), five from Aurora (28%), one from Arvada (5%), one from Broomfield (5%), one from Centennial (5%), one (5%) from Highlands Ranch, and one (5%) from Englewood (5%). Three participants resided outside of Colorado: one from Jacksonville, FL (5%), one from Baltimore, MD (5%), and one from Snohomish, Washington (5%). Nine participants identified as widowed (50%), four as married (22%), two as unmarried (11%), one as divorced (5%), one as having a significant other of 30 years (5%), and one declined to answer (5%).

Participant annual income is reflected in Figure 1.

<sup>&</sup>lt;sup>1</sup> I further address this challenge and lessons learned later in this chapter as well as in the Discussion chapter.

# Figure 1



### Participant Annual Income

Sixteen participants identified their ethnicity as White (90%), one identified as Asian (5%), and one identified as Hispanic or Latino/White/Other (5%). Eight participants identified as Christian (44%) with four identifying as Christian Catholic (22%), three Christian Protestant (17%), one Christian Protestant, Jewish (5%), and one Christian without an identified denomination. Two participants identified as agnostic (11%), one as agnostic atheist (5%), one as Buddhist (5%), one as spiritual but not religious (5%), and one as humanist (5%). In response to the statement: "the Covid-19 pandemic significantly impacted my grief and loss experience," eleven participants said they strongly agreed (61%), five said they agreed (28%), and two said they neither agreed nor disagreed (11%).

To qualify for the study, participants had to have lost someone meaningful to them to death during the pandemic. Eleven participants reported losing one person (61%), five reported losing two people (28%), and two reported losing three people (25%). Of the 26 reported deaths, participants indicated that 18 were male (69%) and eight were female (31%). Ten deaths occurred in 2020 (38%), twelve in 2021 (46%), and two in 2022 (8%). Six people died of Covid (23%), six died of cardiovascular disease (23%), six died of cancer (23%), and the remaining eight people died of other causes (31%). Participants reported that the ethnicities of those who died: 24 were White (92%), one was Asian (3%) and one was White/other (3%). Ages of those who died were between 53 to 97 years, with the average age 77.2.

# **Recruitment Process**

Once the University of Denver's Institutional Review Board approved the application, I began recruiting participants through various gatekeepers of outlets serving older adults. I sent the gatekeeper recruitment email (see Appendix J), asking them to forward a recruitment email to their contacts (Appendix L) to the Denver Public Library, HeartLight Center, a grief support nonprofit; the Knoebel Institute for Healthy Aging (KIHA); Fairmount Funeral Home; Agape Hospice; and a local hospice social worker. I also emailed personal contacts that I knew had connections with older adult women (see Appendix L).

Interested participants contacted me via email, and I responded with a reminder of participation criteria (Appendix B), the Qualtrics survey link that included the consent form (Appendix H), and demographics survey (Appendix F). Once participants completed the Qualtrics survey, I sent an email with dates for an orientation session, either on Zoom or at the HeartLight Center (Appendix B).

# Procedures

Each participant completed three stages of participation: orientation, storytelling through photos, and the storytelling interview. To accommodate individual needs, some

participants attended group orientation sessions, while others preferred individual sessions (Simmonds et al., 2015). The following section outlines each stage of participation beginning with orientation, followed by storytelling through photos, and then a more detailed explanation of the storytelling interview.

### **Stage 1 and 2: Orientation and Storytelling Through Photos**

Ten participants attended group orientation sessions and eight chose to meet individually. I hosted two separate in-person group orientation sessions at the HeartLight Center. The first group included two people; the second group was five. The rest of participants attended via Zoom. During orientation, I shared who I was and why I wanted to do this study as well as the purpose of the study. The intention of orientation was to teach the participants what to expect (see Mitchell, 2011, p. 53). Previous research (Novek et al., 2012) indicated that older adults struggled with identifying a "suitable" photo; thus, orientation presentation included detailed instructions on how to approach the assignment with examples and time to ask questions. Appendix C contains the orientation script and Appendix M provides the accompanying PowerPoint presentation.

At the beginning of each orientation session, I introduced myself with a collage of photos of my family and personal interests. To build community and group trust, I also included an icebreaker question (What is your breakfast food and why?) in group sessions (Desyllas, 2010).

Then, I explained the purpose of the study. I reminded participants of their rights as participants: that they may stop participating at any time and that they do not have to talk about anything they don't want to. I also provided a list of grief support services (see Appendix I) (Fisher, 1989; Frank, 2013).

Next, I told the story of how I came up with the topic of my dissertation, telling the story of how two classes helped me come up with my research question. I briefly explained how photovoice is an arts-based method that asks participants to answer a research question through photos, a process that first began when photographer Wendy Ewald (1985, 1996) taught children how to take photos of themselves and their communities in the 1970s.

The remainder of the orientation session focused on preparing participants for Stage 2 (storytelling through photos) and 3 (storytelling interview). First, I shared a slide of tips for taking photos with one important note about getting explicit permission from anyone that appears in their photos. I also provided copies of photovoice release forms for participants to take with them for the specific purpose of obtaining consent (Mitchell, 2011) (see Appendix D). Next, I shared with the participants an example of taking photos that facilitated storytelling. The exemplar originated from a project in my photovoice methods course in the spring of 2021. In that class, I told the story of being a caregiver during COVID-19 through photos. I shared the question guiding our class project (What is your story of being a caregiver during COVID-19?). Then, I walked participants through my process of taking photos and choosing my best four photos, explaining how each photo addressed a particular story element. This helped participants generate ideas and envision how they might approach the photo-taking stage (see Willer, 2012). My original photos facilitated participants' understanding of the process of choosing their 5–6 photos.

Each participant was provided a handout that explained in detail what they needed to do titled "Making Sense of Loss: Photovoice Stories of Older Women's COVID-19

Grief" (based on Willer, 2016) (see Appendix E). This document included the purpose of the study and the participant photo prompt: "Take 10–15 photos that represent your story of the loss(es) of your loved one during the pandemic." The handout mirrored the orientation presentation and included further details in four parts: before taking photos/prompts, taking photos, sending photos, and scheduling a storytelling interview.

These original photos were to represent their story of the loss(es) of their loved one(s) during the pandemic. On the handout, I included a variety of prompts that gave them ideas of pictures they might take (see Appendix E). The handout also explained that they will spend time reviewing their photos on their own, carefully considering which ones best represent their story, narrowing down their images to 5–6 photos that tell best the story of the loss of their loved one(s) during the pandemic (Jongeling et al., 2016).

I showed examples of the types of images they might choose to photograph, tips for photograph composition including playing with angles, zooming in and out, trying different perspectives, and taking pictures of ordinary objects as representations of their stories (see Appendix I). I encouraged participants to go beyond the literal when taking photos. For example, instead of taking a picture of a person (or a picture of a picture), I invited them to think of an object that captures the essence of that person. I used my example of taking photo of a fence to represent my son to further explain this concept. I reminded them that they would email or text me their 5–6 most meaningful photos—the ones that most answer the prompt, which might not be the most aesthetically pleasing ones. After the orientation session, I emailed participants reminders of due dates as well as links to online instructional videos for reference (see Appendix K). Some participants requested a copy of the presentation, which I provided in the follow-up email (see Appendix K). I explained that once they emailed or texted me their photos, I would schedule their storytelling interview via email (see Appendix L).

At the end of the orientation session, I answered questions and gave the participants a chance to share their thoughts (Novek et al., 2012). Some participants wanted to talk at length about their ideas at the end of the orientation session. Participants then sent me 5–6 photos two weeks after their orientation session. Since orientations were scheduled on a rolling basis, each participant's due date was inserted on their handout (see Appendix E) as well as included in their orientation follow-up email (see Appendix K). This three-stage process continued until all participants completed their interviews.

I explained to participants that in their one-on-one interview, they would be telling their story of losing their loved one(s) during the COVID-19 pandemic through their photos. Rather than just describing their experiences in general, I said that they would need to include important details in a story form (Riessman, 2008; Yamasaki et al., 2014), which I detail in the following section.

### **Stage 3: Storytelling Interview**

The foundation for the structure of my interview questions is based on Koenig Kellas et al.'s (2010) definition of story. I explained in the orientation session how I define "story":

During the one-on-one storytelling interview with me you are going to be telling me the *story* of losing your loved one(s) during COVID-19 with your 5–6 photos. For our purposes, a *story* is a telling of a life event. Stories include a plot (a 34 sequence of events), characters (you, your loved ones who died, perhaps those close to you and the person who died, and health care providers), and usually some type of meaning (a point, a conclusion). So, during the storytelling interview, rather than talking about your story of COVID losses generally (e.g., it was hard; I miss her; I was sad), I will be asking you to tell me the *story* from the beginning to where you are today. You will do this by arranging your photos in the order that makes sense to you. For example, you might start from March 2020 when COVID first hit the U.S. and take me through to when your loved one got sick or had a diagnosis, when you learned they died, and how you have been coping since then, with the understanding that grief never really ends. Given you may have lost more than one loved one, your story may include more than one 'chapter.' In the telling of your story, you might also share timing, motivations, any defining moments, turning points, or lessons that you learned.

### **Testing the Interview Protocol**

After preparing participants, I prepared myself as an interviewer. In order to anticipate potential pitfalls in the interviews and given the sensitive nature of the research question, I enlisted my 86-year-old mother as my "informant" which familiarized me with the process (Charmaz, 2014). My mother completed each stage leading up to a video-recorded in-person interview. She met all qualifications to participate, which made her an excellent resource. During Stage 2, she worried that her photos were not good enough, which reinforced my decision explain to future participants that the best photos are the ones that answer the research question—not the most aesthetically pleasing ones in the orientation session. I interviewed my mom at a study room in her local library in

Illinois, which provided an inclusive and accessible space. I timed the setup, the interview, and take down to streamline Stage 3—the storytelling interview. Through my practice session, I learned to make a checklist of all the items I needed for the interview and had them on a sticky note on my research notebook. This checklist included a camera, tripod, printed participant photos, interview script, pen and notebook, laptop, charger, backup recorder, snack, bottle of water, and tissues. This list kept me organized for each interview.

#### **Interview Logistics**

To ease transportation issues for participants, I chose a location that was accessible to all. I briefly considered using a space at the University of Denver, but the lack of free parking eliminated it as an option. I ultimately decided to interview participants at the Sam Gary Branch at the Denver Public Library. The library allowed me to make a two-hour reservation in a private study room up to a week in advance. Library staff were friendly and helpful, and the building was accessible with free parking on site.

For three participants, this library branch was too far for them to drive. I consulted a DPL librarian, who helped me locate another local branch in Sheridan, Colorado, that also had study rooms available for reservations. This branch was in the southern suburbs of Denver, which was closer to some participant homes. Additionally, the HeartLight Center offered space for me to interview, and one participant chose that location. I conducted all interviews during the winter in Colorado, which posed minor weather challenges. One participant tried driving through the snowy roads to get to the interview, but turned around and went home due to unsafe road conditions.

### **Interview Process**

During the first round of interviews, I kept a spreadsheet with last date(s) of contact, date of next action, orientation registration dates and attendance. For the second round of interviews, I used Calendly, an online application that automatically scheduled interviews and supplied specific Zoom links for each interview. This application also sent participants reminder emails which streamlined the rolling schedule process.

# **Preparing for Interviews**

Once participants emailed their photos, I ordered 8x12-inch prints from a local pharmacy, which offered inexpensive same-day printing services for in-person interviews. For Zoom interviews, I downloaded their photos into a folder and shared their photos through screensharing. I arrived 15 minutes early for all interviews to set up my cameras and test my recording devices, including Zoom. In addition to using a webcam on a tripod for in-person interviews, I used a backup battery-operated voice recorder. During the third interview, the camera failed, and I had to use the backup recording. With the topic of the interview as sensitive as grief, I wanted to make sure that I was emotionally present with the participants as they told me their stories, so I did not take many notes during interviews. Videorecording interviews allowed me to focus on the women's stories instead of taking notes.

#### **During the Interviews**

At the beginning of each interview, I established rapport by chatting about their drive and offering them water and chocolates. I also had tissues on the table next to their printed photographs (Tracy, 2020). For Zoom participants, I made sure that they could see and hear me clearly before starting the interview. Then, I reviewed the informed

consent that the participant completed online and reminded participants they could stop the interview at any point and/or decline to answer any questions. I also asked their permission to record before reading the interview script (see Appendix G). I reminded participants that the recordings would not be shared with anyone other than my dissertation advisor and their stories would remain anonymous in my findings. Participants either chose their own pseudonym or were assigned one by me. All other names mentioned in the interviews were assigned pseudonyms by me. As previously explained in the orientation description, the storytelling interview participants told their story of the loss of their loved one(s) during the pandemic through their 5–6 photos.

# **Responsive Interviewing**

Tracy (2020) discusses the importance of researchers engaging in "active listening by concentrating, understanding, remembering, and sometimes responding to what is said" (p. 185). I approached each interview with what Tracy (2020) calls "responsive interviewing" (p. 161), an approach that acknowledges the reciprocal relationship between researcher and participant. I did my best to limit my interruptions, honoring silences and remembering to allow space for the participants to tell their stories in their own words (Tracy, 2020). After participants finished their stories, I asked the questions (see Appendix G) to further capture story details and information about the photos (Yamasaki et al., 2014):

- Who would you say are the most meaningful characters in your story and why?
- Does your story have any heroes or villains?

- Who or what was the greatest obstacle in your story? Who or what helped at that time?
- Were there any physical environments or settings that were important in your story? How so?
- Were there any turning points in your story?
- Are there any lessons that come from your story?
- (If there are any photos whose meaning was not clear from the storytelling), can you tell me more about why you chose to take this picture?
- Looking at your photos, what would be a caption for each one?
- If you had to choose one photo and one caption for the title and cover page of your story, what would it be and why?
- If your photos were included in an exhibit about COVID-19 related loss, what would you want visitors to know about your story?
- Is there anything else you want to share about your story?
- Is there one photo that captures your entire story? Why or how so?

Finally, I asked participants if there's anything else they would like to share about their story and/or their photos that may not have been captured by these prompts (Desyllas, 2010). At the end of the interview, I let them know that they would receive an email for a Target gift card for \$50 as a token of my appreciation<sup>2</sup>.

<sup>&</sup>lt;sup>2</sup> This compensation was funded through a grant from the Strear Family Foundation through the Knoebel Institute for Healthy Aging at the University of Denver.

Theoretical saturation is considered complete when no new themes are identified through the collection of additional data. Therefore, this study concluded recruitment at 18 participants as this was the number at which theoretical saturation was reached (Charvat et al., 2021).

### Self-Reflexivity Exercise: Journaling

The purpose of writing in journals was to increase my awareness of biases that may impact my interpretation as a researcher. Validity threats can occur when I am not aware of how my identities may impact how I conduct and interpret the data from the interview. Tracy (2020) designed a writing exercise that aims to address these threats with the following questions:

- What obvious physical traits or demographics [of yours] will your participants see or notice during the interview?
- What other qualities/characteristics of yourself and conversation style will be visible during the interview process?
- How do you see these traits and identities impacting or influencing the interview, the data, and the relationship with the participant? (Tracy, 2020, p. 157).

Instead of specifically answering questions, I used them as a guide for two journals: a written and a visual journal. By practicing in this reflective writing exercise, I made explicit the possible impacts that my identities may have on the orientation and the interview.

On the day I sent out my recruitment emails, I began writing in both journals.. The first one was a simple diary of my thoughts and feelings through each stage of the process, from launching recruitment all the way to data analysis. The second journal was a visual journal that combined drawings along with writing, which allowed for me to include the "seeable if not sayable" aspects of my position as researcher (Riessman, 2008, as cited in Harter, 2013, p. 33). Throughout the process, I wrote in both journals to take note of significant moments in my research that emerged during each stage. Tracy (2020) states that it's important to "consider the ways that [researchers'] subjectivity affects the research" (p. 157). Furthermore, a researcher's appearance or other characteristics may impact how participants react in an interview. Having an awareness from the start helped me "treat the respondent and the resulting data with ethical care" (Tracy, 2020, p. 156).

Making space for awareness helped me reduce my biases as a researcher. Below are two samples of my reflexive writing in my written journal:

First interview. A little nervous, but mostly excited. I have my backup recorder in case something happens with Zoom. Jane is Black and I am aware of the history of white researchers exploiting and traumatizing people who look like her. This is on my mind, and I hope she senses my gratitude. (Journal, 11-28-23)

On December 7th, I wrote:

I want to make a note about how challenging yesterday's interview was. The story of this woman's mother's death in a nursing home is awful. What does witnessing look like for me? I'm not a therapist—so I can't make it better. But to be in the presence of that level of emotion—the pain, the guilt, the horror. It's a lot. I hope I am providing a good energy for these women! It's big time suffering I'm seeing. (Journal, 12-7-22) Creating space for my thoughts and feelings about my position as a researcher allowed me to record my thoughts and feelings that impacted how I read and interpreted the data. In particular, the December 7 journal entry reminded me of how important it was to take care of myself emotionally as I witnessed these upsetting stories. Taking time to write down my feelings meant that they had less of an unconscious bias on my data analysis. Had I not named and recorded what was going on with my emotional responses, I ran the risk of subconsciously making judgments without appreciating the full picture of my personal response to the stories I was hearing. This journaling process allowed me to I honor as well as contain my feelings and biases.

I also created a visual journal to record the various feelings I experienced during various stages of the dissertation process. Having the freedom to draw, scribble and generally play on the page let me shift out of the researcher position and into just being human. This journal proved to be a crucial aspect to my process as it revealed that several participants turned out to be fraudulent. Figures 2–5 illustrate this discovery.

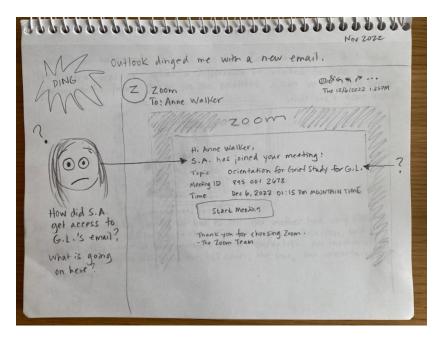
# Figure 2

Visual Journal, 11-16-22

Nov 2022 Listening to my first 2 interview recordings were strange. Both women would not turn on their cameras, even after I explained how my hearing loss made it hard to understand them. They both sound like the same person. Same accent. Same tone of voice. Different photos and stones, though. I hate to admit it, but part of me wonders if she is the same woman. But why would she do this? For a \$50 gift card to Target? I wonder it my instincts that something is weird is really just unacknowledged racism. These women - based on their photos - live somewhere much different from me. What it they are sisters, cousins, or good friends? What it my lack of cultural understanding is playing a part in this? The reason why I thought about this is that one participant, G.L.has been a no-show 3 times for orientation sessions. I decided to schedule one more in hopes that she would show up. After 10 minutes on Zoom, I emailed her, asking if she was having trouble logging on. What came next ->

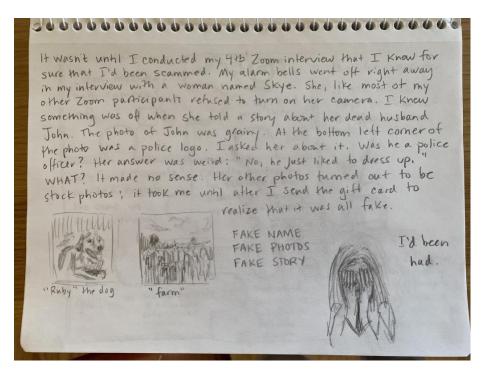
# Figure 3

Visual Journal, 11-16-22, (2)



# Figure 4

*Visual Journal, 11-16-23 (3)* 



# Figure 5

Visual Journal, 11-16-23 (4)

Zoom meetings with cameras off	\$50 O sitt TARGET On my versuit- ment tiger	It all fit together. It took me three days to clean out my spreadsheet.
"Jane" and "Daniela" sounded exactly the same in their interviews.	Calendly time zones for scheduled inter- views kept showing up as East African Properties	
Instant mistante universite qualtrics, XM Showed day IP Address and duplicat is cations	es teeling Jue had since the first Zoom	Out of my 28 active participants, only 13 were legitimate And only one was a

The journaling exercise made me aware that something was not quite right with my interviews. Giving myself permission to scribble in pencil on the page the myriad feelings, questions, and worries led me to uncovering a threat to the validity of my study, something that I directly attribute to my journals.

### **Data Analysis**

The research question that guided this study asked what common themes emerged in older women's photovoice stories of the loss of a loved on during the COVID-19 pandemic. I followed Braun and Clarke's (2006) six phases of analysis: 1) familiarizing yourself with your data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report (p. 87). I also incorporated Tracy's (2020) qualitative analysis method of asking myself what the data set is telling me by asking "What is happening here?" This was helpful as it kept me consistent with my approach to coding. With 18 participants, the data set included 108 photos and 18 interviews ranging from 1–2 hours, resulting in 692 pages (single-spaced) transcripts. All recordings were transcribed by an online AI service (Temi.com). I carefully listened to each one, cleaning up the transcript for accuracy and replacing names with pseudonyms. I printed out a hard copy of each interview and placed each in a separate folder with printed photos before analysis (Tracy, 2020, pp. 203, 205).

### **Step One**

Braun and Clark's (2006) six-phase process is one of immersion by repeatedly reading the data for "meanings and patterns" by taking note of potential themes to code for later (Braun & Clarke, 2006, p. 88). Therefore, in step one I listened to the interview

recordings while simultaneously reading the computer-generated transcript. This process allowed me to make corrections and pseudonyms to the transcripts. The second part of this phase is transcribing the recorded interviews for analysis using an "orthographic transcript—a 'verbatim' account of all verbal utterances" (Braun & Clarke, 2006, p. 88). The computer-generated transcript sometimes included nonverbal utterances, and I included specific notes that indicated nonverbal gestures such as pointing at a photo and hitting the table. This further clarified and contextualized the meaning of the participants' words (Braun & Clarke, 2006).

# **Step Two**

The second step of the analysis, generating initial codes, involved discovering content from the data and organizing it into "meaningful groups" (Braun & Clarke, 2006, p. 89). I began by underlining lines that seemed significant to me with a pink pen. Then I took a moment and wrote brief notes of memorable moments from the transcript on one sticky note. I went back and reread each transcript and assigned codes to them in the margins written in a blue pen. As Tracy (2020) states, "[y]ou know you have found a code when you can answer the question, 'What is this expression an example of?" (p. 214). I read all transcripts responding with line-by-line gerunds answering: "What is happening here?" (Tracy, 2020, p. 215). An example of this comes from Louise's transcript where she describes putting her feelings aside in order to take care of others: "I felt like could—boy, this is probably fairly typical of women … put my feelings on hold so that I could support them at the same time." Next to this line, I wrote "putting feelings aside to help others; delaying grief." Louise's line was just one of many data points that matched the code of setting feelings aside, which then fit into the third theme of the

study, *responding to loss(es)* within a subtheme of feeling the struggle. After I coded each transcript, I created a page in my research notebook for each participant and listed the codes followed by the page numbers for each code. Next, I wrote out sticky notes for each code and placed it on a poster with the research question at the top, collapsing codes as I went along when necessary. This iterative poster method helped me revise codes and begin to notice patterns in the data.

# **Step Three**

At this point in the analysis, I reread Byrne's (2022) article that provided updated guidance on this approach, called reflexive thematic analysis (RTA), which became my third step. About halfway through coding, I grouped the sticky notes, placing codes that seemed to be positive responses, contexts, and situations at the top of the poster and negative at the bottom. I placed what seemed like neutral or both in the middle. I noticed that spousal losses had particular codes, and I placed those on the edge of the poster. By the end of the initial coding process, I had a poster filled with yellow post-it notes with codes that were grouped by thematic elements. (See Appendix N for photos). Once all codes were on sticky notes, I went back to each participant's list of codes and wrote a 1–2 sentence summary of their story. Following are examples of this:

- Susan tells a story about losing her partner suddenly with little support and finding a way to rebuild her life.
- Louise tells a story of the deep pain of losing her brother-in-law and sister-inlaw whose absence overwhelmed her due to the multiple stressors of COVID.

- Emma Jane tells the story of her inability to help her mother as she died in terrible conditions, like a prisoner in solitary confinement. She feels powerless to change anything or fix anything and sees things as practical. She's mostly pessimistic.
- Bobo tells a story of how COVID forced her to be alone and finally stop performing that she was okay. She learned how to feel her feelings and "break open," thereby increasing resilience. (Research notebook, 2023).

This step of summarizing each participant helped solidify my deep knowledge of the data, which became an important asset during my analysis. Reading, re-reading, summarizing, and remembering the interviews and stories made it much easier to identify data extracts from memory and make connections between participants and the common themes.

### **Step Four**

In the fourth step, I transferred all codes from the sticky notes to notecards and wrote the name of each participant and the corresponding page number on the back of the notecard. Over a period of two days, I sorted and resorted them into groups on my dining room table, collapsing some codes as I arranged them (see Appendix N). In addition to organizing initial codes into themes (and subthemes) I also collected codes that didn't seem to fit into the initial themes and marked them as "miscellaneous," eventually folding them into other codes (Braun & Clarke, 2006, p. 90). I also created a continuum of the failure of the healthcare system as well as lists of the nature of each death in case there were significant patterns. At this point in the process, I noticed that I was inconsistent with recording codes as gerunds in response to "What is happening here?"

(Tracy, 2020). I went through each code and made all codes with an "-ing" suffix. This iterative process helped collapse and combine codes into broader themes by making each code parallel and comparable to other codes as verbs and nouns were more difficult to collapse and discern. After the codes were established, I stopped revising codes into gerunds and instead changed them to nouns. I reread all participant quotes and re-coded them as needed. I also highlighted "miscellaneous but important" quotes on the transcripts to be revisited later in the analysis. At the end of this part of the process, I had arranged all codes into themes and subthemes. At this point, I once again read Byrne's (2022) note about themes: "Construing the importance or salience of a theme is not contingent upon the number of codes or data items that inform a particular theme. What is important is that the pattern of codes and data items communicates something meaningful that helps answer the research question(s)" (Byrne, 2022, p. 1403). Reading and rereading Byrne (2022) helped me stay focused on the process.

Within this fourth step, I relied on Tracy's (2020) constant comparative method that involves modifying codes to include new data as I moved back and forth between the themes and codes (p. 220). I wrote longhand analysis memos in my research journal which helped identify important themes (Tracy, 2020, pp. 228–229). When I found extracts that did not fit the theme, I either revised the theme to include the extracts, found another theme for them (when appropriate), or removed them from the analysis altogether (Braun & Clarke, 2006, p. 91). The second level in this phase is to evaluate if the "thematic map accurately reflects the meanings evident in the data set as a whole" (Braun & Clarke, 2006, p. 91). The purpose of this rereading is to assess whether the themes match the data and to "code any additional data within themes that has been missed in

earlier coding stages" with the understanding that "coding is an ongoing organic process" (Braun & Clarke, 2006, p. 91). An example of this process was the following: feeling hopeful, feeling hopeless, experiencing false hope, collapsing them all into "hope." Additionally, "COVID impacting everything" started as a code, moved to a theme and then landed as a subtheme of COVID as villain/obstacle in the final analysis. Defining and refining helped me identify the "essence' of what each theme is about" (Braun & Clarke, 2006, p. 92). For each specific theme, I organized my collected quotes into "a coherent and internally consistent account, with accompanying narrative," including an explanation of why each of the extracts are significant (Braun & Clarke, 2006, p. 92).

# **Step Five**

The fifth step required me to stack the notecards, paperclipping them into subthemes and then onto piles underneath a pink sticky note of themes. Initially, I had four themes, but realized that one theme, *feeling the struggle*, was actually a subtheme of the main theme, *responses to losses*. Following that change, I also updated the subtheme of *feeling the struggle* to *emotional responses* along with two other subthemes *physical responses* and *repairing/rebuilding*. I then created an electronic table of themes, subthemes and page numbers, and I was able to further clarify my themes, merging two subthemes into one to make *COVID as villain/obstacle*. Once all page numbers were on the table, I went back to the transcripts and identified the "golden lines" for each code, cutting and pasting from each transcript. Golden lines were moments I remembered in the interview as being especially salient, emotional, or otherwise memorable. However, I was careful about making sure this didn't turn into a never-ending thematic process and I stopped when additional revisions didn't add significant change (Braun & Clarke, 2006, p. 92).

I came to a point where the iterative process led me to eliminate the theme of COVID as villain, as naming this as a theme created a limitation in my study, given that I directly asked participants who the villain of their story was. Instead of writing up that as a limitation, I removed the theme and then broke apart subthemes and second-level subthemes into 11 main themes: social isolation, fear of virus, efficacy of support (subthemes: supportive and unsupportive), efficacy of the healthcare system (HCS) (subthemes: unsupportive care and supportive care), multiple losses/stressors all at once, interpersonal conflict, political divide, delayed grief/rituals, experience of gradual loss, responses to the loss(es) (subthemes: emotional responses, physical responses, repairing/rebuilding), and presence of deceased. I created a table with subthemes and data extracts (Braun & Clarke, 2006). This table was then split into three separate tables for each theme. I arranged the themes in a logical order, which subsequently served as an outline for writing up my findings report.

# Step Six

This final step encompassed the complete write-up of the thematic analysis, "tell[ing] the complicated story of [my] data in a way which convinces the reader of the merit and validity of [my] analysis" (Braun & Clarke, 2006, p. 93). In this final write-up, I included compelling details from extracts that illustrate how these themes answer my research question regarding older women's stories of losing loved ones during the pandemic. In this phronetic iterative method, I went back and forth examining the data, coding for emerging themes, and "progressively refin[ing] [my] focus and understandings" (Tracy, 2020, p. 210). My research notebook as well as my two journals served as a "chronological map registering how the codes emerged and changed over time [with the understanding that] codebooks themselves are iterative" (Tracy, 2020, p. 224).

Additionally, my dissertation journal and visual journal memos created a kind of conversation with myself as researcher (Tracy, 2020, p. 228). These creative endeavors "call for free writing [and] creativity" (Tracy, 2020, p. 228). In addition to revealing fraudulent participants, my drawings, writings, and photographs helped me conceive larger concepts that otherwise may have gone unnoticed.

### **Member Reflections**

In her book on qualitative research methods, Sarah Tracy (2020) explains the importance of "member reflections," which she describes as an opportunity for participants to ask "questions, [provide] critique, feedback and/or affirmation" (p. 278). This gave participants an opportunity to clarify and refine the study's results. Hearing directly from more than half of the participants that the themes reflected their experiences gave me confidence that I had truly captured the common themes in their stories. Hosting this meeting and giving space for feedback strengthening the validity of this study. Overall, the participants who attended this meeting reinforced my themes with many of them stating that I captured their experiences. It was important for me to hear of any contradictions from participants before completing the analysis. Below is a summary of the hourlong session and its impact on the findings.

I sent an email inviting all participants to a Zoom session at the end of the analytical process (Appendix O). Of the 18 participants, 11 attended a Zoom session. One of them missed the original meeting and instead attended an individual session. I began with a short slide show of the findings that included the name of each theme, an interview example, and (when possible) a photo. This took about 10 minutes, and then I asked them for their feedback. "What resonates with you?" I asked them. "Is there anything missing in these findings that you think I should have included?" It was important to me to give them an outlet to share any disagreements with the findings, because....

The majority of the attending participants related to all of the themes. There was only one participant who said that she could not relate to the sadness described but said that it might have been because she was surrounded by her children and family throughout the pandemic. She noted that the pandemic "forced her to think about things more" and left her with a sense of gratitude. This participant's interview was much different from the others, reflecting her comment. Throughout her interview, this participant explained how COVID made things better for her, not worse. Her story was dominated by moments comfort, connection, and hope.

The topic of the healthcare system dominated the discussion with one participant speaking about the HCS's treatment of her mother as she deteriorated. Her sister (who was in the study and on the call) countered with her perspective as a long-term care nurse:

I don't disagree with [my sister] at all, but I think one of the things that you never mentioned ... was how angry people are at the nursing staff. And I happen to be a long-term care nurse, and I don't think, and, and the group may be angry with me 53 when I say this, that you all don't appreciate what it's like to take care of somebody for days, weeks, months, sometimes years. And they are also part of your family. And they die.

This rich discussion between the two sisters reflected both supportive as well as unsupportive healthcare with many people explaining how inconsistent the care was during the pandemic. This validated my findings regarding this topic, which increased my confidence in the validity of the theme of the efficacy of the healthcare system.

Participants also discussed the limitations of the study, including how the cause of death of the loved one(s), the age of the participant and the nature of the relationship of the loved one(s) impacted people's grief differently. One participant remarked how helpful it was to have had excellent bereavement counseling in the past and how she drew upon those learnings with her grief during the pandemic. Since all of the participants agreed with the themes and had no suggestions for revisions, I felt secure in the credibility of the findings.

Given that more than half of the participants attended this member reflections meeting suggests that many of them felt highly invested in the results of their participation in this study. I wanted this experience to be meaningful for them, and I designed the methods with the hope that they would feel that their stories mattered. The member reflections meeting assured me that I had succeeded in this intention.

#### **Chapter Three: Findings**

The present study examined common themes of older women's stories of loss during the pandemic guided by the research question: What common themes emerge in older women's stories of losing loved ones to death during the COVID-19 pandemic? It resulted in eleven main themes: social isolation, fear of the virus, efficacy of support, efficacy of the healthcare system (HCS), multiple losses/stressors all at once, interpersonal conflict, political divide, delayed grief/rituals, experience of gradual loss, responses to the loss(es) and presence of deceased. Table 1 highlights themes and subthemes. Next, I provide an overview of the main theme, and provide a detailed look at the theme's related subthemes. In reporting these finding, I use excerpts from participant interview transcripts as well as their photos. Although participant photos were not individually analyzed, I include their images here to further illustrate themes from their stories.

# Table 1

Theme	Definition of Theme	Subthemes	Interview Excerpts
Social isolation	Negative impact of being or feeling alone		And, so, we couldn't even share our grief except in phone calls. And, so, it was very isolating. It was, it was very isolating. So not only was the world turned upside down, but we were in what I call cruel isolation.
Fear of virus	Anxiety of being infected or infecting others with COVID-19		That's why we were not having any human interaction because we were afraid of getting COVID from one another.
Efficacy of support	Help or lack of help following loss(s)	Supportive	We have a really good neighbor. And anytime I had a problem, he would come over he's a hero.
		Unsupportive	And I did go to this one grief share group, and it's like a canned program. It's horrible. And the facilitators are like, lay people who like

Themes, Subthemes, and Interview Excerpts

			took a CPR class and now they know how to do it. All they really want to do is talk about Jesus.
Efficacy of healthcare	Extent to which healthcare was helpful or hurtful		
system (HCS)		Unsupportive care	You know, so nobody took care of [Mom], and I couldn't be there to monitor. They wouldn't let me in [her room].
			[The aides]never called. Their main thing was, "your mom keeps calling the staff on the call button, and we're really annoyed." And I said, "that's it?" And her neighbors were the ones who saw the trays on the floor outside the room, and they didn't report it to me until after Mom died.
		Supportive care	I'm in the hospital and I'm getting all this tender loving care.
Multiple losses/stressors all at once	Emotional overwhelm from two or more sources of distress		So I started kind of swirling down because these were not the only losses that I had. There were other losses of

		other friends. Andwe haven't even gotten to my daughter yet. In the three months around her death, I lost three friends.
		It was, it was very stressful for me because I'm the oldest and I felt a lot of the [sobs]excuse meI felt a lot of the responsibility in getting help from my mother, helping my dad, helping my sister.
Interpersonal conflict	Strife in one-on-one personal interactions	I still have to deal with a Millennial attitude about COVID from my pseudo stepdaughter who is a flight attendant. And she just throw it in my face about how I am so much more guarded and not able to live my life than she is. You know, I mean, it just has impacted my relationship with her severely
Political divide	Negative impact of civic dissent	[Politics] was in the forefront and it was ugly and that's

			why I had to shut off all media.
Delayed grief/rituals	Postponement of memorials and/or bereavement		And then she died. Then we couldn't have a funeral. And it was, it was unreal.
			[W]e have no closure because of COVID. Because I couldn't have a mass for [my life partner]. Churches weren't open. There was no memorial service, nothing. They just weren't open. And then when I finally did call the church to say, can I have a mass? They said, you have a one year wait. Yeah. <laugh> I'm just like, forget it.</laugh>
Experience of gradual loss	Incremental grief over period of time		I lost him long before he died.
Responses to the loss(es)	Various individual reactions to grief	Emotional responses	There's a lot of anger. A lot of anger. So, you know, a lot of anger and some guilt, too

		Physical responses	And I went with him to the bank to open the deposit box, feeling like I was going to be sick to my stomach
		Repairing/rebuilding	So I felt that after COVID and after the death of my boyfriend, had to rebuild again. And I had to rebuild from scratch because I'm rebuilding in a post COVID environment, which is not the same as pre-COVID.
Presence of deceased	Individual connections to loved one(s) after death		It's like all the people who have, who are not in my life, are all right here. You know, they're all, they're gone, but they're not gone?

# **Theme: Social Isolation**

Whether it was because of the virus or the specific stay-at-home mandates, the theme of feeling isolated showed up in many participant stories. These feelings were not only experienced by participants' themselves, but also by those they lost. Mary, age 77, felt isolated and noted this theme through household reminders of a more social time in her life. Mary's photo (Figure 6) shows rows of intricately carved crystal glasses on a shelf — a reminder that she wasn't hosting parties anymore:

[W]hen I look at this, it's all these wonderful things that we have, you know ... We entertain, we have crystal, we have China, we have, you know, wonderful silver and stuff. And, and it's like, 'what's that?' ... It's just dusty and taking up space ... It's way up high and we're not going to be able to use it. I mean, that's from another lifetime.

### Figure 6

Gathering Dust by Mary



Emma Jane, age 79, believes social isolation caused her mother's eventual death. Her mother's loneliness from being trapped in an assisted living facility was the real cause of her mother's death, she feels: I remember seeing how many people had already died in nursing facilities. And, you know, I assumed it was because they had gotten COVID, but it never occurred to me [that] people really did die of loneliness and no social contact. And that's what it was. [Mom] was a social person. Without people around, she could not live.

Similarly, Bobo, age 74, describes the isolation as feeling like a prisoner. After her friend died, she couldn't go anywhere except towards her death. Her photo (Figure 7) shows a grey hallway with a green exit sign in the distance. She said, "I remember looking at that hall and it seemed like it went on forever and there was nowhere to go other than exiting." She took this photo to represent joining her friends and family who have died:

# Figure 7

No Exit by Bobo



[T]here's an exit sign down there, and I'm just walking to the end and joining my friends, joining my family. It's the exit. It's the end of life. It's, the years have been before me. There's more behind me than can ever be before me. It was, it was really hard. It was, yeah. It's like, yeah, there's doors, but all the doors are closed. All I can do is walk to the exit, walk to my death.

For Tammy (age 71), Judith (age 86), Grace (age 78), and Mary, their isolation intensified from caring for ailing husbands. Doctor's appointments became Tammy's only social outlets during lockdown, with her classes and social groups no longer meeting. Similarly, before the pandemic, Grace relied on community programs for her husband who had Alzheimer's disease. But with COVID, she lost all outside socialization. Mary also described being "trapped in the house and with this sick guy," wishing that more people understood what it was like to be isolated without any support during COVID. Ann Rufft, age 69, also felt isolated following the death of her life partner, rooted in his abrupt death. The night he died, she heard the sound of a gurgle and was shocked to discover him slumped over on their bathroom floor. Despite her frantic call to 911, she was unable to revive him. The bathroom haunted her, but she wasn't able to avoid the room, leaving her feeling isolated, trapped in her own home.

Loneliness in isolation was especially common for those who lost spouses and partners. Before her husband's death, Tammy had only recently moved to Denver. She had not yet created strong friendships, and she reported lots of time alone in her house. Judith felt very alone as well, as she lost both her husband and her sister during the pandemic. She considered the two of them her best friends, and she was still struggling to socialize at the time of her interview. She preferred to just be at home alone:

I'm starting to get into being with people again. And there's one lady. You know, I'm starting a little bit, but I don't, I can do without it. I know you're supposed to interact and I'm trying.

Likewise, Ann Rufft's life partner wasn't just her significant other. He was also her trusted colleague as the two of them worked together as real estate agents. Being alone both at home and as well as at work was a struggle after his death.

### **Theme: Fear of Virus**

Another theme that emerged was a fear of the virus, something that many participants mentioned exacerbated their grief. Louise, age 65 spoke about how her husband's immunocompromised status heightened her fear of the virus. Tammy also was afraid that her immunocompromised adult daughter who lived with her would catch the virus. Similarly, Leigh Ann, age 68 was afraid that she would bring COVID to her parents as she cared for her ailing father. Likewise, Susan, age 69 said that her boyfriend was unwilling to go to the ER with chest pains because of his fear of COVID. He died of a heart attack shortly thereafter, and Susan feels as though he may have survived had he gotten care sooner. Grace, age 78, whose husband died of complications due to Alzheimer's disease, explained how her fear of the virus made things more stressful for them. There was so much they didn't know about the virus and how to stay safe. She knew of people who had lost loved ones from the virus, and she knew that her husband was in a risky age bracket. She describes the fear as having "really closed out the laughter we had in our lives." Emma Jane, age 79, wondered if she had made the right decision to stay at home instead of flying out to visit her ailing mother during the pandemic. She was afraid to go out "because you didn't know who was sick and who wasn't." She explains how the fear of the virus was the biggest obstacle in her story:

I guess the greatest obstacle was fear for myself. And you know, I used to think, is there anything that's worth risking my life to do? And would it help? I don't know. I will never know. You know, should I have gone? Should I be guilty about not going? These are the questions that I think a lot of other people must feel. And if I had gone, what could I do? What was I going to do? Take [my mother] home with me? She was already past the point where she probably wouldn't have made it on a plane.

#### **Theme: Efficacy of Support**

The next theme is that of the efficacy of support. Within this theme included two subthemes: supportive and unsupportive. Participants reported support from myriad sources, not only from close friends and family members, but also by grocery store clerks, and other people with whom they had contact. There were also many situations that participants found to be unsupportive. The following sections outline both of these subthemes with examples and photos to illustrate.

## Supportive

Many participant stories included feeling supported by family and friends who knew them well. A majority of participants named close ties as strong supports during their time of crisis. Marcella Nicole, age 65, spoke of the comfort of close friends who had "watched [her daughter] grow up" and knew her history, something that Marcella said served as an important source of support in her grief. Similarly, when Leigh Ann's father died, she relied heavily on her hometown contacts, with whom she felt close to due to her father's small business in the midwestern town. So many people knew and loved him: "[P]eople came into what we call the shop all the time, to visit with him, not necessarily to buy anything, but they would come in and visit with him because he'd just loved to have coffee." Leigh Ann also identified her husband as someone who supported her in her grief:

My husband spoke [at the funeral]. [He] and I have been together [voice breaks] since we were like, 15 and a half. And [we] got married when I was 20. He did such a nice talk because of the fact that really, truly, my dad was a second dad to him.

Leigh Ann's photo reflects her husband's strong bond with her father (Figure 8) in an image of a pair of worn black leather slip-ons placed on green grass.

### Figure 8

We'll Never Be Able to Fill These Shoes, by Leigh Ann



After her father's death, Leigh Ann's husband took his shoes and wore them "all the time." Leigh Ann wanted to tell him that the shoes were old and worn out and that her husband should get new ones. But her husband was attached to them:

I mean, he wears other shoes, but, but he does wear these a lot. He didn't tell me this till later, but he said, 'you know, Leigh Ann,' he said, 'I really wanted to say I'm wearing Hugh's shoes and I'll never be able to fill them.'

Her husband's deep ties to her family and in particular her father proved to be an important support for Leigh Ann. Through her Christian faith, her story also included feeling supported by never being alone. She felt that Jesus "was always with [her]." This came from her close ties to her grandmother, who lived with her family in her last years. Her grandmother normalized the dying process and prepared the young Leigh Ann for her eventual death. This experience with her grandmother was at the root of her decision to become a nurse. She was not afraid of death because she believed she was never alone. I'm never alone." Similarly, Jennifer, age 74, reported her grandmother and great-grandmother's portraits as giving her strength and support when grieving the loss of her mother. The portraits linked her to "the old country and to [her] Jewishness."

Others found support outside of family and friends. Tammy's oldest daughter lived only a few minutes away, but she didn't see her in person as she worried about contracting the virus or infecting Tammy's immunocompromised younger daughter who lived with her. She "hated Zoom" because "it was so impersonal." However, during this isolation, Tammy considered the grocery store clerk an important source of support. The two would have a conversation as the grocery employee loaded her food into her car. They were not emotionally close, but her presence in Tammy's life was a lifeline of support. Similarly, Bobo found support in someone she only knew professionally. Her insurance agent gave her a children's book on grief when he heard she had lost a loved one. The book sat on the shelf for years, but when Bobo finally read it, she said that it was a turning point; it allowed her to express deeply buried feelings and to finally grieve the loss of her daughter. So even though Bobo was not emotionally close to her insurance agent, his kind gesture provided her great support.

Similar to Bobo's insurance agent, many other participants told stories gaining support beyond close friends and family. Tammy found her what she called "social touches" after her husband's death through various outlets. For example, she audited a college English class with undergraduates, which she thoroughly enjoyed. She remarked how her interactions with "those crazy students" played an important support role in her recovery. Tammy also took a job where she could help teach healthcare students through acting. Her job was to behave in a way that would help the students improve their communication skills with difficult patients. She enjoyed the interactions so much that she signed up for acting classes at the local performing arts center. Likewise, Grace, whose husband had dementia, relied on programs that got her and her husband out of the house that were "memory friendly," at the art museum and library. When those closed down, Grace remembers how important the grocery store was for her with her husband—a war veteran suffering from memory loss. She would take him to the store, wearing his veteran's hat, so he could talk to people. Strangers would come up to him and thank him for his service, something that Grace believes was like "medicine" for him. Kids and clerks would talk to him, charmed by his sometimes off-color sense of humor. Her photo (Figure 9) shows her pushing a cart down the colorful aisles of a grocery store.

# Figure 9

Community and Loyalty by Grace



She describes how the store became an important form of support:

[T]he grocery store...represents one of the social things that we did. I take him to the grocery store with me and he pushed the cart, because he was a little unsteady with his feet. And we'd go around, and he would socialize with all the people. Similarly, Louise remarked how important the hotel proprietors were to her when they had to travel to her brother-in-law's town after he died. They would greet them by name and showed great concern, even though they were just hotel guests.

Others found support in the mental health sector. Marcella Nicole noted at times that "therapy helped" as she grappled with multiple losses. However, Ann Rufft's story of a group she attended illustrates just how powerful an organized grief support group can be. Ann attended a grief support group from a list of local outlets I provided to all participants. Ann highlighted a crucial moment in her support group:

So, then the lady next to me starts speaking, and she had been to the grocery store and came home and said, 'Hey Fred, where are you?' You know, just talking to her husband. And she starts walking through the house because he is not answering her. And she starts hearing this gurgling noise. So, I am like bent over in my chair with my hands and my face [voice breaks] listening to her story. And it was very similar. How she had to, he was on the floor, but his arms were like out like this [gestures]. So, he'd had a massive heart attack. I think [my husband] Alan had a brain aneurysm that just burst. Anyway, I couldn't believe her story. I mean, I was just weeping. I was just weeping. So, I did tell my story and I couldn't believe how impactful it was and how I had like a, a body experience. Like I was shaking. I was literally shaking. So yesterday was recovery day, <laugh>. Yesterday, I felt so down and so like exhausted. But I realized how necessary that was because, and, and I even told them, I said, 'I'm so sorry. I feel, I feel sorry to share this with you because it's so, it's so intense. It's so visceral and it's so, it's horrible. So not many people can sit with that'... Oh, my God. So, thank, thank you so much for that resource.

The power of hearing someone else tell a story so similar to hers was an important part of Ann's healing. She mentioned her hesitation in sharing on the first day of the support group and was surprised at how supportive the group turned out to be for her.

Many participants also mentioned stories of support from people who took on everyday chores and tasks. Sometimes this support came from family, like Louise's son, who "navigated with logistics" with her travels, researching hotels as well as finding an estate attorney for her. Similarly, Lisa, age 74, spoke of her family stepping in when she needed help caring for her brother. When she told her son that his uncle would need to be moved to an assisted living facility because he could no longer care for himself, her son told her that he was not going to let that happen. She recalled: "When push came to shove, [my son] was right there."

Others turned to professional caregivers and hired help. For Grace, her husband's dementia meant that she relied on caregivers throughout his decline. Although this became more difficult during COVID with staff shortages, she appreciated all of the caregivers who were able to help her out. One of them eventually became a friend.

For some participants, they were the ones offering support to others, despite their own loss(es). Lisa provided caregiving for her friend who fell ill and could no longer take care of himself. She made phone calls from her hospital room, oxygen flowing through a tube in her nose. Similarly, Louise, despite being overwhelmed with her own grief, supported her grieving husband by taking over various administrative tasks.

## Unsupportive

Although many participants in the study shared stories of people and spaces of support, they also indicated those that were unsupportive, the second subtheme. Mary, whose husband suffered from many complications including dementia, was "devastated" when her son moved to a town nine hours away during the pandemic. Having him far away meant support for her. Likewise, Emma Jane noted that although her ailing mother had contact with her friends, it wasn't the same as family, which was "scattered all over the world." Bobo's story was similar in that she was unable to be with either one of her friends who died during the pandemic. She worried about who would be there for her when it was her time. The fear of not having physically proximate support was on Tammy's mind, too. She wondered what people without spouses and children would do when they entered old age. Tammy remarked that in some ways, it was easier for her during the pandemic after her husband died because they had moved to Denver from the Midwest months before he died. She said, "I don't even think of it as James's house. It's my house. Whereas our house would've been maybe different." Her new home didn't contain all of the decades of memories that she and her husband shared together.

Marcella Nicole, who lost several loved ones during the pandemic, spoke about how people can say such unsupportive and hurtful things under the guise of offering condolences. Her advice to others was simple: "Think before you say something to someone who's grieving." Her daughter died suddenly from injuries from a car accident a few months prior to the interview. Marcella Nicole explained how the nature of her daughter's death was actually a blessing, given her history with drug addiction: The only saving grace about her accident is that [my granddaughter] can say, my mama died in a car wreck as opposed to the needle in her arm somewhere. And, and that is true, and it is valid for me, and I get to say it because I'm her mom. I wouldn't really want anybody else saying that to me ...

Marcella Nicole spoke of this because of a hurtful text she received from her cousin, who texted her shortly after her daughter's death a text: "So was Michaela born addicted? Just wondering."

Marcella Nicole found the question "wildly inappropriate" and she chose to not respond. She commented that "so many times I think people think, well, I wanted to say this for a long time, you know, [and they] kind of slide it in under the cover of condolence, and it's not."

Linda, age 74, also received hurtful comments following the death of her husband. It was about a month after he died when she attended synagogue. She explains an interaction with an acquaintance at the service who upset her with unkind remarks:

This woman came up to me, she goes, 'why are you wearing your wedding band? You're not married anymore.' Which just hit me right between the eyes. And at one point, not when she did this, maybe a year later, I took it off and I felt so uncomfortable for six months, I put it back on ... [a]nd that same person said, 'you know, you don't have to wash your sheets as often because you can sleep on both sides.' And I just, oh, my God. So, this this was at the beginning of my aloneness. She just tore me up. Sometimes, participants found grief support groups and therapists to be unsupportive. As with the HCS, the mental health support system proved uneven for the participants with most women describing mental healthcare as less than helpful. Linda had a series of phone conversations with a grief counselor, which didn't help. She wondered if it would have been different if it had been in person. Even though the sessions were free, she stopped scheduling them after a while:

And I would tell my friends, I didn't want to talk to [the counselor], but she was calling. I felt like I had to tell her something. So, I just told her what she wanted to hear... I didn't get anything out of that whole situation. In fact, I ended it early. I just didn't want to talk to her anymore. And I had [another] opportunity with the funeral home [which] could have given me a year's worth of counseling. But I opted not to do that. And, so, I just dealt with it in the house by myself.

Similarly, Judith did not make a good connection with her grief counselor. During a session, Judith's counselor suggested seemingly out of the blue that Judith's mother had abandoned her. This statement felt like "like a slap in the face" to Judith. After that experience, she vowed that "[n]ever again will I go to a counselor." Janice, age 66, whose husband died of COVID, hit a wall after joining a Facebook grief group. She had hoped to find support but instead she encountered the opposite:

I got kicked out of a grief group on Facebook because I wasn't following the rules on the thing. Because I had negative things to say about healthcare. No one wants to hear that. Nobody wants to hear criticisms about the healthcare system and those angels out there. Nobody. Janice's anger wasn't welcome in that group, and she had nowhere to express her feelings of betrayal spurred by the nature of her husband's death from COVID. As a Catholic, she was okay with a religious support group, but that didn't work out, either: "Most grief groups are affiliated with a churchy thing. But I'm so mad at God and they don't want to hear that. No one wants to hear that." Similarly, Tammy didn't find much comfort in organized grief support groups. She had a hard time relating to other widows' experiences in the group and took a photo that illustrates her experiences. In her photo (Figure 10), you see her covered in a traditional black veil, shrouding Tammy's face and head.

## Figure 10

Widowhood by Tammy



She explained why she took this photo:

I don't think I grieve like a lot of people do, at least in the grief groups that I went to. So, to me, this represented traditional widowhood that you're supposed to be draped in black, that your life's over, that you're supposed to be depressed for years...Was I sad? Of course I was sad. Did I miss my husband? Sure. Was my life over? No, I and I knew that from the get-go...[I want to say that] [n]ot everybody grieves the same way. [Y]ou don't have to be this person [taps on photo of Widowhood].

Tammy tried to find support in books, as this was something she enjoyed before her husband's death. But it didn't work, as she was unable to read during the first year of grief. She couldn't concentrate in the way she could before her husband died:

When I read, I'm in my head, right? I couldn't stand to be there. I had to have television and just noise. ... I could knit. I could still knit because I could still have noise on radio, radio, podcasts were fine. That's the voices talking. Music? No. But not being able to read was horrible.

Other participants noted that old conflicts cooled after the death of a loved one, giving them a respite from tension or estrangement and a brief time of support. Marcella Nicole was never close to her sister-in-law, despite longing for a meaningful relationship. However, when her brother died, her sister-in-law reached out and they were able to support one another in their shared grief. At first, Marcella Nicole thought this was a new beginning. But then new conflicts arose. After a short-lived connection over their sadness, their relationship "wasn't the same." Similarly, Lisa noticed a respite from estrangement from her brother as their sister's health deteriorated. Their "common cause" allowed them to briefly support one another, although the estrangement resumed shortly thereafter. Lisa also talked about her stepdaughter sending her cards and staying in close contact after Lisa's husband died. Their close connection was short-lived as Lisa noted: "She has not talked to me since her dad died."

Marcella Nicole, who did not have a close family to lean on in her grief, longed for support from strangers. She often felt frustrated that no one understood what she was going through with multiple deaths in such a short time. She longed for others to understand, even if it just meant signaling that she was suffering. She imagined wearing a black armband that would let everyone around her know that she needed grace:

[I]n those first few days after Michaela died ... I wanted a black armband that basically said, 'get the fuck away from me. All of you, everybody. Don't you see? Don't you see what's in here? [sobs] Don't you see how raw I am and how I cannot take this? ... Get away!' Walking in the stores, walking wherever I was in the world. And they don't see it. They don't know because, because we don't have that recognized symbol...of a black armband. 'I'm hurting. Just let me be and leave me alone.' You know?

### Theme: Efficacy of Healthcare System (HCS)

The efficacy of the HCS emerged as a theme in participant stories, many of whom had frequent encounters with healthcare providers near the end of their loved ones' lives. Within this theme are two subthemes: unsupportive care and supportive care.

## **Unsupportive Care**

Jennifer believed that unsupportive care contributed to her mother's mental and physical deterioration, ultimately leading to her dying of starvation. Jennifer's mother was living an assisted living facility during the pandemic. Emma Jane, Jennifer's sister (both were participants in the study) explained that their mother became less and less communicative until she eventually stopped talking to her daughters. She notes how the staff were not around at all:

They drop a tray off; they don't even come into your room. That's wrong. And, you know, all of the things that you read about solitary confinement applied to elderly COVID patients. That was very poor treatment.

Mary, whose husband died of a pulmonary embolism, identified the entire HCS as the greatest villain in her story. For months, she struggled to get an accurate diagnosis of her husband's symptoms, which included dementia, incontinence, and pain, none of which he got adequate care. She frequently took him to urgent care only to be sent home with no plan. At one point, she inadvertently discovered that her husband was officially diagnosed with Alzheimer's disease months prior while logging into her healthcare account. No one had contacted her to tell her. She understood that her husband's case was complex and difficult to diagnose, but she believes her experience is a representative of the entire system:

I think the villain is the healthcare system. I mean, it's easy if you have to have a hip replaced or you have to have a sleep study or hearing aids or something...anything mechanical, you'll get in the system and they'll get their money. But, you know, the villains are the ones that, you know, just won't.

It's important to note that Mary's son was an administrator at a local hospital, and even with his connections, she wasn't ever able to get adequate care for him. The advent of COVID also brought about various safety policies which greatly limited hospital and doctor visits. Marcella Nicole wasn't able to see her best friend before he died because of the hospital's policy of only one person visiting per day. Janice's husband died of COVID, and she was unable to be near him at all in the hospital. She did her best to communicate with him on his cell phone, but his condition made him confused, and it was difficult for her to know what was going on. The closest she and her sons were able to get to him was through a window from outside. Janice described just how gut-wrenching it was to stand outside, looking in:

And you're standing in the back of the hospital by the dumpsters outside looking in a dirty window. And he, we'd go down there three, four times a day, just stand there and try to talk through the window. But he was like, he was unconscious and ventilated and you're trying to figure out what these little yellow sign is and what this is over here. You know, you're just trying to figure out like what's going on.

Other families gathered outside the hospital windows carrying signs, praying and gathering. Janice said it was horrible. Her photo of a hospital room (Figure 11) illustrates what it felt like to her being away from her dying husband.

# Figure 11

Horrible, Pain, Suffering, and All of the Above, Fear by Janice



Donna, age 80, was also the recipient of unsupportive care when her son was taken off life support. The hospital had closed down and they wouldn't let her in. She said, "It's like, 'oh, heck no. I mean, you're old. We don't want you anywhere near this hospital." Similarly, Jennifer wanted to monitor her mother's care in her assisted living facility, but they wouldn't even let her inside the building.

For many participants, confusing HCS COVID policies led to unsupportive care. Janice received work emails that indicated there would be extensive cleaning in her office buildings, but she never saw any evidence of that happening. This made her mistrust authorities and questioned safety COVID policies. She was also confused about the policy of the hospital requiring her family to wear protective gear around her deceased husband, which made no sense to her. "He's already dead," she questioned, "Why are we wearing this?" Similarly, Louise was shocked to see people allowed in the ICU unmasked in 2020. Ann Rufft also felt that she never knew if she needed to take off her mask when a caregiver walked into her room while she was in a rehabilitation facility. Furthermore, a nurse's aide told Ann that she didn't believe in vaccinations, which made her feel incredibly unsafe in the facility. In fact, when I asked Ann about her experience losing someone during the pandemic, she spoke about how safety compliance profoundly impacted her grief. I asked her what she would want others to know about her story:

How much people's not complying with masking and getting vaccines added to my [and to] Alan's isolation. And vastly increased the amount of grief I went through because of no human contact. Out of fear. And created abject loneliness and hopelessness. Because it just felt like people didn't care.

Likewise, Janice felt that no one cared, especially during the moment she was able to see her husband who had just died. A chaplain followed her into the room, hovering over her, pressing her to tell him what funeral home she has chosen. Janice responded to him, "I said, 'we just got here. Can you give us a minute? Can you like, get the hell out of here?" She knew he was sent in to hurry things up so they could clear out the room, and all she wanted was some privacy so that she and her sons could pray with her dead husband. Likewise, Ann Rufft's story included moments of individual cruelty. A few months after her husband died, she was trampled by two dogs at a dog park and underwent major surgery requiring months of rehabilitation. It was in the rehab facility when a caregiver left her a pain pill on her tray. Before taking it, she become

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overwhelmed with grief. But the caregiver who came in did not comfort her. Instead, she yelled at her, saying:

'I gave you that pain pill an hour ago. I mean, if you would've, it's still sitting there. If you would've taken the pain pill, you'd be okay now and wouldn't be feeling the pain!' So, I just reacted in such anger [voice breaks]. I told her to get the hell out of my room. I mean, it totally launched me into anger. So, I started yelling [and] told her to get the fuck out of my room ... Anyway, she came back the next day and apologized. And I told her I really appreciated that. And I said, what you need to understand is I wasn't crying because I was in pain [sobs]. I was crying cause I was grieving. And missing Alan.

The harm towards older adults in the HCS was illustrated by Jennifer's photo of a brown garbage can next to a fence in the winter (Figure 12). She describes joining a support group online for people with loved ones in nursing facilities.

## Figure 12

Cruelty by Jennifer



Human trash. I feel like I owe it to all the elders living in facilities and alone who suffered and died during the COVID pandemic. During mom's final illness, I joined a group on Facebook called "Caregivers for Compromise, because Isolation Kills." After reading many posts, but not writing any of my own, I had to stop. The posts were wrenching, tragic, hopeless calls by mostly children of elderly parents and facilities who couldn't see or assist them in any way. Many of the residents became disoriented, ill, and some died without contact with family.

Many other participants also felt dismissed by healthcare workers. Mary said, "we weren't able to see doctors, we would go in there and they wouldn't admit him." She said that he was incontinent and in pain, but "no one was really helping us with that." Likewise, Donna waited months to find a therapist after experiencing extreme anxiety after the death of her son. After meeting twice with her therapist, Donna was told that she was retiring: "And I'm going, what? You took on this client, I'm coming to see you for this and you're retired?" Donna described her anxiety at that time as "so off the wall," and she knew she needed medication. But her doctor said she didn't give older people anti-anxiety medication.

Among participants, Janice struggled the most to get information from the HCS. On one occasion, she described the ICU waiting room, empty of medical staff:

There's no receptionist, there's not one goddamn person on that floor. My son walked around that whole floor. He stood outside his dad's room and could see him, but he was kind of out of it. So he didn't go in there or anything. There was not one person. We waited probably 22 minutes. I remember. Nobody ever asked us like, 'can I help you? What are you here for?' Whatever.

Jennifer's story also included incidents of poor communication from the HCS. The only time she heard from her mother's caregivers were to report on her mother's bad behavior. Her mother pushed the call button incessantly, and this bothered them greatly. The charge nurse, whom Jennifer did not like at all, called her to complain. Her response was outrage:

And I said, 'that's it?' And her neighbors were the ones who saw the trays on the floor outside the room, and they didn't report it to me until after Mom died. Understandably, the staff began to get irritated [with her behavior, but] what could I do about it?

Jennifer also expressed "hating the government and especially the president for their cruelty toward the sickened population." As her mother deteriorated in her assisted living facility, she wondered, "Who cared about an old, emaciated woman?"

Many participants expressed anger about the care surrounding the care and the death of their loved one(s). Janice, whose husband died from COVID, felt betrayed and angered by the treatment she received from the HCS. The inconsistency of policies and care at different hospitals enraged her. She expressed anger over the better treatment a co-worker received: "She got a visitor every day. And then once her COVID was over, she got more than one visitor every day ... she survived, and I hate her." Similarly, Ann Rufft was infuriated by doctors who made errors that might have extended her husband's

life. In particular, she recalled one oncologist who typed on his computer during their appointment, barely listening to her husband.

## **Supportive Care**

Although the HCS was frequently characterized as unsupportive for many participants, they lauded a few individual healthcare workers. No participants thought the HCS worked well consistently; however, Lisa reported positive experiences during her stay in the hospital. She had contracted COVID and was confined to a hospital room for 29 days. She described it as "the rest and vacation I needed and deserved." She wasn't in any pain and was only in the hospital because she needed oxygen. Being hooked up to oxygen, according to Lisa, was a minor inconvenience. She spoke highly of the nurses who took care of her. She shared an anecdote about jellybeans, her favorite candy:

So, I told one of the nurses, I dropped my jellybeans, do you think I could order [some from] the gift shop? And would they send some up? And, so, I tried that and I said, the gift shop won't send them up ... So, the next day she came in with Mike Ike and Tamales...that was so sweet of her. I mean, where else do you get that?

Other participants shared moments of gratitude for doctors who helped them. Jennifer called one of the doctors who saved her husband's life "a hero." Tammy, whose husband had to go into a clinic for treatment frequently called it a "great support system." Even Janice, whose overall experience was horrific had a doctor in the beginning who was really "wonderful ... real personable." Likewise, Leigh Ann and Grace both lauded the work of their hospice workers through the deaths of their loved ones. Grace describes one particular hospice worker as angelic:

[Y]ou talk about an angel; we had a good hospice group. [I]t's been two years now, but I need to write him a note. I figure he was an angel in human form because he came in and he was so respectful of my husband ... he would shave him and be very quiet and very respectful and it looked so calm afterwards. I just, he was a gift from God, I believe [voice breaks].

### Theme: Multiple Losses/Stressors all at Once

A majority of participants shared stories of simultaneous losses happening during the pandemic, which emerged as the theme of multiple losses/stressors all at once. Many participants experienced multiple deaths and traumas during COVID, leading to grief overwhelm. A day and a half after her brother-in-law was rushed to the hospital for a stroke, Louise, aged 65, learned that his wife had "collapsed, dead in the driveway at their home," in the early days of the pandemic. Additionally, Donna, who lost both her son as well as her best friend noted that these two deaths left her overwhelmed with grief. Her photo of a cracked sidewalk (Figure 13) captures this sense of grief multiplied. As she described, this photo illustrates her "losses [that] just kept growing and growing and growing."

# Figure 13

Secondary Losses by Donna



Marcella Nicole also lost several people during the pandemic. Additionally, she survived a carjacking where a man shattered her windshield as she sat in the driver's seat. This trauma profoundly impacted her grief. Marcella Nicole took a photo to illustrate her burnout (Figure 14). A curled metal frame sits on a colorfully striped rug in her photo. She remarked that the photo captured how she felt with so many losses at once:

There were other losses of other friends. And even in the three months, you know, we haven't even gotten to my daughter yet. In the three months around her death, I lost three friends...[a]nd I just said, Joe, 'I love you.' You're going to have to take a number ... and it just felt like this swirling and swirling and swirling thing and just pulling me in and in and in.

## Figure 14

Grief Upon Loss Upon Grief by Marcella Nicole



Elizabeth, aged 68, also experienced multiple stressors as a hospital chaplain during COVID. Her story of losing her best friend was further complicated by witnessing so many other deaths at the hospital where she worked. Like many healthcare providers, Elizabeth struggled to keep going, feeling irritable, saying to herself, "I don't want to go to work, I don't know what I want to do. I just want to crawl up in a ball and sleep." Jennifer also experienced multiple traumas in a short period of time. Her husband had a near-death illness shortly after her mother's death. During that time, a mass shooting happened at her neighborhood grocery store:

[It] was a huge blow. I feel like I channeled my grief from into the situation at the grocery store as a sort of mask for how, how I felt about [my husband] and what happened and his near death only a few months after mom had passed.

Lisa's story also included multiple losses. Shortly after Lisa herself was admitted to the hospital for COVID, she learned that her sister had just died of the virus. Months later, her husband died of Alzheimer's disease.

#### **Theme: Interpersonal Conflict**

Participants in the study shared stories of conflict increasing all around them. Many of the participants spoke of conflicts with both family and friends. For example, Susan not being officially married to her boyfriend meant that she was not involved in the funeral arrangements after he died. Her boyfriend's daughter, whom she was not close to, scheduled it out of town and Susan didn't hear about it until the day after. Conflict in the family was also theme in Louise's story of grief, too. She was warned by her brother-inlaw that if he died, a family member would "come in here and take everything." The situation after his death was so bad that Louise had to hire security guards at the funeral service for fear of further family conflict. She admitted that her husband's anger over the behavior of family members may have been displaced. She noted that it was easier for him to express anger at others instead of feeling the deep loss of his brother. Donna spoke about how the conflict between her son and daughter impacted her grief. Since there was an estrangement and some "big misunderstandings," she was unable to have the closeness of her family in her grief. Marcella Nicole's story included family conflict as well. When her ex-husband/best friend died, she felt left out of his family. They had "built a wall around themselves" which made it hard for Marcella Nicole, who wanted to have family around her as she grieved his death. She noted that in that family, "if you're in, you're in and if you're out, you are out. You are just out." Leigh Ann felt close to her ailing father,

but struggled with her mother's controlling behavior, which caused a great deal of conflict for her. She also noted the tension that arose with her sister after they sold her father's farm to cousins. Her sister wanted in on the deal, but "it didn't work out," according to Leigh Ann.

Ann Rufft felt conflict with her good friend, who had accused her of giving her COVID, even after Ann tested herself four times. They eventually made up, but the conflict made her fearful:

[A] friend of mine thought I had given her COVID because I was sick. And they had been over at my house that day. And so they, she, I got sick and I called her and said, I'm feeling really bad, you know, and I just don't know what it is. And she's like, have you taken a COVID test? And she's like, blaming me for giving her COVID. And this is like my best friend, so there's that fear of losing friends and not having the companionship.

Marcella Nicole drove an Uber during the pandemic, and she spoke about how difficult it was to overhear younger people in her vehicle speak about how the virus wasn't all that bad since it only impacted old people. She wanted to shout at them that she was an old person, too.

### **Theme: Political Divide**

At times, interpersonal conflict overlapped with the theme of political divide. At times, political conflicts led to interpersonal conflicts. This overlap was exemplified by Marcella Nicole's experience as an Uber driver. She also noticed that other drivers were much more aggressive during the pandemic, cutting in front of her and driving too fast. She attributed their recklessness to the overall political climate:

In the last couple of years, we've had a lot of social unrest and other things. And it was as though the people said to the cops, you can't catch all of us. And it was as though the cops went, yeah, you're right. <Laugh>. And they just came up and it's like, you blinked, guys, you know?

Other women described the strain that disagreements around masking created with friends and family. Rhonda, age 78 had a friend from church who didn't understand how important it was for people to be masked around her immunocompromised husband. She said that when she told him to pull his mask over his nose, the friend "made light of all of it," not understanding just how vulnerable he was to the virus. Similarly, Ann Rufft loved the woman who cleaned her house but had to fire her because she refused to wear a mask. Ann identified political conflict as the villain in her story:

The whole politics of all of this to me was a villain...it just was awful. I have not been able to watch news, read newspapers or any kind of news since all of that occurred ... I just can't do it. It gives me anxiety.

For Janice, aged 66, the conflict in the news also brought conflict into her family. Her "ultra-conservative" husband would tell her not to watch certain TV shows because they supported "fake news." She wasn't supposed to buy Coke, either because "they were liberal." She noted that "a lot of his beliefs he instilled in my children, and I would always argue about it because I would say I work for the government." She was required to get vaccinated or she would have lost her job, which caused great tension in her family. Figure 15, Janice's photo of a Trump flag draped over an emergency food package exemplifies her husband's and sons' political beliefs.

# Figure 15

Our Family Truths and Beliefs by Janice



#### **Theme: Delayed Grief/Rituals**

The next theme that emerged was delaying grief or rituals. COVID mandates led to the cancellation of most gatherings, which put a damper on rituals that could have helped the participants process their grief. At the time of her interview, Ann Rufft had not had a funeral for her life partner, who died nearly 3 years prior:

We didn't have a funeral for Alan because they weren't doing funerals. They weren't even funeral celebration[s], celebration of life. So that's been a huge part that is missing and has really impacted my grief.

Ann Rufft mentioned attending a grief support group and meeting people who were experiencing delayed grief of their loved ones after losing their homes in a wildfire that happened during the pandemic. Since Ann's accident happened right after her partner's death, she related to being in a "survival mode," not being able to process the grief because she was so focused on healing her broken leg. Similarly, Nicole Marcella had to wait several months for her brother's funeral as well as that of her best friend. Susan also remarked how different grieving her boyfriend felt in contrast to her late husband, saying that "it was so much easier to just be out and about after my late husband died. But not after my boyfriend died during COVID. I just took too long. It's taking too long. I'm still working on it." Similarly, Linda, age 74, has felt a delay in her grief. Due to the safety mandates in place, she couldn't have a lot of people gathering at her house to sit shiva, an important grief ritual in her Jewish faith. Because there were fewer people there, she felt the absence of all of the stories and memories that she expected to hear, something that she knows would have given her such comfort in those early days of her grief. She still longs to hear those stories that she would have heard at the shiva, but instead she hears from friends intermittently and much later than she wanted. For Louise, her delay in grief came from putting her own feelings "on hold" in order to support her husband. It was easier for her to help him than for her to feel her feelings. Elizabeth, like Louise, set aside her own feelings of grief in order to help her deceased best friend's daughter, who was struggling a lot and needed Elizabeth's help:

[H]is daughter's health ... was so fragile. It was like I had to put my grief on hold and be present for her. I was spending hours on the phone with her, trying to help her process what was going on with her body and her mind and her spirit.

## **Theme: Experience of Gradual Loss**

Many participants experienced the feeling of gradual loss, especially those who were caregivers for their ailing spouses. This theme includes stories that contain participants' smaller losses that occurred before the eventual death of their loved one(s). It does not include losses outside of the death of their loved one(s).

Tammy's story included enduring her husband's deterioration, reflecting this theme. His poor health changed his personality, and she felt like he wasn't the same person: "Dealing with depressed James was awful, because he changed [sobs]." Mary's husband also changed when he fell ill, and it was devastating for her to witness his decline. Her photo (Figure 16) shows a grid of black and white clocks with different times on each face.

## Figure 16

*Time Passing by Mary* 



The photo represented when Mary's husband was asked to draw the time on a clock at a doctor's appointment as part of a cognitive assessment. She explains how this photo represents her husband's dramatic decline:

So here he is, the Supreme Court justice, who's just finished a book and has three mediations, and he can't draw a clock. And that's when I called my sister-in-law, who was a palliative care nurse, and said, I am really scared. So, you know, and it was like, he couldn't, he couldn't do anything. Things like load the dishwasher. He couldn't load the dishwasher.

Similarly, Rhonda described how difficult it was to watch her husband's health deteriorate who suffered from vascular dementia near the end of his life. She told a story about the day she left him home alone, something she hardly ever did unless he was sleeping. She said that he liked to do "all those manly things, so he took [out] the trash." She explains what happened:

I was gone one day and came back and ... there was a trail of blood leading into the house. And I thought, oh no, what has happened? And I went in and he had two or three towels that were bloody ... [I noticed that] his face was all messed up. And I said, well, what happened? He said, I took the trash out. And now see, he walked with a walker, so there's no way he could take the trash out and have the walker with him, too. So he didn't use his walker. And so he took the trash out. He got it safely out there, but on the way back, he fell down and broke his nose. Rhonda's photo (Figure 17) shows the path with the garbage can at the end that illustrates her husband's accident.

# Figure 17

The Ramp/Sidewalk Where Garbage Cans Were Kept by Rhonda



Rhonda later described what it felt to watch the slow deterioration of her husband to Parkinson's disease.

It's just hard to watch somebody die inch by inch. You know? What he's got is terminal, and so there's not ... going to be a turning point for the better if somebody's got a terminal disease.

## Theme: Responses to the Loss(es)

This theme encompasses the ways that participants responded to losing someone meaningful to them. Three subthemes emerged within this theme: emotional responses, physical responses, and repairing/rebuilding. The following section explains each of these subthemes.

## **Emotional Responses**

A majority of interview data revealed various moments of strong emotions, as participants grappled with the death(s) of their loved one(s). Many of them recalled painful feelings that included helplessness, powerlessness, losing faith, anger, guilt, and regret. Emma Jane, whose mother died in an assisted living facility, felt powerless to help her as her health declined dramatically. She noted, "it gets to the point where, you know, she just doesn't want to live anymore. And I couldn't fix it. [My sister] couldn't fix it. And it had to be." Ann Rufft felt regret, wondering what might have happened if vaccines had been developed sooner. Perhaps her husband would have gotten treatment for his cancer earlier, since appointment wait times were so long during COVID. If she knew he had such a short time, she might have planned a trip to cherish their last days. Similarly, Jennifer described feeling stuck in guilt over her mother's passing. Her friends thought she was a great caregiver, but she felt inconsistent and wished she had been more responsive.

Likewise, Elizabeth felt angry at her friend who died of COVID and who didn't get vaccinated. She wondered why she didn't push him to get the shot; yet her anger didn't last that long. As a hospital chaplain, Elizabeth remarked that grief was her "bread and butter," and she understood that her anger was a common feeling for the bereaved. Bobo's anger was more complex, reporting a mixture of love and anger:

They're all heroes. I'm pissed off at moments at all of them. Sometimes they're villains because they really pissed me off. Excuse my language. They left. They

left. And I love them, and I miss them. And how dare they? For whether it's my daughter who took her own life or the others who were ill and old and died.

Many participants shared stories of hopelessness and despair, some of whom even considered suicide. Marcella Nicole, who lost several loved ones to death during the pandemic, was frightened by thoughts that she would be okay if something were to happen to her—like a fatal accident or dying by a sickness. She said she never considered harming herself, though. Janice, who identified as Christian (Catholic) describes her disillusionment with faith: "I prayed so hard for Arthur to get better … There's no God out there."

For Donna, trees were a useful image to illustrate her grief. Her photo (Figure 18) shows two leafless trees with a grey sky and brown grass with snow in the ravine.

#### Figure 18

Death and Rebirth by Donna



Donna explained that the trees sparked anger in her:

And of course, I'm angry at these trees because these trees are ready to move forward with new growth. I'm stuck right here. I'm not ready to move forward with new, so I'm angry at the trees; I'm angry.

Bobo also described her grief as a very emotional time for her, feeling alone with her sorrow during lockdown. She describes this time as a sort of "reckoning" with her grief, a time of deep depression along with confusion:

I didn't, I didn't want to go to the grocery store. I had my groceries delivered and I didn't have to go to the doctor's. And you didn't want to go to congregate with anyone. And you know, oh God, I'm looking at this and getting all depressed again. I'm remembering that feeling of, of such emptiness from not having dealt with grief. It was the emptiness of the loved ones. And not knowing how to grieve, not allow—I haven't allowed myself. And now that I was like, well, here, what could I do? You know, I don't know what else to do. I did my crying and, you know, I just, it's the end of my life. So what else do I have to do? And I don't know what to do. And I don't know how to grieve. I mean, it was maybe a time of confusion as well.

Other participants described the overwhelming feeling of paperwork and bureaucracy following the death of a loved one. For example, Louise felt overwhelmed with paperwork and the bureaucracy following the death of her brother- and sister-inlaw—neither of whom had formalized their wishes through a last will and testament. Louise's photo (Figure 19) shows a row of colorful file folders that she organized as she worked on handling her late brother-in-law's estate.

# Figure 19

Reduced by Louise



# **Physical Responses**

The second subtheme that emerged in responding to losses was physical responses. Many participants told stories of how their grief was exacerbated by physical injury or conditions. Grace's health also took a turn shortly after her husband's death, following years of intensive caregiving for his dementia. She felt the dramatic effects:

I suddenly realized I was really in very bad health. But you have to do what you need to do. I was living on 15, 16 cups of coffee a day, and ... it was very stressful. And I was always proud. I said, I am the healthiest person around. And I hung in there. But it was wearing me down, but I ignored the symptoms of it. Like my legs were really hurting and things like that. And as it turned out, after he passed and a month and a half later ... I ended up five days in the hospital [while on vacation] in Kauai.

Susan was also rushed to the hospital for chest pain shortly after boyfriend's death. After some testing, she learned that she had damaged the muscle to her heart. Louise also described the physical impact of learning the news of her sister-in-law's death two days after her brother-in-law went to the hospital for a stroke: "I still remember seeing that on my phone, and I thought, my knees were going to collapse. Just...what?"

The impact on participants' sleep was also significant. Judith continued to wake up exactly at midnight, months after her husband's death, leaving her with poor sleep. The photo of her bed (Figure 20) illustrates this impact on her sleep as it shows a kingsized bed with a wooden headboard with an alarm clock on the nightstand and a painting of a woman on the wall above.

## Figure 20

# Trying to Sleep by Judith



Likewise, Ann Rufft also struggled to sleep after witnessing her husband's traumatic death in her bathroom: "I couldn't sleep at night because of the images I would see. It took me a year to move upstairs." Ann Rufft's grief was further intensified after an accident just a few months after her life partner died where she had to undergo surgery and intensive rehabilitation. Similarly, Rhonda suffered from a stroke within months of her husband's death, which resulted in monthslong physical therapy to teach her how to walk and speak.

## **Repairing/Rebuilding**

A common subtheme among participants when it came to responding to their loss(es) was the process of repairing or rebuilding. Participants reported these concepts in both metaphorically and literally. Participants repaired and rebuilt their lives in various ways, though they expressed it as a slow process requiring lots of patience. The result of the repairing and rebuilding is resiliency, which shows up in many participant stories. It's important to note just how difficult it was for participants to repair and rebuild their lives after the death of their loved one(s). Janice articulates the slow process of rebuilding, stating that there hasn't been any turning points in her grief, that it's more like a big curve in a road:

And I'm on that curve. I don't feel like my story's done. I'm like, well, this is how it is. It sucks. I don't like it ... I know what I have to do ... they'll tell you [that] you need to make new friends. [But] when you talk to people, you have to learn to say, oh, I'm doing okay and move on. And the energy it takes to filter and worry about other people and how I'm coming off is too much for me. So I'd rather stay by myself and in my bubble ... so my turning points are little, teeny ones along a big curve.

In this subtheme, the majority of participants spoke of some kind of creativity as a way of repairing. Donna took a Japanese Kintsugi pottery class designed to help her heal by breaking something and gluing back together, and then painting the crack gold to honor her grief of her son. Her photo (Figure 21) is that of the bowl that she broke and then glued back together — the golden line prominent in her image.

# Figure 21

Deal with Damage by Donna



Donna describes the process as difficult but ultimately helpful:

I got to the point where I go to break this, and I'm thinking, I can't break this. Hmm. No. Mm. I can't break this. And then I'm thinking, well, the process or the purpose of doing that is to put back together what once was because your world has definitely changed. For Louise, playing the piano and listening to music was instrumental in repairing her life after her brother- and sister-in-law's deaths. She "played and played and played and played and played" the piano in response to her losses. Judith noticed how her experience of music was mechanical at first but got better as time went on: "When I sit and listen to the music [now], I feel it more. I feel it more."

Nearly all participants spoke about how helpful participating in this study was for them. In fact, Marcella Nicole notes that the photo assignment—taking 5–6 photos that tell the story of losing someone meaningful during the pandemic—marked a turning point for her in her grief:

This [study] was very helpful ... My daughter had just died. And I have to go take these pictures, [I] gotta take these. And so probably a lot of what I did taking the pictures kept me busy. And then the narrative and the questions that you asked was very helpful in helping me to get to that turning point.

Marcella Nicole's turning point happened when she staged a photo (Figure 22) about trying to be Wonder Woman as she struggled through so much grief. In the photo, she placed a frying pan on top of a Wonder Woman cape with the magic bracelets on top of two \$50 bills.

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## Figure 22

I am Woman, Enjoli Woman, Wonder Woman by Marcella Nicole



Marcella Nicole explained the image this way:

When I first thought about this, I was going to shred [the Wonder Woman cape] and leave it in tatters on a bush somewhere. Like to basically say, I am not Wonder Woman. I'm not, and I am not. And how much more can I take? It's like, well, you made it this far; I guess you couldn't take it. So I used it more as a pivot point and decided I'm going to do this. So...I still have to cook dinner when I get home and I'm bringing home the bacon,<sup>3</sup> and I'm doing all this and I've still got to be an amazing Amazon in bed. And, you know, it's like, holy crap, what can I

<sup>&</sup>lt;sup>3</sup> Marcella Nicole's reference to "bringing home the bacon" comes from a popular commercial for Enjoli perfume

in which a well-dressed woman sings about her strength:  $\underline{https://www.youtube.com/watch?v=jA4DR4vEgrs}$ 

do? And so all of that just kind of came to all of this. [I said] I can't do it anymore. And then I thought, yes, you can. And I used this as a pivot point. I am woman, I am strong, I am invincible, I am woman. I can face anything.

Similarly, Leigh Ann's story of repairing and rebuilding is used as a metaphor for the damage done to her family after the death of her father. Losing the patriarch of the family sent ripples through her extended family, as her father was no longer there to support the family. Her photo of a construction site depicts cascading gravel next to a wall of bricks (Figure 23). In the photo, she evokes both the damage and the rebuilding process.

## Figure 23

Hope by Leigh Ann



Leigh Ann explained how she framed the photo:

I took this picture. I took it from several different angles—[I] tried to get all the stuff I wanted. And this [photo] really is the best because it's got the ones falling down over here, and then they are rebuilding [over] there.

Even though Susan spoke about how she needed to rebuild her life after the sudden death of her boyfriend, rebuilding was not just a metaphor for her grief. Since her husband's death occurred at home, she literally renovated it into something new and different. This is illustrated in her photo (Figure 24) which shows white pillows on a trundle bed, a lamp next to it with a painting of a lighthouse placed on the wall directly above.

## Figure 24

Repairing a Bad Situation and Moving on by Susan



[H]e was dead when he hit the hit the ground ... so I didn't want to see that desk anymore. I didn't want to see the chair; I didn't want to see the chest. I was tired of looking at it in that room. So, I went out and got a trundle bed and put a nightstand, and I got rid of the chest, got rid of his chair, and I took the desk and put it on the other side of the room and painted it a totally different color because I couldn't stand the color of the desk. Many participants reflected on their experiences of loss and giving back as they began to rebuild their new life without their loved one(s). Susan's story included many instances of volunteering, especially with the American Legion Woman's Auxiliary, which helped her stay connected to her father, who was a World War II veteran. Similarly, Marcella Nicole focused on finding a home for her granddaughter after her daughter's death, which helped her think about someone else instead of focusing on her own grief.

Trying new things was a large part of Linda's process of repairing and rebuilding. After her husband died, she had to learn how to cook since he was the chef of the house. Since his death, she has "learned to walk into a room and be part of the room and not the wallpaper <laugh>... I've come out of this shell because I have to." When Tammy signed up to take college classes, she felt energized being around the younger students. She describes a time when she suggested they socialize outside of class:

I [asked the students], if you guys are in the student union, do you talk to each other? And they said, well, we'd say hi. I said, well, I don't get it. I said, you come in here twice a week for at least 30 minutes and obviously enjoy each other's company. I'm shocked because I bet you have a lot in common. They all sat there and went, you know, you're right. And exchanged phone numbers. Two of them found out that they both played some [video] game. And they [said], 'well, I play in that game.' I [said], you probably played each other. And they all laughed. I mean, I don't think they would've done it had I not [suggested it]. Additionally, Linda was beginning to embrace being alone after the death of her husband, which became part of her rebuilding process. She and her husband traveled frequently together. After he died, she enjoyed not having to worry about someone else when she traveled. She only had to think about herself. Linda's husband preferred to go on cruises, while she preferred land travel. She viewed cruise ships as floating shopping centers, but she went along. Her photo (Figure 25), a blurry close-up of her passport, represented how she is finding clarity in traveling alone. After his death, she says that she's having more clarity in using her passport, which is why she wanted to make the photo blurry:

So, I went on the cruises. I mean, I had an okay time, but it was really for him... [b]ut that was his thing, and I went along with it. Now I'm doing it my way. And I'm learning. I'm learning to be me.

At the time of the interview, she had just come back from Iceland with her college roommate and had traveled to Israel a few months prior.

## Figure 25

Finding Clarity in Your Life by Linda



Leigh Ann's experience was similar. Through her Christian faith, her story included a strong theme about never being alone. She felt that Jesus "was always with [her]." This came from her close ties to her grandmother, who lived with her family in her last years. Her grandmother normalized the dying process and prepared the young Leigh Ann for her eventual death. This experience with her grandmother was at the root of her decision to become a nurse. She was not afraid of death because she believed she was never alone. Her grandmother told her, "Do not be afraid…Jesus is with you. You're never alone. I'm never alone."

Resisting depression was also another way that participants repaired and rebuilt their lives. Donna spoke of a movie, *The Banshees of Inishirin* that spoke of the resiliency she needed after the loss of her son:

[The movie is] all about this guy a man who his friend one day says to him, I'm done with you. I'm not talking to you anymore. We're done. Well, it just goes downhill from there. And, of course, the guy can't figure out what he's done. What have I done? What have I said? So, you see this character going downhill, the main character who was always, you know, pretty positive and fallen in that rabbit hole. And, and you know, I'm thinking, yeah, you don't want to end up there. You know, you don't want to end up on that where you go down that rabbit hole and can't get help for yourself or those around you because then it makes it worse. So, I'm fighting back in a battle in that movie. <Laugh>

Many other participants also told stories of their resilience in response to loss. Resistance to depression was a quality that Tammy shared when she spoke of her identity as a widow. Her photo shows her wearing a stereotypical widow's veil, completely covering her face (Figure 26).

# Figure 26

Widowhood by Tammy



Her explanation of the photo illustrates her resilience in the face of grief:

I don't think I grieve like a lot of people do, at least in the grief groups that I went to. So, to me, this represented traditional widowhood that you're supposed to be draped in black, that your life's over, that you're supposed to be depressed for years ...Was I sad? Of course I was sad. Did I miss my husband? Sure. Was my life over? No, I and I knew that from the get-go.

Linda, whose husband died of cancer, also rejected the term *widow* as a way to describe herself. She found the term "depressing" and "harsh." Similar to Tammy, she demonstrated resilience by trying new things and learning how to live on her own. Here she explained her rejection of the word, *widow*:

I went from Mrs. to *widow* or married to *widow* ... the first time somebody called me that, it just was like a knife. Just stuck. And it's just a tough word. Yeah. I don't use it very often myself, but the first time you hear that word and it's you, it's hard.

Other participants articulated their resiliency by accepting that death is a part of life. When asked what lessons come from her grief, Rhonda, whose husband died of vascular dementia, responded with one sentence: "Everybody dies."

Acceptance of death was something that Leigh Ann also frequently mentioned in her story of grief. Her grandmother's influence in her early years taught her that death was a normal part of life and that was something that has stayed with Leigh Ann ever since. In addition to acceptance, many participants told stories of gratitude — even in the midst of profound loss. Rhonda described a sense of "release, not relief" when her husband died. Glimmers of hope were also common in participant stories. In Bobo's interview, she spoke at length about seeing herself in a nearly dead houseplant. She took a photo (Figure 27) of the plant, which shows mostly dead stems with touches of green. On the edge of the photo, she included a blue glass ornament.

# Figure 27

Dead or Alive by Bobo



As Bobo explained:

It's a plant, it's actually like a tree that I have in my house. And you can see it's not doing really well. <Laugh>, which was me. I wasn't doing real well, and my caption, dead or alive. What am I? And I started to question my own being, my own life. I've lost many, many people in my life, and I was very alone during COVID. And recognizing the loss of these two friends, just, why am I here? Why am I alone? Am I on my way out like this tree? Is there still life to be had? I found it interesting when I looked at the picture again that I have some glass that hangs from my window. And it was like, well, there's a spark. You know, there's something pretty, there's something ahead that maybe I'm not just dying like this tree.

Participants also shared how repairing and rebuilding ultimately changed their lives. As noted, many women who lost their spouses or partners talked about the strength they felt as they learned to live on their own. Knowing they could do something so difficult often resulted in pride in themselves. Tammy, whose husband died after an illness, talked about how she decided to put herself first, going back to college, acting, and trying new things. When asked who the hero of her story was, Tammy replied, "I kind of like the fact that I think I'm my own hero. I think I've done the things I needed to do." Later in the interview, Tammy added another statement: "I don't want to be saved. I want to be able to save myself." Similarly, Bobo credits the work it took to rebuild her life after losing so many loved ones. She reflected on how the losses softened her:

Like, right now, I mean, normally if I were doing this interview three years ago, I wouldn't have my voice breaking. I wouldn't have tears in my eyes ... I would've done a great performance. And maybe because of this, it's interesting because of revisiting this, I feel all the more authentic and hopeful for whatever I have left in my life.

Elizabeth, whose best friend died of COVID, illustrated her resilience facing loss by weaving in the good with the bad. She took a photo of a tree in the winter (Figure 28) at night, and described how this demonstrates the beauty of joy and loss:

What [this photo] brings to me is that in the midst of the starkness and the cold ... this absolute beauty and a warmth that comes from seeing the world in all of its beauty and all of its sadness, and not taking it apart and going, this is good and this is bad. It's just like, this is it, this is life and it's all beautiful. And maybe that's it. Maybe it's all beautiful.

## Figure 28

Beauty in the Midst of Winter by Elizabeth



# **Theme: Presence of Deceased**

The last theme includes participants feeling the presence of their deceased loved ones, which sometimes felt painful and sometimes gave them comfort. Participants included stories of unexpected moments that interrupted participants' daily lives. For example, Louise remembered how much her brother-in-law loved the *Grinch Who Stole Christmas* and thought of him when she saw Grinch decorations in December. Janice had a similar experience at the grocery store, feeling immense grief looking at a can of beans and remembering how much her husband loved them. Similarly, Susan struggled with being in the room where her boyfriend died, remembering the trauma of seeing him slumped over his desk. Susan also struggled with the 4<sup>th</sup> of July, a date that continued to haunt her:

July 4<sup>th</sup> is a very terrible problem for me because my late husband died on July 4<sup>th</sup>. My dad's funeral was on the weekend of July 4<sup>th</sup>. And my late boyfriend died a couple days past July 4<sup>th</sup>. And also I served on a murder case on 4<sup>th</sup> of July weekend.

Coincidentally, her boyfriend's memorial happened on the 4<sup>th</sup> of July as well. Because Susan wasn't close to his daughter and wasn't married, she was left out of the funeral decisions and only learned of it after the fact. Tammy also struggled with the date of her anniversary, something she felt was particularly painful for widows:

Everybody always worries about the first year and all the holidays—you have to get through the one that's not highlighted enough, in my opinion. [My wedding anniversary] was the hardest ... because I was the only one who knew it. Think about it. Who knows that? I mean it was like, that's our whole life, and yet nobody but me knew that it was my wedding anniversary [sobs].

Janice's photos illustrate the pain of ordinary reminders of lost loved ones. Her first photo depicts four potatoes lined up on the oven rack (Figure 29); in the second, there are only three (Figure 20).

# Figure 29

Family by Janice



# Figure 30

Three Potatoes by Janice



She described the significance of the photos:

After Arthur died, I had a hard time with a simple thing as putting the right amount of potatoes in the oven [sobs]. And I would always put four potatoes in the oven automatically because there were four of us. And now I have to put three potatoes in the oven, which is my last photo. And I automatically get four potatoes and put them in the oven. And then I realize I don't need four potatoes anymore.

There were also many moments in participant stories when their presence brought them deep comfort. Elizabeth, whose best friend Timothy died of COVID, shared a moment when she felt his presence. It was an ordinary moment, just brushing her teeth in the bathroom. She described it as "having a sense" that he was there. The moment brought great comfort, as she explains:

I swirled around with a toothbrush in my mouth. And I had this sense, and I'm not really woo-woo, but I'm open to things. I had this sense that he was like a little two-year-old on a tricycle, and he was wheeling around the universe, like, look at me! I've got this! But what he said to me was, *I'm gonna be okay. Don't worry.* And then he was gone. And I knew then that he was actually dead then. It was a week before they took him off the [ventilator], but I knew that his spirit was practicing leaving his body or maybe had already left.

Bobo's experience of presence mirrored Elizabeth's. She described knowing that her loved ones are still with her, even though they died: "It's like all the people ... who are not in my life, are all right here." Similarly, Linda actively conjured her husband with two rituals: her journal writing and observing Shabbat, the weekly Jewish ceremony on Fridays and Saturdays. These two activities kept Linda connected to her husband's presence, despite his death. She wrote to him about what she was feeling in her journal: "Whenever I [write], there's a date, but it always ends up with love always or double kisses, because that's what we used to do." Shabbat was a ritual that she treasured with her husband and continued doing after he died. In her photo (Figure 31), you see her

hands covering her face. This is what she would do to summon her husband's presence.

# Figure 31

Don't Hide Behind by Linda



Linda explained the ritual:

So, it started Friday night and go on to Saturday. So now when I do this, I say the prayers, you have to cover your eyes. You light the candles, you cover your eyes and you do the prayer. And now when I do it, I stay in this for an extra few seconds and I actually kiss the palm of my hand as though it was his head. And [I] tell him that I know he's not hurting anymore.

Likewise, Judith, whose husband died of Parkinson's, would sit in his chair and talk to him as if he were there and could hear her. Conjuring his presence was a comfort to her. Similarly, Leigh Ann remarked that she has always felt her grandmother with her throughout her life; she thinks of moments that would make her proud. When her aunt and uncle died during the pandemic, she also felt their presence:

You can just really kind of feel like they're there. It's kind of a weird thing, but, but really, truly, I think that people that are important in your life, you just take a part of them and it becomes a part of you, you know?

# **Interconnectivity of Themes**

The previous section outlines distinct themes that emerged in the stories of study participants. Although all themes are distinct, each one also connects to other themes in various ways (Braun & Clarke, 2006). The following section summarizes the definition, characteristics, and boundaries of each theme and includes an explanation of the interconnectivity between them. (Braun & <u>Clarke, 2006)</u>.

## Social Isolation

Social isolation reflected the negative impacts of being alone, and it includes loneliness and social disconnection of participants as well as their loved ones. It does not include stories of being alone in general or the self-reliance of participants. This theme highlights the unique situation of grieving during the COVID-19 pandemic with stay-athome measures resulting in forced isolation. The theme of social isolation is associated with the themes of efficacy of support and multiple losses/stressors all at once. The efficacy of support for participants was greatly impacted by social isolation due to the safety mandates that kept people physically away from others. The usual support systems of social groups and in-person meetings disappeared during the pandemic, especially during the early days of lockdown, exacerbating the social isolation of participants. Social isolation also added to participants' multiple losses/stressors all at once by forcing them to deal with their difficulties on their own, adding another layer of stress to their grief.

## Fear of Virus

Stories of participants feeling fearful of the virus included moments of worry about getting sick or infecting others with the COVID-19 virus. It does not include fears or anxieties that do not specifically mention the virus or getting sick from the virus. Participants' fear of the virus indicates the particular impact of the pandemic on grief by adding another layer of distress for participants. This theme is also associated with multiple losses/stressors all at once as well as interpersonal conflict. Similar to social isolation, the anxiety that participants felt in potentially getting sick or infecting their loved ones intensified their already full plate of stressors during the pandemic. Being afraid of the virus also caused interpersonal conflict when loved ones or strangers disagreed with threat levels and safety measures.

## Efficacy of Support

The efficacy of support theme encompassed moments where participants identified what really helped them in their experience of grief. It also included moments where participants identified the absence of support resulting in two subthemes: supportive and unsupportive. This theme impacted the themes of multiple losses/stressors all at once, interpersonal conflict, and delayed grief. Participants experiencing multiple losses/stressors all at once needed extra support as they grappled with their acute needs. Since the pandemic impacted everyone, participants felt challenged in receiving support from family and friends as well as other sources of support outside of their social connections. Participants noted that everyone else was struggling during the pandemic, and they felt that there wasn't enough support to go around. This collective struggle during the pandemic meant that participants felt more interpersonal conflict as it felt as though everyone was on edge. Since many participants felt a lack of support in their grief which may have contributed to their experiences of delayed grief, another theme in this study.

### Efficacy of Healthcare System

This theme of the efficacy of the HCS included any story that comprised memorable interactions with healthcare professionals including mental health professionals as well as grief support groups. It is separate from the theme of support and focuses solely on the care received within the HCS. This theme also highlights the fragility of the HCS during the pandemic and its impact on grief. The subthemes included unsupportive care and supportive care as well as general opinions about the HCS. The efficacy of HCS was impacted by participants' experiences of multiple losses/stressors in that they needed more support with their healthcare at a time when support systems dissolved. The HCS struggled to keep up with demand, which meant that fewer healthcare providers and appointments were available during the pandemic. Participants' high needs conflicted with the low resources in the HCS during the pandemic, which may have contributed to participants' experiences of interpersonal conflict. Healthcare workers experienced long hours and impossible demands, which may have led to short tempers and less empathy towards patients. The lack of support from the HCS may have led participants to feel as

though they had to process feelings of betrayal before addressing their grief of losing a loved one. This may have also resulted in delayed grief for participants, another theme in the study.

#### Multiple Losses/Stressors All At Once

The theme of multiple losses/stressors all at once consisted of stories of participants experiencing more than one difficult situation at the same time and the overwhelm that followed. It did not include stories of multiple losses and stressors that occurred before the onset of the pandemic. This theme reflected the various negative reverberations of the pandemic by increasing the number of stressors on participants. Participants with overwhelm of loss and stress required more support at a time when everyone was isolated and low-resourced, including friends and family as well as other support outside of participants' inner circles of support. The piling up of losses at once may have delayed participants' grief as well.

### Interpersonal Conflict

The theme of interpersonal conflict referred to stories of negative interactions with other people. However, this does not include participant stories of inner conflict. This theme spoke to the broad social unrest during the pandemic, especially in the summer of 2020 and indicates the tenuous nature of friends and family for participants during the pandemic (Taylor, 2021). This theme connected to political divide, fear of virus, and social isolation. Participants spoke of disagreements between friends and family regarding masking, which indicated the impact of the political divide on interpersonal relationships. Participants' fear of the virus may have also contributed to an increase in

interpersonal conflict as disagreements about safety measures were often points of tension in relationships. Finally, social isolation kept people from being able to interact with one another in person, putting a strain on relationships and potentially intensifying interpersonal conflicts.

### Political Divide

This theme of political divide contained stories of conflict stemming from disagreements regarding elected leaders, street protests, or governmental mandates. It did not include healthy disagreement about politics; instead, it comprised of moments where the divide led to isolation and frustration for participants. For some participants, these disagreements kept them from staying connected to friends and family, which may have led to an increased feeling of social isolation. This also overlapped with the theme of efficacy of support in that political disagreements may have lessened the support participants needed in their grief.

### Delayed Grief

This theme related to statements regarding cancellations of memorials, funerals or other grief rituals as well as stories of participants feeling as though their grief happened later than they imagined. This theme did not include general grief stories without mentioning it occurring later than expected. Participants' delayed grief were likely impacted by the nature of the death of loved one(s). For instance, for deaths that involved medical errors, participants may have been distracted by their anger instead of feeling sadness over the loss their loved one(s). Multiple stressor(s) may also have led to a delay in grief as participants needed to respond to various other problems before expressing their grief. Additionally, the impact of stay-at-home mandates meant that many people had no place or space to memorialize their loved one(s) which may have resulted in the delay of grief. This delay may have been the result of social isolation without the inperson support associated with memorials and other gatherings that help participants feel connected to others.

#### Experience of Gradual Loss

This theme referred to the incremental loss that participants experienced when their loved one(s) experienced illness(es) preceding their death(s). This theme encompassed stories of a series of losses leading up to the death of their loved one. This did not include smaller losses unrelated to the death of their loved one(s). Examples of gradual loss were stories of deceased loved ones who experienced memory loss or physical disabilities that limited their daily lives preceding their death. Losing someone in small increments was distinct from losing a loved one all at once. This type of grief is likely impacted participants' responses in the wake of their loved one's death.

## *Response(s) to the Loss(es)*

This theme included ways that participants reacted when their loved one(s) died. It included the subthemes of emotional responses such as anger, physical responses such as illnesses or injuries, and repairing/rebuilding, which included both the literal (renovating a room) and metaphorical (reimagining a life alone). This theme focused solely on the participants' individual reactions to their loss(es) and did not include how other friends and family members responded to the death(s) of their loved one(s). What happened after the death of their loved one(s) revealed the ways that participants worked through their

feelings of grief. The ways that participants responded to their grief was likely impacted by how socially isolated they felt, how supported they felt by their friends and family as well as the efficacy of the HCS.

### Presence of Deceased

This theme encompassed moments that participants spoke of feeling connected to their lost loved one(s). This included moments of identifying objects that reminded them of the deceased as well as feeling as though their loved one was in the room with them. It did not include stories of their deceased loved ones before they died. This theme showed how important it was for participants to feel close to the loved ones they lost. Whether or not participants felt the presence of the deceased may have been impacted by their response(s) to their loss(es). Those who surrounded themselves with photos or physical objects owned by their loved ones noted how keeping those close by helped them feel their presence, something that was comforting to them.

### Conclusion

These themes show that many of these women had many similarities during the pandemic: the social isolation, the desire to connect with supportive people and contexts stand out as particularly significant. Additionally, the desire to have a more equitable and sustainable healthcare system stands out as a notable finding, especially as it relates to the treatment of older adults. These findings also reflect how individual each person's grief experience was based on the nature and timing of the loss of their loved one. How and when someone died impacted how the participants responded. The following chapter

explains how each of these common themes gives insight to what matters the most to the participants.

## **Chapter Four: Discussion**

Signaling the winding down of the pandemic, the U.S. Department of Health and Human Services (2023) declared the COVID-19 public health emergency to expire on May 11th, 2023. Movie theaters were open, as were restaurants and concert halls. In many ways, the U.S. was emerging from the pandemic. However, our understanding of the layers of impact of this crisis continued to evolve.

While some studies have quantified the impact of the pandemic on older women, their individual voices and experiences have been largely absent in the findings. I sought to discover the nuanced experiences of older women's grief and loss during the pandemic. Thus, I chose an approach that combined narrative and photovoice methods to amplify voices of older women. I used the retrospective theoretical foundation of CNSM, which was useful for a study that included narratives through photography. The CNSM lens helped me identify participant values, beliefs, and sense-making through their stories of grief (Koenig Kellas, 2018). Thus, the goal of the present study was to address this limitation by using a combination of narrative and photovoice methodologies guided by the following research question: What common themes emerge in older women's stories of losing loved ones through death during the COVID-19 pandemic?

This study included 18 women aged 65 and older who lost a loved one during the pandemic. A majority of participants lived in greater Denver, and three lived out of state.

I conducted data analysis using reflexive thematic analysis (RTA) based on Braun and Clarke's (2006) and Byrne's (2022) approaches. This method of analysis allowed me to compare stories and identify common themes within and between participants. This iterative process produced eleven themes: social isolation, fear of the virus, efficacy of support, efficacy of the healthcare system (HCS), multiple losses/stressors all at once, interpersonal conflict, political divide, delayed grief/rituals, experience of gradual loss, response(s) to the loss(es), and presence of the deceased.

In this chapter, I begin with a discussion of the impact of COVID and its magnification of older women's grief. I then explain the connection between the findings and current research. Next, I provide an explanation of how CNSM principles paved the way for insights into participant experiences. Throughout this chapter, I include moments from my journals (written and visual) to illustrate the research process as it unfolded. I also explain ways in which the findings illuminated the common values, needs, and beliefs of participants. I also explicate the study's strengths and limitations, followed by recommendations for future research and practice.

#### **Impact of COVID**

Ninety five percent of COVID deaths were among those aged 50 and older, intensifying an already challenging life stage for older women (CDC, 2022). The longer women live, the more cumulative grief they experience (Lekalakala-Mokgele, 2018). And grief does not get easier with more experience; older women's needs around support reflect those of younger generations (Lekalakala-Mokgele, 2018). Before the pandemic, bereavement studies showed that in general, women reported more suffering in grief than men (Williams et al., 2006). More than half of women aged 75 and older identify as widows, and many find themselves serving as caregivers, which adds to their stress levels at this life stage (CDC, 2014; Williams et al., 2006). Women also have wider social networks, leaving them vulnerable to friend loss as well (Wang et al., 2021).

Participants qualified for this study because they believed that the pandemic significantly impacted their grief and loss; this reality was reflected in a majority of participant stories. For me, COVID was a magnifying glass that allowed me to see their grief up close. For instance, Marcella Nicole's story was filled with the repeated phrase, "because of COVID," related to various stressors and complications impacting her grief experience. Because of COVID, she was unable to visit her incarcerated daughter. Because of COVID, her brother's funeral was delayed by months. Because of COVID, she couldn't visit her best friend in the hospital. Ann Rufft's experience mirrored Marcella Nicole's with her declaration that COVID "heightened and exacerbated" everything related to her grief experience. I have seen this first hand, witnessing the losses my 87-year-old mother endured, especially in the past decade.

I am also reminded of study participant Elizabeth who spoke of the loss of her best friend due to COVID; he was not only a friend, but a colleague. Similarly, Ann Rufft spoke of her life partner as not only her significant other, but also a trusted coworker. Their stories are just two examples of how the pandemic damaged the architecture of supportive relationships for the participants in this study. The women spoke of losing friends and family to death, but also the losses related to interpersonal conflict, further exacerbating their grief. All of these factors put grieving older women at a particularly high risk for mental health challenges during the pandemic (CDC, 2022; Treml et al., 2020; Wang et al., 2021). I wrote my thoughts about COVID in my journal:

COVID was in all the stories, of course. What surprised me was that there were positive aspects of COVID—but mostly bad, which mirrors the theme of the healthcare system. COVID brought people together through "bubbles" and Zoom groups. And COVID also destroyed relationships either because of physical distances or the stress of the pandemic causing strife (masking/political differences). Families came together and pulled apart—sometimes back and forth within one family. Many of these women were frozen out—whether due to an already strained relationship that couldn't survive the pandemic, or friends dropping them because they were no longer part of a couple. (Journal entry, March 7, 2023)

Although each of the participants' grief stories were unique, they all spoke of the major impact the pandemic had on their bereavement process. Along with COVID, other collective traumas occurred during the years of the pandemic that included job losses, social unrest, wildfires, destructive weather events and mass shootings, to name a few (Silver et al, 2020, p. 4; Boulder County News Archive, 2022; Giebel et al., 2021; Katz et al., 2020; Maddrell, 2020). Previous studies indicates a particular vulnerability to mental health risks for people experiencing collective trauma (Silver et al., 2021). The findings of this study may be useful in future studies of collective trauma. In particular, the increase in disastrous weather events caused by climate change continue to impact the

mental health of large populations (Silver et al., 2021). Future studies should consider the impact of a collective traumatic experience on the bereaved.

## **Beliefs, Values, and Sensemaking in Common Themes**

The foundation of CNSM lies in the assumption that narrative is communication. Looking into the content of stories can reveal storyteller identities, motivations, and beliefs (Koenig Kellas, 2018). Participants shared their stories and photos during the interview process, which opened a window into what participants cared about, what they believed, and how they made sense of their grief and loss. In this section, I explain how each theme suggests certain beliefs, values or sense-making processes of participants, prompted by CNSM's retrospective heuristic (Koenig Kellas, 2018). In doing so, I illuminate what's behind the main themes and how they might translate into practical applications (Koenig Kellas, 2018).

#### **Social Isolation and Efficacy of Support**

Throughout the study, isolation and efficacy of support showed up in participant stories. As explained in Chapter 3, social isolation impacted not only the participants, but also their ailing loved ones. Jennifer's mother, who deteriorated in her assisted living facility is an apt example of this phenomenon. Already feeling alone after losing their loved one(s), participants felt even more isolated due to the stay-at-home mandates, especially during the first year of the pandemic. Participants felt trapped and lonely in their grief. This was exemplified by Ann Rufft's story. She had to walk in the bathroom where her life partner died, unable to avoid the painful memories of seeing him slumped over on the floor. She felt trapped in her own home. A few months later, Ann describes a feeling of "abject loneliness" in a medical rehabilitation center. Not having people physically by their side was an important aspect of this social isolation.

The themes of isolation and efficacy of support underscored participants' value in a diverse constellation of support. This value is exemplified in Louise's experience with the hotel proprietor during her time of crisis. His kindness and care kept Louise afloat as she grappled with grief. People living close by helped—like Lisa's neighbor doing chores or Louise's son, who found lodging for her after the death of her brother-in-law. Others from afar also supported participants, like Linda's son who called her on the phone every night. Even casual acquaintances supported participants, like Bobo's insurance agent who gave her a meaningful book about grief. Yet still others found support within themselves, exemplified by Linda honoring her desire to travel on her own terms.

The CNSM retrospective structure allowed me to rethink these stories of isolation and efficacy of support from the lens of values, beliefs, and sense-making. I wrote about this in my journal, titling it "Deep Ties/Weak Ties in Community":

These social ties were crucial in how these women told their stories. The importance of family and friends who "knew them when" provided support during their moments of despair. Weak ties were anything but weak. A cleaning lady, a grocery store worker, a pharmacist, someone standing in line next to them at the store—they all either provided support at times or were not there anymore. Having small conversations with strangers was important. (Journal entry, March 7, 2023)

Going further into this theme helped me see that underneath their stories of isolation and support are participants' deep appreciation for other people. Although good friends and family are important, strangers and acquaintances were also highly valued by the participants. Tammy exemplified this value in what she called "social touches," interactions with all kinds of people, from grocery store workers to students in her college classes. Even short and seemingly minor conversations were something that the participants spoke of frequently in their stories. Ordinary kindness from strangers and acquaintances were elevated by participants and much appreciated.

It's also important to note that moments of unkindness also affected participants. Dismissal and cruelty highlighted the impact of other people's impacts on these grieving women. Linda's story of an acquaintance asking her why she wore her wedding ring after the death of her husband is a key example of this phenomenon. The person who spoke those words was not a close friend, but it didn't matter. It still hurt. Linda described it as "hitting [her] right between the eyes." Marcella Nicole's story of her cousin (with whom she is not close) asking her over text about her daughter's drug use is another example of the impact of unkind words on participants.

## Fear of Virus

Reading stories of participants' fear of the virus brought me back to the early days of the pandemic, when so little was known about its transmission. Fear of the virus became clear in participant stories in various ways. Participant stories revealed a constant vigilance against inadvertently infecting themselves or others during the pandemic, indicating an awareness of their own vulnerabilities. Using the lens of CNSM on this

theme, I considered what was behind this fear and how it fear indicated what mattered to them. I realized that many participant decisions during the pandemic were rooted in the difficult nature of risk assessment. For example, Emma Jane, who lived far away from her ailing mother, didn't feel comfortable traveling by plane to see her. She worried that she would contract the virus and give it to her fragile mother. Similarly, Louise, whose brother-in-law died in the early months of the pandemic, spoke about how this fear permeated every decision, including choosing a motel that had good air ventilation. She also spoke of how frightening it was to go into the ICU to see her dying brother-in-law, only to see that no one was wearing masks. She was unable to go to restaurants and had to make do with a hot plate in her motel room. Likewise, both Tammy and Leigh Ann worried a great deal about inadvertently infecting their immunocompromised family members. As much as the participants valued social interactions, they knew the virus was deadly. This also shows an awareness of their mortality. They knew firsthand what it was like to lose someone to death, and this made them protective of their own health and others.

#### **Efficacy of the HCS**

When I asked participants to tell their stories of grief, a majority of them included intricate details of illnesses and the nature of their deaths. I had not expected to hear so much about how people died and the specifics of what led to them. In my naivete, I expected people to begin after their loved one's death. Instead, much of their stories included the failure of the healthcare system. This reflected their sense that the healthcare system was broken. I noted this in my journal during the analysis stage: Thoughts after analysis ... ideas, musings. Watching someone die and not being able to help or do anything. Lots of airtime on the illness. Less on their grief. Their grief is interpreted or storied in the death of their loved one. Is this because I didn't do a good job of directing them to tell the story of their grief? Grief begins, I guess, with the illness or the moment you realize your loved one might die. The loss starts there. (Journal, February 8, 2023)

I quickly learned the importance of the healthcare before and immediately after the death of a loved one was for participants. I also drew a continuum of failure and taped it to my wall in my office, wanting to put my thoughts in some visualization (Figure 32).

#### Figure 32

Failure Continuum of HCS

poor communication lack of enough vesources	overhelm ofsystem bumont	uneven/ in consistent polities regarding masks, Usiting	agersm disposable old prople	Unelty Janice's Sty Ridge topchoce fenn: fer's mother stanving to death mean cangines Ann Rufft being yelled at for crypty feeling unsete

Although there were moments in stories of effective healthcare, the majority of the stories reflected the system overwhelm, which was well known throughout the pandemic (CDC, 2022). This theme within suggests a belief among participants that the HCS is broken and undervalues older adults. Several participant stories included lack of supportive care during critical moments with their loved ones, especially at the end of life. This was exemplified by Janice's story of a hospital chaplain pressuring her to make funeral decisions just minutes after her husband's death. Participants spoke of many moments where they felt helpless with their ailing loved one(s), confused by policies or frustrated by mistakes made by healthcare providers. Some participants spoke of feeling betrayed, which further intensified their grief process. Such experiences led to feelings of guilt, regret, and fear that their loved one's death was preventable. Moments where participants were able to find compassionate healthcare were lauded as pivotal in their grief process. Lisa compared being in the hospital to the "vacation" she deserved. And Grace noted the "angels" from hospice at the end of her husband's life, thereby reinforcing participants' value of compassionate healthcare.

#### **Political Divide**

Throughout the pandemic, the country experienced social unrest, especially during the summer of 2020 following George Floyd's murder. Additionally, the election of Joe Biden, followed by the storming of the capitol on January 6, 2021, created a climate of political divisions. These events signaled a deep political divide, which was reflected as a theme in participant stories. This reality sent many participants into an anxious tailspin, unable to watch or listen to the news because it was so upsetting. Many spoke of not feeling like they could do anything about it, which reflects their belief of pessimism and/or helplessness. Janice exemplified this belief, feeling as though no one understood "the other side," and that nothing she could say would change people's minds anyway. Emma Jane also spoke of how she really could not do anything to make the world any better. She believed that the people in charge did not really care, leaving her helpless among the violent rhetoric of extremists. Emma Jane's helplessness reflects the research naming the "heightened emotions" (Katz et al., 2020, p. 433) as well as numerous stressors exacerbated during the pandemic (Govieas & Shear, 2020).

#### Multiple Losses/Stressors

Compounding the isolation and loneliness, older women reported "cascading collective traumas" (Silver et al., 2020, p. 4), resulting in multiple losses/stressors. This theme reflected participants' value of strength, as many of their stories were those of survival. This value is visible in Tammy's story of signing up for classes, making an effort to meet people, and not letting her grief take her down. Ultimately, she named herself the hero of her own story.

#### **Delayed Grief**

Delayed grief was a common theme in participant stories and occurred in various contexts. For instance, Ann Rufft's story of physical and emotional suffering from a major accident just months after the death of her life partner meant she needed to focus on her own health before she could process the loss. She needed energy to heal from her injuries before she could make sense of her profound loss. Likewise, Marcella Nicole described feeling like there just wasn't enough space or time to make sense of all of her losses. These two stories align with "decision fatigue" associated with COVID-19 grief (Stroebe & Schut, 2021, p. 508). Too many decisions delayed the grief process.

Other times, though, delayed grief prompted other reactions. Bobo, for instance, spoke of how the stay-at-home mandate facilitated her unexpressed grief over her daughter's death by suicide in 2017. Bobo felt that being alone at home forced her to finally feel her feelings about her daughter's death; it was the pandemic that unearthed feelings she had not felt before. She considered this to be a good thing, although very difficult. She said she realized just how much she was performing being okay. Her sensemaking was delayed for reasons she could not articulate.

Louise reported that her delayed grief came a need to care for her husband's grief first. She also believed that this may have something to do with gender roles where women put their own feelings last, reflecting the research on women carrying extra stress in the caregiver role (Williams et al., 2006). She also indicated that her delayed grief may have also been self-imposed. She said it was easier to stay in her intellect and avoid her feelings. It seemed as though some of those feelings and perhaps the beginning of sensemaking were loosened in her interview, where she shed tears and felt lightheaded as she spoke of her grief. Her experience exemplifies Koenig Kellas's (2018) statement that stories reflect and impact "sense-making and health" (p. 65).

#### **Interpersonal Conflict and Gradual Loss**

Interpersonal conflict emerged in various ways in participant stories. For some, the conflict occurred with close family and friends. They also showed up with strangers and acquaintances. Gradual loss emerged as a theme that highlighted stories of people losing loved ones to long and debilitating illnesses such as Parkinson's Disease and cancer. This particular kind of loss stretched out participants' grief as they suffered small but not insignificant periodic losses along the way. Prompted by CNSM's principles, I pondered what values might be hidden behind their stories of interpersonal conflict and gradual loss. This led me to discover that both of these themes indicated participants' value of grace. Their stories reflected moments of both giving and receiving grace as well as asking for more of it. Furthermore, gradual loss also indicated a belief in persistence, something that participants demonstrated as crucial as they slowly lost their loved ones.

Marcella Nicole's story of interpersonal conflict reflected this, as when she described the need for strangers to give her grace as she sorted through her multiple losses. Likewise, Leigh Ann's story included a moment shortly after her father was diagnosed with Alzheimer's disease where all of her family members sat at the dining room table and shared their feelings. A social worker had gathered everyone together to share their perspectives, something that Leigh Ann says helped her extend grace to her sometimes difficult sister. Ann Rufft also told a story of feeling deep frustration with her life partner's daughter who couldn't relate to Ann's cautious behavior during the pandemic. Behind Ann's anger and frustration was a value of grace for people in different situations and with different perspectives.

This concept of grace as well as persistence is exemplified in Grace's story. In an email after her interview, Grace wanted to identify her chosen pseudonym as such. She described that her whole experience could be summed up through the concept of grace. She was grateful for everyone who offered her grace, especially while she managed her husband's sometimes inappropriate outbursts from his dementia. Her story also reflected how she learned to offer herself some grace after landing in the hospital on vacation. Grace's experience taking care of her husband also reflects the value of persistence in the context of caregiving. The extra load caregiving added during the pandemic added to the list of stressors that older women faced (Williams et al., 2006). Despite the extra work, Grace was persistent in her commitment to finding social outlets at museums and libraries for her husband, whose dementia made this process extra challenging. Rhonda also described how difficult it was to watch someone die "inch by inch," and yet she was persistent in supporting him, despite the difficulty. Mary's story of her ailing husband, whose illness was never fully understood also indicated the belief in persistence. Although she never found the help she needed, Mary did everything in her power to find doctors and resources that could help her husband.

#### **Responses to the Loss(es)**

The theme of responses to the loss(es) was present in all participant stories and reflected three subthemes: emotional responses, physical responses, and repairing/rebuilding. With the help of the retrospective lens of CNSM, I asked myself: How do my participants' responses to their losses reflect what they care about? How might these response suggest a value, a belief system, and how they make sense of their grief? My answers resulted in identifying three distinct values of participants: justice, vulnerability, and hope.

The first value of justice comes from participants' emotional responses of anger, betrayal, and a sense of helplessness. Many times, the feeling of anger and betrayal stemmed from what they considered an injustice. Midway through my analysis, I wrote about these responses in my journal, indicating an intertwining of the themes of failure of HCS, responses to loss(es), and efficacy of support:

Betrayal. The betrayal at the time of death or from healthcare workers is at the root of a lot of these women's anger. Treatment of older people in rehab centers and assisted living facilities was egregious—the cruelty of individuals in these centers was extremely damaging and left many of these women feeling powerless and hurt, causing deep anger at the failure of the system. The protocols were inconsistent and haphazard, causing many of these women to feel unsafe (unmasked, unvaxxed nurses) and also betrayed (friends from other hospitals could visit, but they couldn't). Calling and needing help. This is related to betrayal as many women tried everything to get both medical care for their loved ones or help for themselves in their grief only to hear silence or dismissal when they reached out. Only a few women felt supported by extended family. These women had exceptionally supportive family systems that swarmed support for each other (Louise, Leigh Ann, and Lisa). Their stories had a much more hopeful tone than others without that deep support. (Journal, March 7, 2023).

Ann Rufft's story was filled with feelings of anger that she wasn't able to get her loved one into the doctor quickly, something that she feels may have extended his life. She also felt angry at the nurse's aide who yelled at her while she shed tears when she was in the rehabilitation facility following her accident. Mary's anger at never getting a clear diagnosis for her husband also left her feeling that no one could help them. Janice's anger also stems from the injustice she felt she received from hospital staff, who were consistently unavailable throughout her husband's decline. Janice's anger over being rushed out of the hospital room at the time of her husband's death reflects the hastening of rituals that negatively impacted the grieving process (Mayland et al., 2020, p. e36). Participant anger reveals a value of justice, indicating that they (and their loved ones) deserved better treatment.

For participants whose stories included a physical response to the loss(es) indicates an understanding of their own vulnerabilities. This is exemplified by Grace's experience of ending up in the hospital shortly after her husband's death. She considered it a wake-up call to her own vulnerability, something that was lost during her time as her husband's caregiver. Likewise, Louise's interview included moments where she felt light-headed as she shared her story, frequently taking breaths and small breaks in order to stabilize her physical responses, demonstrating her appreciation of her own physical vulnerabilities as she expressed her grief.

The subtheme of repairing/rebuilding indicates participants value of hope. Many participants turned toward the creative arts, with many of them specifically referencing how this study's photo assignment helped them make more sense of their loss(es). I wrote about hope in my journal:

Hope and silver linings. This is another interesting code (theme?) that I find interesting. Many participants talk about moments that feel so awful—the depths of grief, the emptiness, the anger, the <u>missing</u> of their loved one(s), the hole that is left. And how they are able to find glimmers of hope to continue on. Somehow they find a sign that they can do it. Others actively resist the "poor old widow" by refusing to give in to the grief. (Journal, March 7, 2023).

In addition to hope as a part of rebuilding their lives, some participants' stories were literal, exemplified by Susan redecorating the room where her life partner died suddenly. Seeking a sense of purpose, she painted old furniture and added treasured photos on top of it. She believed that renovating a room with such bad memories and replacing them with good ones gave her a measure of closure, something she was denied due to the pandemic's stay-at-home mandates. Leigh Ann's photo of a crumbling wall is another indicator of hope. In her explanation of the photo, she acknowledges the damage of her father's death, but also the rebuild that was simultaneously occurring in her family.

Additionally, on participant's response to her loss reflects the CNSM assumption of the function of storytelling as a way to "make sense of and cope with" struggles (Koenig Kellas, 2018, p. 64). This was reflected in Marcella Nicole's experience of "swirling" from grief overload. Her story of grief burnout led her to taking a photograph that reflected and conjured up her inner strength, which also exemplifies CNSM's assumption that stories have the capacity to both *reflect* sense-making, but also *affect* sense-making. (Koenig Kellas, 2018). For example, while staging a photo of "surrender," Marcella decided to change the story into one of strength. She did this by conjuring the fictional characters of Wonder Woman and the Enjoli perfume woman. Marcella Nicole's story also aligns with CNSM's assertion of a link between positive content and individual wellbeing. Positively framed stories are positively related to health and wellbeing, something that Marcella's superhero story so poignantly demonstrated (Koenig Kellas, 2018).

#### **Presence of Deceased**

The last theme in this study was the presence of deceased, a common theme in many participant stories. This theme reflected the value of deep connections that many participants had to their loved ones through ordinary objects or shrines of their own making. Their stories included small moments of visual reminders through objects that reminded them of their loved ones, with many of them talking about the chair their loved ones sat in (Judith and Rhonda), the gardens they tended (Rhonda and Louise), the potatoes they ate (Janice), and the piano they played (Lisa). Similarly, Marcella Nicole arranged a necklace in a circle at a shrine to represent the loss of her daughter. Elizabeth created a special shelf that held mementos and photos of her deceased best friend. Furthermore, handwriting was something that participants spoke of as particularly meaningful (Mary and Leigh Ann). These ordinary reminders did not always result in hope; indeed, many people felt the searing pain of their loved one's absence when encountering them, but frequently within those moments of deep sorrow were indicators of slivers of hope.

Four participants—Linda, Elizabeth, Bobo, and Leigh Ann—spoke of conjuring their loved ones as if they were there with them. Linda's ritual of kissing her hands at Shabbat brought her husband's presence into the room, keeping her closely connected to him despite his death. Likewise, Elizabeth's story of her dying best friend visiting her in her bathroom and hearing him speak to her brought her great comfort. Bobo's story of feeling that all of the people she has lost are still with her also exemplifies this value of hope. Leigh Ann's feeling that her ancestors have always been with her was rooted in her Christian faith and her grandmother's wisdom surrounding death and also provided comfort as well as hope in her time of deep loss. These particular moments of presence suggest participants' value of staying connected to loved one(s) after their death.

## **Theoretical Considerations**

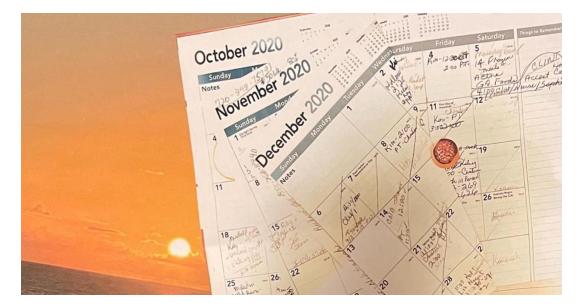
# Affecting and Reflecting Sense-making

One of the main principles associated with the retrospective heuristic of CNSM is that stories have the power to "affect and reflect sense-making and health" (Koenig Kellas, 2018, p. 65). In the present study, I witnessed both of these elements (affecting and reflecting) in participant interviews. I heard in their stories how the process of piecing together their stories affected how they made sense of their grief. Likewise, the content of the stories reflecting participants' sense-making of their grief, complete with lessons and moments of integrating grief into their lives.

Many participants spoke about the helpful nature of completing the photo assignment on making sense of their grief (What is your story of losing someone meaningful to you during the pandemic?). Many noted this process as clarifying and for some, impacting the way they told their stories of grief. Some of them spoke as if they would not have accessed these stories without the photo assignment. Marcella Nicole's experience of taking photos and preparing for the interview exemplified this CNSM principle of affecting grief sense-making. As she drove around town, she looked for opportunities to take photos, which she says helped her think more about what her grief meant to her. One of her photos marked a turning point in her grief, which was discussed in Chapter 3's findings. She was so overwhelmed with her "spiraling" grief that she bought a Wonder Woman costume, complete with a cape and powerful bracelets. She added a frying pan and placed two \$50 bills on top of it, illustrating the super woman who makes money, makes dinner and fights evil. Her plan was to set it on fire and take a photo. But she didn't. It was precisely at that moment that marked a turning point in her grief, the moment that she found her inner strength to keep going, to not let her grief destroy her. When I asked her what she titled her photo, she chose one unlike other titles of photos in this study, complete with repetition, strikeouts and references to Wonder Woman, the Enjoli commercial and Helen Reddy's "I am Woman" song from the 1960s: *I am Woman, Enjoli Woman, Wonder Woman* poignantly demonstrates how the process of telling her story affected the content of her story. This is a perfect example of Koenig Kellas's (2018) concept of stories affecting people's well-being and health.

Other participant stories demonstrated CNSM's principle that stories not only affect sense-making but reflect it. Lisa's photos and story are an excellent illustration of stories reflecting sensemaking. Her photo (Figure 33) shows a paper calendar with October, November, and December of 2020 with scribbles of notes on the days. In the background is an orange sunset above a body of water. In the middle of her calendar is a small image of the COVID virus structure.

# Figure 33



COVID Hits. Attitude is Everything. Silver and Golden Linings by Lisa

Throughout Lisa's story, she speaks of the orange color of this photo as representing the golden and silver linings of her grief. This theme is woven through her recounting losing both her sister as well as her husband during the pandemic. She spoke vehemently about how much gratitude she felt within her time of great loss. She said, "COVID made us all sick, but it also made us all need each other. We had to help each other." Lisa's story was filled with moments of people who took great care of her: hospital workers, friends, family, they all swarmed her with support. She made sense of the loss through gratitude of what she gained. This is an example of how using the lens of CNSM reflects sense-making of storytellers.

Like Lisa, Elizabeth's black and white photo of a tree at night in the winter (see figure 28) is another great example of a story reflecting sense-making. She chooses to take a photo of the tree to reflect her belief that life is full of both beauty and sadness, and

they are intertwined together. She explains that she cannot separate the good and the bad in her story; they are both necessary and encompass the beauty of life.

## **Photos as Catalysts**

Asking participants to take photos to represent their stories of grief created a portal to deeper stories that emerged in interviews, reflecting the power of merging artsbased methods with CNSM. Visual methods like photovoice are particularly suited for distressing topics because they bring "clarity to experiences that may be too difficult to put into words" (Harter, 2016, p. 145). The use of photos in the present study is a positive response to the call that Pangborn and Harter (2020) make for more creative approaches in narrative inquiries:

Fostering storytelling through creative programming is a practice full of possibility. Yet, communication scholars generally gravitate toward spoken or written texts. Sharf urged scholars *to be careful about over-privileging the verbal such that other important sensory contributions are not recognized and credited*. As she suggested, there is much to be discovered in the potential of creative forms of narrative, as they might open dialogue in ways that better reflect the unique experiences of suffering individuals. (p. 3).

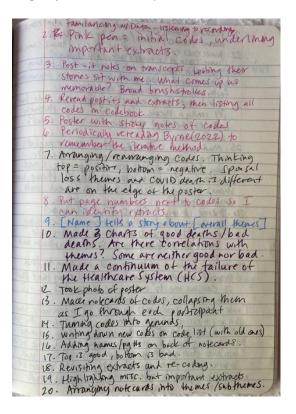
I chose to include elements of photovoice in this study for the reasons stated above, but also because of the way that the process challenges the hierarchical relationship between participant and researcher (Holm, 2018). Sharing photos has become such a common bonding activity with the ubiquity of cell phones which may have facilitated the ease with which many of the participants told their stories.

# **Reflexive Iterative Analysis**

The reason I chose RTA as my method of analysis is because of the "researcher's active role in knowledge production," but also because of its iterative nature (Byrne, 2022, p. 1393). As explained in Chapter 2, I kept two journals—a written as well as a visual—to keep track of the iterative process. I also was advised to keep track of each step in the process, which is illustrated in Figures 34, 35 and 36.

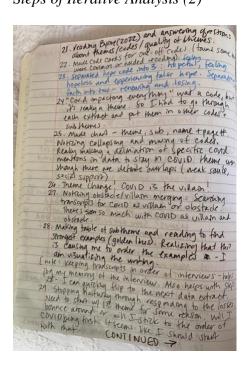
## Figure 34

Steps of Iterative Analysis (1)



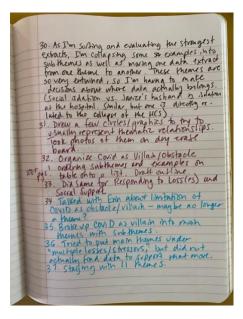
# Figure 35

Steps of Iterative Analysis (2)



## Figure 36

Steps of Iterative Analysis (3)

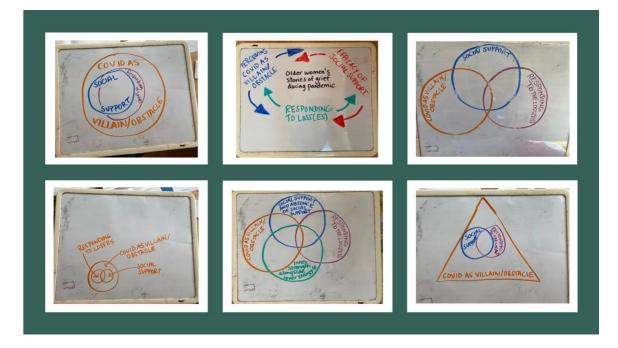


This master list helped me keep track of the twists and turns involved in this iterative method, something that was incredibly helpful during the final write-up. This will also be helpful for me in future studies to remind me of the iterative nature of RTA.

Another helpful addition to the RTA process was using a white board (Figure 37), which helped me think more about the relationship between my themes. Using dry erase markers on a white helped me better understand the relationship between themes. The medium of dry erase markers provided an energetic release where I could play around with the themes without feeling attached to any one image. Later, after drawing on the whiteboard, I realized that the COVID theme presented a limitation in my study. In my interview protocol, I directly asked participants to name the villain and obstacle in their stories which meant that this theme did not emerge like the others. This turned one big theme (COVID as villain/obstacle) into several smaller themes, resulting in 11 main themes. Although my themes ended up in a different direction, I share my process here to demonstrate the benefits of adding white board drawings to RTA.

# Figure 37

Iterations of Theme Structures (May 2023)



The top center model reflects my last iteration. What is notable about this image is the arrows that indicate the impact that each theme had on each other. This is something that I notice even with the final 11 themes. While it's important to separate each theme, it's also important to note that they impact one another in many ways. For instance, there was often a relationship to how participants responded to their loss(es) based on their treatment from the healthcare system.

#### **Support of Previous Research**

This study's findings support much of the previous research regarding COVID impacts. The following section explains how the themes in this study mirror the research outlined in Chapter 1. The following categories of research were present in this study and

are explained below: social isolation, bad deaths, multiple traumas, delayed responses, lack of closure and fear of the virus.

Previous research indicated that social isolation contributes to an increase in depression and anxiety (Pera, 2020). This fact was reflected in this study throughout women's stories within the theme of social isolation. In this theme, women's stories told of psychological symptoms such as insomnia, nightmares, and emotional overwhelm. The literature on the extreme social isolation in nursing homes during the pandemic was also present in this study, with one participant's mother suffering alone in her assisted living facility as well as another participant feeling isolated in a rehabilitation center following an accident (Barnett & Grabowski, 2020). Research on the negative impacts of lack of human contact (Frieden, 2020) also came up frequently in the present study with women's stories reflecting their value of even the smallest of social interactions during the pandemic.

Research that indicated a negative impact at the moment of death (Young et al., 2020; Wakam et al., 2020) was also reflected in this study through women's stories of communicating on an iPad and having very little communication with their ailing loved ones at the time of death. Women's stories indicated many examples of "bad deaths," characterized by difficulty and lack of loved ones (Krikorian et al., 2020). Participants whose loved ones experienced a bad death reflected the research that indicated their negative impacts on the bereaved (Carr et al., 2020; Verderi et al., 2020). People not getting the bereavement care they needed was also reflected in many participant stories

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(Stone, 2021). Additionally, the theme of failing healthcare system reflects the overwhelm of the hospitals, clinics, and other facilities (Myers & Liu, 2022).

Previous research indicating the increase in multiple traumas (Silver et al., 2020) was also present in this study, as many participant stories mentioned multiple losses and stressors, which became a theme of the same name. The disruption of social support systems spurred on by the pandemic (cancelled gatherings, stay-at-home orders) were also present in the majority of women's stories, reflecting Murphy's (2020) research that indicated participants expressed as experiencing a "void of support" when they needed it most (p. 246).

The women in this study also felt the negative impact of the federal government's delayed response to grief (Global Strategy Group, 2020), illustrated in stories of anger at the president and the system that devalues older adults (Ng et al., 2021). The delay demonstrated by the government mirrored individual participant experiences having to wait to host memorial services and gatherings. The impact of this delay was indicated in participant stories of wishing for closure and desire to feel the presence of their loved ones—a common theme in this study. A lack of a goodbye puts grievers at a disadvantage in their bereavement process and places them at risk for mental health complications (Goveias & Shear, 2020; Mayland et al., 2020; Murphy, 2020; Testoni et al., 2021). This was reflected in participant stories of not being there when their loved one was dying; it was also present when participants spoke of not having information about the cause of death because they were not there to ask or gain information (Testoni et al., 2021). The negative impact on participants reflects the research through stories of sorrow of

disconnection around the time of death (Mayland et al., 2020; Goveias & Shear, 2020; Testoni et al., 2021; Murphy, 2020).

Additionally, the common theme of fear of virus reflects Katz et al.'s (2020) research indicated the emergence of an increase in the worrying around health and safety during the pandemic. Many stories included moments of anxiety-ridden risk assessment as they decided whether or not to leave their homes.

#### Strengths of the Study

In this section, I outline the strengths of this study and its contribution to the field of communication studies. I first explain the nuances and depth of individual stories that this method produced and its particular usefulness for studies of sensitive topics. Then I explain how adding photography to the CNSM's retrospective approach expands the power of understanding participant values and beliefs. I also explain how participants themselves reported appreciation for the study. Finally, I explain how this study expands the work of previous CNSM and visual narrative studies.

The first strength of this study was the nuance and depth reflected in the stories and photographs. As outlined in Chapter 1, many studies have successfully used CNSM's retrospective heuristic to illuminate experiences surrounding illness, bereavement and loss (Barney & Yoshimura, 2021; Taladay, 2021; Gunning, 2021; Cooper, 2021; Flood-Grady & Koenig Kellas, 2019). This study expanded the use of the retrospective heuristic by adding photos to the participant process, thereby deepening the understanding of grief and loss during the pandemic. Another strength of this study is the emotional impact of including photographs with data examples from interviews. Although the photos themselves were not analyzed for themes, their presence along with examples from interviews brought to life the stories of these women in ways that went beyond words. The moment Janice shared the photos of potatoes in the oven moved her to tears. Her reaction was something reminiscent of Barthes' (1981) "punctum," which describes being moved emotionally by a photo. It's the moment when you see something in a photograph, "that accident which pricks me (but also bruises me, is poignant to me)" (Barthes, 1981, p. 27). In sum, adding photographs to the stories of participants takes CNSM's retrospective approach beyond just words, expanding the power of this heuristic in communication studies.

Another strength of this study its benefit to participants. The cathartic nature of this creative project helped participants express themselves in a safe environment through photographs and stories. At first, I thought that asking so much of participants would be burdensome given their grief experiences. For instance, the orientation session was akin to a mini photography class, complete with a short lesson on composition and homework assignment. To be sure, some participants were initially a bit skeptical of being able to produce appropriate photographs. However, after teaching them basic composition skills and showing them examples of my own photos, participants approached the study with enthusiasm and curiosity. Some participants went as far as creating an extensive portfolio of photos and writing. The project moved Mary to write a poem about her grief, which she shared with me in her interview.

Many participants spoke of how they tried to keep themselves busy as a way to cope with their grief. This study provided them a creative outlet to *do something* with their grief, to put it to use in some way. This aligns with research indicates that storytelling is particularly useful in communication of illness and death because it helps participants synthesize the "wreckage" of the experiences (Frank, 2014). This approach also aligns with concept that narrative aids in the "understanding and managing [of] the powerful effects of loss" (Bosticco & Thompson, 2005, p. 409). For many participants, taking the photos and being interviewed helped them better understand themselves and their grief.

#### Limitations of Study and Recommendations for the Future

This study was effective in illuminating the individual experiences and values of its participants; however, it also has its limitations, which I address in the present section. Within each limitation, I propose a recommendation for future studies along with practical applications that could help those who work with this particular population. **Preparation** 

A study of this kind includes extensive preparation of participants, requiring them to attend a 30-minute orientation session as well as complete a photo assignment along with a 1–2 hour interview. My own background consists of facilitating an intergenerational community program, which provided me the connections and experience in teaching and facilitating with older adults, something that was crucial in the success of this study. Furthermore, the amount of administrative work this places on the researcher can be burdensome with keeping track of participants and the substantial

amount of scheduling and communication involved. This is a lot to ask of both researcher and participants, so it's important that the researcher has experience working with older adults. Future research should understand the preparation involved and include community partners to help with recruitment and facilitation whenever possible.

## **Demographics**

The first limitation of this study is its demographics. The vast majority of the participants identified as White (90%) and Christian (44%), which does not account for participants of color and of other religions. My own identity as a White woman who was raised in a semi-Christian household was an advantage in that participants may have been more likely to trust me since we share similar backgrounds. However, my background poses a limitation in that I likely missed other themes that indicated the influence of Christianity and Whiteness in the themes that emerged. Future studies should aim for a more diverse group of participants in order to widen the understanding of older women beyond White Christians.

Whiteness also revealed another important limitation to this study surrounding social unrest, which was present throughout the pandemic, especially during the summer of 2020, when people protested in the streets following the murders of Brionna Taylor and George Floyd (Taylor, 2021). Research indicated the negative impact that social unrest has had on the wellbeing of older women, especially those who identify as Black and Asian (Ni et al., 2020). However, in this study, social unrest emerged briefly, but only within the theme of political divide. There was very little mention of racially motivated violence in the stories, something that dominated the social landscape during

2020 in particular. Race was mentioned once by a participant who identified as atheist, referring to hateful political rallies that spoke about violence against Jews and Black people. It is important to contextualize these findings with race and ethnicity in mind.

In addition to the participants mostly sharing the same identity, a majority of participants were located in the metro Denver area, with 15% of participants living out of state. The limitation of this study is due to governmental responses to the pandemic that varied state by state. Likewise, focusing on one geographic area would help to better understand how different locations can impact people's grief experiences, given the impact that geography can have on people's experiences, particularly if that location is impacted by disastrous weather events or mass shootings.

Furthermore, this study places all women 65 and older into one category, which conflicts with the research that shows distinct stages of older age (Cohen, 2005). Cohen identifies four stages of aging with specific motivations and values at each stage. For example, Cohen (2005) marks people in their mid-fifties through mid-seventies as Phase II of older age, a time of "liberation, experimentation, and innovation" (p. 52). This is much different from Cohen's (2005) Phase IV, occurring in the mid-seventies through the end of life which is a time of "inner push for reflection and a desire for continuation and celebration" (p. 53). Given that women ranged from age 65 to 86, this clearly poses another limitation of this study.

Near the end of the analysis, I hosted a member reflections meeting for participants in order to share the findings of the study as well as give the participants an opportunity to add more details or ask questions about the study (Tracy, 2020). During this group meeting, one member said that she did not relate to the theme of social isolation as she was surrounded by friends and family throughout the pandemic. After the meeting, she emailed me more of her thoughts, suggesting that her Buddhism and Japanese roots likely informed her response. Future studies should take note of participant backgrounds and examine the relationship between themes and cultural backgrounds.

Another limitation is the absence of political affiliation in the demographics survey. Future studies of this type would also be strengthened by including a political identity question in order to better understand how the political landscape impacts values and belief systems. Given that two main themes were interpersonal conflict and political divide, it would have been helpful to understand how participants described their political identities. The theme of political divide indicated how much people's beliefs impacted their grief, and knowing where people landed in terms of politics could enlighten how their beliefs impacted their sense-making.

Another limitation stems from the month and year of the death(s) of participants' loved ones. The dynamic nature of the pandemic led to where things changing dramatically from month to month also posed a limitation of this study in that someone whose loved one died during the 2020 lockdown is much different than during the summer of 2021, when vaccines were widely available. Future studies should take timing into account when examining grief and loss, especially those focused on pandemic grief.

The relationship that the participant had with their deceased loved one(s) also poses a limitation in this study. The experience of spousal loss is not the same as losing a best friend, for example. Likewise, the cause of death of the loved also poses another limitation in this study. Some people experienced a great deal of betrayal at the time of their loved one's death, which makes their experiences much different than those who were at their loved one's bedside, for example. Additionally, the loss of a loved one due to COVID was also a much different context than other causes, due to the safety mandates and political climate surrounding exposure to the virus. It would be helpful in future studies to examine specific relationships in grief studies such as one just on spousal loss. Studying grief that focuses on one particular cause of death would also strengthen the research.

Methodologically, this study used both online and in-person communication, which also poses a limitation. The experience of a storytelling interview on Zoom, for instance, did not allow for the power of in-person communication. Participants who came to the library for their interview were offered a bottle of water and chocolates along with tissues, which the Zoom participants did not have. Additionally, participants in person had printed out photos to touch and arrange. Zoom participants instructed me on which photos to share on the screen, which were very different experiences. This difference may have impacted the quality and depth of interview data from participants. Future studies should take into consideration the location and mode of the interview when designing the method.

## **Practical Applications and Future Directions**

#### **Reflexive Thematic Analysis**

Conducting this study using RTA furthered my commitment to including my positionality and identity as part of the research process. Byrne (2021) states that the reflexive approach "highlights the researcher's active role in knowledge production" (p. 1393), something I found important to my process of identifying emerging themes. Being reflexive as a researcher means avoiding the idea of "accurate" or "reliable" coding and instead focusing on "the researchers' reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process" (Braun & Clarke, 2019, as cited in Byrne, 2021). The use of my written and visual journals were foundational to my process as a researcher. I found many takeaways from both of these reflexive exercises that I outline below.

#### The Geography of Data

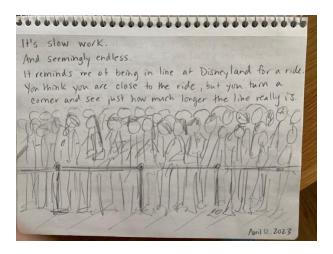
Without consistently writing in my journal, I likely would have forgotten key moments in my process that facilitated my analysis. In the entry below, I write about how much I appreciated being able to touch the pages of my data and its importance to my process:

I am taking a break to note how important physical touch and data geography has been. I have the transcripts (somewhat) in order, and I am flipping through them as I discern which extracts will make it into the dissertation. I'm noticing how important it is for my memory to literally flip through the pages and reread the data. I'm catching mistakes or nuances of the data as I go—a code that was early and should've been recoded or collapsed—I am catching these. It's taking a while to do this, but I can feel myself memorizing names, data and examples in subthemes. It's all around me—I'm swimming in it. (Journal entry, March 28, 2023)

The work was slow and required meticulous attention on my part. At times, I longed for a research assistant to help me with the work. It took a long time to go through each stage of interviewing, cleaning up the transcripts, coding, and re-coding. I noted this experience in in my visual journal (Figure 38).

# Figure 38

Visual Journal, 4-12-23: Attachments, Trust and Boundaries



However, I was quickly able to get a return on my investment of time by really knowing my data. My intimacy with the data meant was incredibly helpful as I pieced together codes and developed them into themes (Tracy, 2020). Another consequence of immersion in the data is that I became very attached to the participants. My attachment to them was a strength in that I felt protective of their stories and felt compelled to produce a thorough report of my findings. I didn't want to cut any corners because I really cared about the women in the study. My attachment also indicated the risk of my own vulnerability, potentially negatively impacting the process. For instance, near the end of my interviews, I wrote in my journal about feeling a need to please one particular participant:

I want to write about how protective I feel about my participants. I had already decided when my last interview would be because I feel like I have theoretical saturation. I also knew that it was time to stop interviewing because of my stamina. I've been interviewing people for four months off and on. I could feel my energy waning in these last few, and I did not want to bring that lack of energy to more interviews. However, due to my fear of upsetting my participant who gave me the name of a friend who wanted to participate, I didn't tell her that I was done [with interviews]. I feared upsetting her. I also briefly considered interviewing one more person as something I could do for her friend, given how helpful the process has been [for other participants' grief]. But then, about an hour after I ended the interview, I realized that I'm not doing anyone any favors by adding one more interview. I won't bring my full self to it (due to my waning energy) and that could cause harm. So I emailed my participant that I would not be able to include her friend after all. And I worry about how that might upset her—and her friend. I regret not saying something in the moment, but I do not regret setting a healthy boundary. (Journal entry, March 11, 2023).

This study taught me how important it is to build trust with participants. I have also learned an important lesson about setting protective boundaries around myself as a researcher. As I explained in Chapter 3, I was the victim of fraud during the early phase of recruitment, something that I did not expect in this study. The IRB did not expect it either. In one of my conversations with my IRB contact, we discussed how quickly technology has advanced which is making it easier for people to defraud researchers. In future studies, I will make sure that I am protective of my participants but also protective of myself.

## **CNSM's Interactional and Translational Heuristics**

The use of CNSM's retrospective heuristic was highly effective in this study identifying common themes of women's experiences during the pandemic. Future work on older women's experiences could also be analyzed using the other CNSM frameworks of both interactional and translational approaches as well. In review, studies using the interactional heuristic focus on the "communicative processes that characterize storytelling" (Koenig Kellas, 2018, p. 66). In other words, it connects the process of joint storytelling its connection to well-being (Koenig Kellas, 2018). The CNSM translational approach focuses on the impacts of interventions that include storytelling in order to predict "health and wellbeing among participants across a variety of contexts" (Koenig Kellas, 2018, p. 67).

Future interactional studies and translational studies could also include photography as an added element to the research process. Family members could work together to choose photos that tell their collective story of grief, for example. Examinations of family members "engagement, negotiation, turn-taking, perspectivetaking and mutual interpretations" could further illuminate family dynamics and wellbeing (Koenig Kellas, 2018, p. 66). Likewise, including photo-taking as part of a storytelling intervention could offer new insights on how adding a visual element impacts grievers' sense-making and overall wellbeing.

Additionally, future CNSM studies should expand the photovoice element to include dialogues and conversations about stories and photographs. Ideally, it is in person and includes community partners to aid in accommodating this population. Adding more photographic instruction to future studies gives participants the chance to grow their creative skills, something that has been proven to be highly beneficial for wellbeing and health (Magsamen & Ross, 2023).

#### **Practical Applications and Recommendations**

Throughout the process, many participants said they wanted to be able to see the other photos and hear the stories of the other women interviewed. They were clearly interested in the results of this project with more than half of them attending the member reflections meeting. In this meeting, participants indicated an interest in a study of older men's grief. One participant stated that she noticed a big difference in how men approach grief as opposed to women. A similar study on men's stories of loss would further expand our understanding of how gender impacts and determines grief experiences of older adults.

The fact that these women were so invested has prompted me to imagine a more extensive photovoice study, one where the participants are more involved in the research process. Including their voices throughout the process—in groups as well as in individual interviews would expand the scope of this work. It would also provide a community of support for participants through the sharing of their stories and photographs. All of this has prompted me to consider a public exhibit of this work. This would allow the women to see their stories on display. It would also allow important stakeholders to gain a better understanding of the overlapping issues surrounding aging, gender, the pandemic, and grief in general. A traveling exhibit of the photos and excerpts would expand the impact of the findings of this study to reach audiences such as grief support nonprofits, retirement communities, rehabilitation centers, hospitals as well as community centers, libraries, and museums. Another potential project stemming from this work is to conduct a formal visual analysis on the photos, something that could offer even a broader understanding of these women's experiences. Furthermore, a study that focused on grief responses of older men would provide an interesting comparison to the themes in the present study given the influence of gender on expressions of grief (Jones et al., 2019). Future studies should examine how various identities such as gender and sexual identity impact on the grief experiences of older adults.

This study offered an up close look at the experiences of loss in older age. As a mother of three children (now adults), I am reminded of the care taken by their pediatricians during well-care visits. Each time we arrived at the clinic, the doctor would hand me resources on what to expect for my child's age. This concept of paying attention to common experiences during childhood is missing in adulthood, especially that of older ages (50 and older).

Professionals who serve older adult women as well as family members should be aware of the presence of grief at this life stage, understanding the needs of older women. They likely are in need of social interactions and grace as they make sense of their losses. Younger generations should understand that the grief process is highly personal and based on contexts that are unique to the individual. Just because older women attend more funerals does not always mean it gets easier. Encouraging meaningful social connections and expecting a wide range of responses in grief is also recommended.

I recommend that there be a more systemic structure for stages of adulthood that guide the health and wellbeing of older adults, with the understanding that these are broad guidelines that should be viewed holistically (Cohen, 2005). People in service roles should expect that an 80-year-old woman has likely suffered many loss(es), perhaps quite recently. The number of losses and the intensity of those losses should be taken into consideration through a simple but powerful question: "Have you lost someone meaningful to you recently?"

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This spring, I've been so lucky to spend more time with Mom. She drove all the way to St. Paul, Minnesota to watch my daughter graduate from college. Then, 10 days later, she flew to Denver to watch my son graduate from high school. Her physical health defies her 87 years; she still regularly beats me in tennis. She continues playing bridge and has an active social life. But many of her longtime friends have moved away as they reach the end of their lives. One of Mom's friends is losing her memory, which makes it a struggle for her to socialize. Her friend has decided she can no longer live on her own and is moving to where her sister lives, about 90 miles away from Mom. "She's moving there to die," Mom said, "She wants to be near her sister."

Another friend of Mom's was found unresponsive in the garage of her home by her housekeeper this past spring. Also in her late eighties, she suffered a massive stroke and fell to the floor. Her body temperature had plunged into the 80-degree range by the time the paramedics came. After she was discovered, the paramedics found her husband on the floor inside the house. He, too, had fallen. Her husband died in April. Just this week, Mom took one friend to visit another in the hospital. She described how difficult it was to be sitting with two of her oldest friends, both of whom struggled to speak in their old age.

Mom friends' health struggles and deaths haunt her. At times, she's talked about wanting to end her life. The thought of her being left alone on the floor for days terrifies her. It scares me, too. We've talked about getting her a necklace with a 9-1-1 button. We also talked about getting her an Apple watch which can detect heart attacks and falls. But neither seems like a perfect solution. Instead, Mom and a friend who also lives alone agreed to text each other every morning. If they don't hear from each other, then they know to send out for help. Just in case.

For the majority of this study, I have been focused on Mom's story: she suffered grief before the pandemic, during the pandemic, and now after the pandemic. It was her experience of grief that inspired me to dig in to the research. Subconsciously, I think I was trying to redeem all of her losses through this work. Perhaps if I have something important to say in my findings, it will make her feel better about all that she's lost. But as I approach the end of this study, I realize that underneath Mom's story of grief is mine. I am just beginning to address my own grief, grief that I have not been able to access before this study.

Two of my children graduating this spring was much more difficult than I imagined it would be. I wondered why this natural stage of letting go was so hard for me. I can see now that their growing up is unearthing painful memories of my own upbringing and the events that have led to yearslong estrangements with my sisters, something that has caused me great suffering. The impact of the hours and hours I spent immersed in the photos and stories of grief is immeasurable. I have learned that there are some losses that have no redemption and offer no meaning. I have also learned that some losses lead to a deeper appreciation of the beauty of life. But the lesson I learned the most in this project is this: The only thing that matters is people. Nothing is more important than relationships. Connection is everything.

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# Appendices

# **APPENDIX A: RECRUITMENT FLYER**

Seeking Women (Age 65+) for Research Study about Grief and Loss During COVID-19

The purpose of this study is to understand women's experiences of grief and loss during the pandemic through a research method that includes photography and storytelling.

In order to take part in the study, participants must:

- identify as a woman aged 65 or older who resides in the United States.
- have experienced the death of a spouse, family member, friend, and/or other person meaningful to them between March 15, 2020 today. The death could be due to COVID-19 or any other cause, but participants should feel as though the pandemic impacted their experience of grief and loss in some way.
- have a smartphone or digital camera that can take and send digital photos.
- speak English.
- complete a 5-10 minute online questionnaire.
- attend one 45-minute group or individual orientation session in person or online.
- take photos on their own within a 2-week time period.
- participate in a 1-2 hour interview in person or online during a convenient time of their choosing.

# NO PHOTOGRAPHY SKILLS NECESSARY TO PARTICIPATE!

Compensation will be available to eligible participants.

## Interested? Email <u>anne.walker174@du.edu</u> for more information.

Principal Investigator: Anne Walker, M.Ed. <u>anne.walker174@du.edu</u> Faculty Advisor: Erin Willer, Ph.D. <u>erin.willer@du.edu</u>

This project helps fulfill Anne Walker's Ph.D. Communication Studies dissertation requirements.



#### **APPENDIX B: PARTICIPANT EMAIL**

Dear [insert name],

Thank you for your interest in participating in my study on older women and grief during COVID-19. This study asks you to take photographs that tell the story of your grief in three ways: participate in an orientation session, take and choose photos, and participate in an interview.

Note that this study will ask you to share stories and take photos that represent your loss experiences during COVID-19. Participants must have lost to death a spouse, family member, friend, and/or other person important to them who died of any cause during the COVID-19 pandemic from March 15, 2020- [date to be determined]. They must also identify as female, be aged 65 or older and be able to operate a smart phone or digital camera that takes and sends digital photos.

If you would like to be considered as a potential participant in this study, please email me the following information:

Your first and last name:

Your phone number:

I will be hosting a required orientation session on [date 1] and [date 2]. Please let me know which date you are able to attend. Let me know if neither date works for you.

In order to participate in the study, I will need you to complete the informed consent form and short demographic survey found here: [insert link]. Your participation code will be: [insert code]. Please use this code when prompted on the survey. Please feel free to email me your questions.

Sincerely,

Anne Walker, M.Ed.

Doctoral Candidate

University of Denver, Department of Communication Studies

#### **APPENDIX C: ORIENTATION AGENDA AND SCRIPT**

#### Agenda:

- 1. Informed consent forms and demographic surveys
- 2. Brief introduction activity and intentions
- 3. Purpose of the study and researcher's journey
- 4. Overview of process
- 5. Specific expectations of participants
- 6. Tips for photo-taking
- 7. Questions and closing

## **Orientation Script**

Thank you all for coming to the orientation session. My intentions for our time together are for us to get to know one another and for you to understand what's expected as a participant in this study.

At this time, I would like to review the consent form that you all signed online before coming. You can stop participating at any time or decline answering any question at any time. There are risks to participating in that it may stir up painful feelings. The benefits of participating are that you may feel better after sharing your story and taking photos. I'm going to hand out a list of grief services (Appendix I) if you feel like you need support.

I want to start by saying how much I appreciate you opening up yourself to what I can imagine has been (and continues to be) a very difficult time for you. I want to share

with you how I decided to research this topic so that you understand who I am as a researcher.

In the winter of 2021, I took a women's health course, which taught me how to conduct arts-based research. One of the assignments was to draw a comic strip that related to women's health. At that time, I had read many stories of loved ones with COVID-19, saying their final goodbyes on FaceTime as it was unsafe to be physically close to one another. I also thought of my mother, who is a widow; I thought of how hard it was for her and how much harder it would have been had my father died during COVID-19. With that on my mind, I made this comic strip, which was the beginning of what is now my dissertation study. I understood how powerful images can be as a way to tell a story of grief and loss. I briefly considered using drawings from participants (since I love drawing), however, I chose photography because it is also a visual representation, but much more accessible and easily shareable. I also took a class on photovoice (a research method), which showed how well this method works for a study like mine.



Now that you have an idea of how this all began, I am going to share with you what you'll be doing as a participant. There are 3 stages in this study that I will explain today, giving examples from my own experience.

The first stage is the Orientation stage—today's session! After today, you will understand the purpose of the study and what you'll be doing. You will understand the difference between a beautiful photograph and the best photograph—the one that answers our research question. This is a time to test out your cell phone or digital camera, understand some tips on how to photograph and discuss the ethics of research photography. Today's agenda will prepare you on your participation in this study.

The second stage is Storytelling Through Photos. This research process is called a photovoice study. It all began when photographer Wendy Ewald handed cameras to children in the 70s and 80s. Suddenly the insiders photographed their world, and it is now becoming an interesting new arts-based research method that asks participants to answer research questions through photos. It broadens the concept of research methodology through visual expression. It also amplifies the voices of the participants.

This part is where you take photographs in response to the prompt: Take 10–15 photos that represent your story of the loss(es) of your loved one during the pandemic. Let's look at the handout (see Appendix E) together. Before you take your photos, I want you to consider elements of a story by asking yourself these questions:

- Who are the main character(s) in your story?
- What places and spaces (settings) represent the story of your loss?
- What kind(s) of conflict(s) did you experience in the loss of your loved ones?

Are there any turning points in your story? What image(s) might represent this moment?

You will notice that there are other prompts on the handout; you do not have to answer all of these questions; they are there to help you think before you take pictures.

After you have taken lots of photos, you get to choose your top 5-6 photographs. Take a look at the photos I took for my class last year on the story of being caregiver during COVID-19. Which ones best answer the question? I needed to choose the photos that best answered the question. I chose Barely Holding Up because it seemed to answer the question the best. Can you see the difference?

Once you have your 5–6 photos, you will need to send them to me. (anne.walker197@du.edu, 303-810-4710). How many people know how to send photos via email? Text? Let's practice by taking a selfie and sending it to me. That way I will know you know how to do this.

The third stage is a one-on-one Storytelling Interview with me. We did not have this stage in my class, so let me explain. We will begin with you arranging your photos in the order that makes sense to you, telling your story from beginning to end, focusing on details and specifics through your photos. I'd like you to think about the story elements as you tell your story. Avoid being general—"I felt sad" and instead zoom in on a specific moment—who was there, what you said, what the room/space was like, etc. I will ask you follow-up questions once you are finished in case there are parts that I'd like to know more about. After you share your photos, I will ask you follow up questions. These interviews will be recorded for analysis and no one except my dissertation advisor (Erin Willer) will have access to them.

Are there any questions before we move on?

It might help for me to show you what I did in my photovoice methods course in the spring of 2021, these were the prompts that I was to respond to. Here are some photos I took in response to our research on how the pandemic transformed us as caregivers [Fenced In, Blurry, Not Enough, Barely Holding Up]. I won't read the entire caption, but you can see why I took each of these based on the question I was given: *What is your story of being a caregiver during COVID-19*? I urge you to think more metaphorically about the question like I did with this photo of the fence falling down, representing my exhaustion as a caregiver in the pandemic.

Now that you've seen how this works, I would like to spend a few minutes talking about some tricks I've learned about photography. Here are a few tips that I'm going to go over that should give you a little bit of guidance as you approach your assignment. Try different angles and perspectives. Play with your camera and take lots of shots. You can take as many as you like but take at least 10–15 so that you have a lot to choose from for your 5–6 photos.

Remember the ethics surrounding taking photos of people. If you'd like to include a person in your photo, you will need to have them sign a release that gives us permission to use their likeness in this research (see Appendix E). I have copies of these waivers for you to take today in case that's something you would like to do. I chose not to include people so that I didn't have to worry about consent; it also allowed me to really think about the essence and quality of my experiences instead of being literal.

Finally, I would like you to think about your story of grief and loss with narrative elements in mind. You might like to jot down ideas to yourself, as I read these questions out loud:

- What settings are significant in your story?
- Who are the main characters in your story of grief during the pandemic?
- What or who caused conflict in your story?
- Was there a turning point in your story or a lesson learned?

## APPENDIX D: PHOTOVOICE CONSENT AND RELEASE FORM

I consent to the use of my image and likeness, as depicted in any photograph by \_\_\_\_\_\_ (photographer) for their purposes, including sharing the image in a published study, conference presentations, and in college classrooms. I understand that the purpose of the photos is to examine the stories of older women's grief experiences during the pandemic.

I give my permission for	(photographer) to use my image or
likeness. My name will not be attached to my image	or likeness in any way (e.g., tagging,
in captions).	
Name (print):	
Date:	
Signature:	
Address:	
City:State:Zip:	_
Phone Number:	
Please contact the principal investigator with	questions or concerns:
Anne Walker	
Doctoral Student	
Department of Communication Studies	
University of Denver	
Sturm Hall	

2000 E. Asbury Ave.

Denver, CO 80208

### **APPENDIX E: PARTICIPANT HANDOUT**

Making Sense of Loss: Photovoice Stories of Older Women's COVID-19 Grief<sup>4</sup> **Purpose of Study:** To examine the unique experiences of older women's grief during the pandemic through photography and storytelling.

Participant Assignment: Explore your world (your house, your neighborhood,

community, etc.) and take 10-15 photos that represent your story of the loss(es) of your

loved one during the pandemic. Choose 5-6 of your best photos and email or text to me

at anne.walker174@du.edu or 303-810-4710.

### **Before Taking Photos: Prompts**

Use these prompts to think about the kinds of pictures you'd like to take.

- Who are the main character(s) in your story?
- What places and spaces (settings) represent the story of your loss?
- What kind(s) of conflict(s) did you experience in the loss of your loved ones?
- Who is the hero in your story of loss?
- Who is the villain?
- Are there any objects that have become symbols of your loved one(s)?
- Are there any turning points in your story? What image(s) might represent this moment?
- What does it feel like to have lost a loved one during the pandemic?
- What obstacles did you face losing your loved one during the pandemic?

<sup>&</sup>lt;sup>4</sup> This handout is adapted from Willer's (2016) Scraps of the Heart Project Creative HeARTs Workshop Final Project handout.

- How has this loss impacted your life?
- What parts of the pandemic impacted your grief?

## **Taking Your Photos**

- If you choose to include people (or likenesses) in your photos (including their faces or parts of their bodies such as hands or personal possessions), they need to sign the Photovoice Consent and Release form. I cannot include images of people or their likeness without the release.
- A smartphone or digital camera is best for this study because they create high quality images. If you find that your camera is not creating good images, please reach out to me and I will get you something you can use.
- Take a few photos everyday instead of taking them all at once. This gives you time to consider each photo and you won't feel rushed.
- Please remember that the best photos aren't always the most aesthetically pleasing ones. The best photos are the ones that answer the prompt: *take photos that represent your story of the loss(es) of your loved one during the pandemic.*

Sending Your Photos

- Send me your 5–6 photos via email or text (<u>anne.walker174@du.edu</u> or 303-810-4710) by [insert date 2 weeks from orientation].
- When sending, you may be prompted to choose a photo size; always choose the largest size (highest quality).
- If you text me your photos, please include your name along with your photos.

Scheduling Your Storytelling Interview

Once I receive your photos, I will email you to schedule your 1-hour storytelling interview where you will tell the story of the loss of your loved one through your 5-6 photos. You do not have to bring them with you; I will have them ready for you at the interview.

Questions? Contact me at <u>anne.walker174@du.edu</u> or 303-810-4710

## **APPENDIX F: PARTICIPANT DEMOGRAPHIC SURVEY QUESTIONS**

Participant age:

Ethnicities (check all that apply):

- □ White
- □ Hispanic or Latino
- □ Black or African American
- □ American Indian or Alaska Native
- $\Box$  Asian
- □ Native Hawaiian or Other Pacific Islander
- □ [write-in option]

How many people have you lost through death since March of 2020?

For each person lost:

Date of deceased's death (month, day, year):

Age of deceased (years):

Participant's relationship to deceased (close friend, wife, mother, sister, etc.):

Cause of death (if known):

Indicate your agreement with the statement below:

The COVID-19 pandemic significantly impacted my grief and loss experience when this

person (or persons) died.

Strongly Disagree

Disagree

Neither Agree nor Disagree

Agree

Strongly Agree

#### **APPENDIX G: STORYTELLING INTERVIEW SCRIPT**

Hello and welcome. How are you? Would you like something to drink/eat?

Before we begin, let's review the consent form you signed. Remember that you can stop participating at any point in this study and that you can decline to answer any questions at any time.

Remember that the purpose of this study is to examine older women's stories of grief during the pandemic through photographs.

I will also be recording this interview with your permission. I may also take handwritten notes in case I want to ask questions about something you said so that I don't forget.

Do you have any questions before we begin?

Do you give me permission to record?

Like we talked about in orientation, this interview is focused on you telling your story of losing your loved one during the pandemic through your photos. Remember that a story usually has a plot, characters and some kind of resolution. So instead of speaking in general about your experiences, I want you to arrange your photos from the beginning (wherever that is for you) all the way to today, where you are now, with the understanding that grief never ends.

Let's start by looking at your photos. You can decide which one to start with. Take your time and arrange them in order. [For each photo] What title would you give for this photo? [After participant has told their story, I will choose from the following list of questions to clarify her story]:

- Who would you say are the most meaningful characters in your story and why?
- Does your story have any heroes or villains?
- Who or what was the greatest obstacle in your story? Who or what helped at that time?
- Were there any physical environments or settings that were important in your story? How so?
- Were there any turning points in your story?
- Are there any lessons that come from your story?
- (If there are any photos whose meaning was not clear from the storytelling), can you tell me more about why you chose to take this picture?
- Looking at your photos, what would be a caption for each one?
- If you had to choose one photo and one caption for the title and cover page of your story, what would it be and why?
- If your photos were included in an exhibit about COVID-19 related loss, what would you want visitors to know about your story?
- Is there anything else you want to share about your story?
- Is there one photo that captures your entire story? Why or how so?

Before we end, is there anything you wished people knew about your experience that you haven't shared already? What question did I not ask that you think I should have asked? (Tracy, 2020, p. 169).

Thank you. I really appreciate your generosity in sharing your story with me today. I know that sharing your experiences of loss can be difficult and it is understandable if you are feeling down or sad after our time. I have a copy of that list of grief support services from orientation if you'd like to take a copy with you (Appendix I).

#### **APPENDIX H: INFORMED CONSENT FORM**

Informed Consent Form

Study on Older Women's Pandemic Grief

Dear Participants:

My name is Anne Walker and I am currently a Ph.D. student at the University of Denver in the Department of Communication Studies. Under the direction of my advisor, Dr. Erin Willer, I am doing a research study for my doctoral dissertation that is aimed at discovering the stories of older women's pandemic grief.

You are invited to participate in this research study. The following information is provided in order to help you to make an informed decision whether or not you would like to participate. If you have any questions, please do not hesitate to contact me or Dr. Willer.

- The purpose of this study is to illuminate the stories of older women and their grief during the pandemic through narrative and photovoice. If you are 65 or older and have lost a loved one during the pandemic (March 15, 2020 to present day), if you identify as a woman, and you believe that your grief and loss were significantly impacted by the pandemic, you are eligible to participate in this study.
- Your identity will remain anonymous throughout the study. I will instead assign a pseudonym for you and your loved ones to keep track of participant data.

- This study will take place at a mutually agreed-upon private location. Zoom is available if in-person interviews are not feasible. The audio and video recorded storytelling interview will take approximately 2 hours.
- In relation to risks associated with this research, there is a risk that you may encounter painful feelings when you discuss your grief and loss. You will not have to talk about anything that you do not want to and you can end your participation in the study at any time. I will provide a list of grief support resources for you at orientation as well as during the interview portion of the study.
- Your answers in the storytelling interview, the audio and video recordings of the interviews and your photographs will be kept confidential by me and other researchers who may help me analyze the data from the study. All data will be kept on a password-protected computer for five years and then will be deleted. No one besides me or the other researchers who may help me analyze the data will have access to the recordings or photographs. I may publish a summary of the study or present the findings at a conference, but I will keep your name confidential. Participating in the study could be beneficial to you because it gives you the chance to make sense of a difficult time. Narrative research has shown positive impacts on telling stories about stressful times by making sense of their grief.

- Finally, participating in this study will give you an opportunity to part of significant research on older women and grief, which has the potential to help others.
- Your rights as a research participant have been explained to you. If you have any additional questions about the study, please contact me at (303) 810-4710. If you have any questions about your rights as a research participant that have not been answered by the investigator or to report any concerns about the study, you may contact the University of Denver Institutional Review Board at IRBAdmin@du.edu.
- You are free to decide not to participate in this study or to withdraw at any time without adversely affecting your relationship with the investigator or the University of Denver.

## DOCUMENTATION OF INFORMED CONSENT OLDER WOMEN'S STORIES OF COVID-19 LOSS

## □ I AGREE

BY CLICKING "I AGREE," YOU ARE VOLUNTARILY MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THE RESEARCH STUDY. YOUR SIGNATURE CERTIFIES THAT YOU HAVE DECIDED TO PARTICIPATE HAVING READ AND UNDERSTOOD THE INFORMATION PRESENTED. YOU

# MAY DOWNLOAD THIS DOCUMENT. YOU WILL ALSO BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP.

Your Name

Please provide your phone number and/or email address below.

Phone Number \_\_\_\_\_

Email Address\_\_\_\_\_

## IDENTIFICATION OF INVESTIGATORS

#### PRIMARY INVESTIGATOR

Anne Walker

anne.walker174@du.edu

303-810-4710

## SECONDARY INVESTIGATOR

Erin Willer, Ph.D.

erin.willer@du.edu

(815) 621-5484

## **APPENDIX I: GRIEF SUPPORT RESOURCES**

Heartlight Center

https://heartlightcenter.org/

11150 E. Dartmouth Avenue

Aurora, CO 80014

720-748-9908

info@heartlightcenter.org

Agape Healthcare Hospice and Palliative Care

https://www.agape-healthcare.com/grief-support/

6041 S Syracuse Way, Suite 220

Greenwood Village, CO 80111

720-482-1988

TRU Grief Services & Administrative Offices

2594 Trailridge Drive East

Lafayette, CO 80026

(303) 442-0961

https://www.trucare.org/our-services/grief-services/

#### **APPENDIX J: GATEKEEPER RECRUITMENT EMAIL**

Dear \_\_\_\_\_:

My name is Anne Walker and I am a Ph.D. candidate in the Department of Communication Studies at the University of Denver. I am working on my dissertation that explores older women's pandemic grief through storytelling and photography. I am currently seeking participants for my study.

I'm writing to see if you would be willing to share the below message and flyer [Appendix A] with your class and/or community group [insert name of group] through your email list, contacts, and/or social media sites. I am also happy to attend your classes or meetings in order to provide an overview of the study in person.

Below is the message you can copy or forward to potential participants.

#### **APPENDIX K: RECRUITMENT EMAIL**

My name is Anne Walker, and I am a PhD candidate in the Department of Communication Studies at the University of Denver. I am working on my dissertation that explores older women's pandemic grief through storytelling and photography. I am currently recruiting study participants. In order to qualify, participants need to:

- □ identify as a woman aged 65 or older who is a U.S. resident
- had a spouse, family member, friend, and/or other person important to them who died of any cause during the COVID-19 pandemic from March 15, 2020present
- □ believe the grief and loss of their loved one was significantly impacted by the pandemic
- own and be able to operate a smartphone or digital camera that can send photos
- $\Box$  speak English

If you decide to participate in this study, you will tell the story of losing your loved one during the pandemic through photographs and a storytelling interview. As a token of my appreciation, you will receive a \$20 Target gift card for participating. I would like to audio/video record our one-on-one interview and then I'll use the information to describe common themes from the story you share with me.

If you are interested in participating in this study, please complete the demographics survey and informed consent form here [insert Qualtrics link].

If you have more questions about this process, or if you need to contact me about participation, I may be reached at <u>anne.walker174@du.edu</u> or 303-810-4710. Also, if you would like to discuss this with my faculty sponsor, her name is Dr. Erin Willer, and she may be reached at <u>erin.willer@du.edu</u>.

Thank you,

Anne Walker Communication Studies University of Denver Denver, CO 80208 anne.walker174@du.edu 303-810-4710 (phone/text)

#### **APPENDIX L: ORIENTATION FOLLOW-UP EMAIL**

Dear Participants,

Thank you for attending the orientation session yesterday. I am so happy that you are willing to share your story in this research study. I have a few reminders to guide you through the next stage of the study, Storytelling Through Photos:

- Your task is to take 10–15 photos that represent your story of the loss(es) of your loved one during the pandemic.
- 2. As you take photos, remember to think about how your images represent elements of your story with characters, plot, settings, turning points, resolution, timing, motivations, emotions.
- 3. I am attaching a digital copy of the handout I gave you as well as a copy of the orientation PowerPoint. Please use these as resources as you take your photographs.
- 4. Remember that if you want to include people in your photos, you must have them sign a waiver that gives us permission to use their image. I have attached a copy of this handout here as well.
- 5. Here are the links to the videos that I shared with you; watch them if you would like further guidance on composition and basic photographic skills:
  - Windsor, J. (2020). 8 important composition tips for better photos [Video]. https://www.youtube.com/watch?v=VArISvUuyr0 (Links to an external site.) (Length: 13:17)

• Joshua Cripps Photography. (2015). *The rule of thirds - photo composition tutorial* (Links to an external site.)[Video].

https://www.youtube.com/watch?v=IpEuYp4\_iSg (Links to an external

<u>site.</u>) (Length: 3:29)

- Joshua Cripps Photography. (2016). Better composition: Using leading lines to improve your photos [Video]. https://www.youtube.com/watch?v=9T3zk2LvbYU&t=2s (Links to an external site.) (Length: 5:14)
- Spencer Cox Photography. (2020). *Light and color: How they impact a photograph* (Links to an external site.)[Video]. https://www.youtube.com/watch?v=6ltk\_eE99Oc&t=2s (Links to an external site.) (Length: 15:55)
- 6. Email or text me your best 5–6 photos by [2 weeks after orientation date] to <u>anne.walker174@du.edu</u> or by text: 303-810-4710. If you text, please include your name so that I know it's you!

As always, please reach out to me with questions.

Anne

anne.walker174@du.edu

303-810-4710 (phone/text)

#### **APPENDIX M: INTERVIEW SCHEDULING EMAIL**

Dear [Name of Participant],

Thank you for sending me your photos. I look forward to hearing all about them in our next stage, the storytelling interview.

This is two hour one-on-one interview where you tell your story of your

experiences of losing your loved one during the pandemic through your 5-6 photos. You

do not need to bring your photos with you; I will print them out myself for our interview.

I have the following dates/times available [in person/Zoom]:

[Date 1 and time]

[Date 2 and time]

[Date 3 and time]

Please let me know if one of those times work or if we need to schedule another time that's convenient for you.

Sincerely,

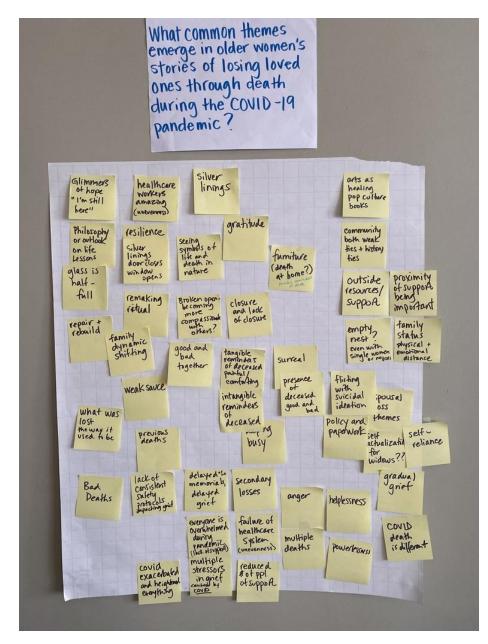
Anne Walker

Doctoral Student

University of Denver, Department of Communication Studies

anne.walker174@du.edu

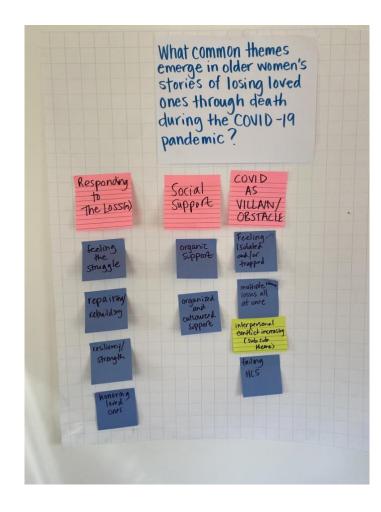
303-810-4710 (phone/text)



### **APPENDIX N: DATA ANALYSIS PHOTOS**

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#### **APPENDIX O: MEMBER REFLECTIONS EMAIL**

#### Hello!

Thank you so much for participating in my research study on older women and grief during the pandemic. I have been thinking about each and every one of you a lot these past 6 months.

It's finally time to share the findings with you!

I will be hosting an optional Zoom session where I will explain the common themes from this study. The purpose of this session is for me to hear your thoughts about the findings. This is a time for you to offer feedback, ask questions, or even share more information for me as I put the finishing touches on my write-up. <u>I will be recording the</u> <u>session</u> so that I can be fully present on the call.

I will be hosting this session next week on Tuesday, June 6<sup>th</sup> from 1-1:45 pm (MST).

Important note: This is a group session, so if you are concerned about privacy, then I recommend you sit this one out. <u>This session is only open to study participants; no one</u> <u>else will be allowed on the call.</u>

Email me back if you would like to participate, and I will send you the Zoom link.

Thanks again, and I hope to see some of you next week! Anne P.S. I'm attaching a photo of my feline research assistant (Jack Jack) for your viewing pleasure!



Anne Walker, M.Ed.

**Doctoral Candidate** 

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pronouns: she/her/hers