

A Content Analysis of Caregiver's Computer-Mediated Communication on Loneliness

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A CONTENT ANALYSIS OF CAREGIVER'S COMPUTER-MEDIATED
COMMUNICATION ON LONELINESS

By

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To all the lonely people.

ABSTRACT
A CONTENT ANALYSIS OF CAREGIVER'S COMPUTER-MEDIATED
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Marquette University, 2019

Loneliness is a mental health epidemic that affects all generations, genders, and cultures. Loneliness is an emotional and social state that requires social interaction to alleviate the symptoms, but meaningful social interaction can be hard to find. Lonely people are stigmatized, which can inhibit self-disclosure, and other stigmatized conditions (e.g., AIDS, depression) can add more barriers in self-disclosure. Communication technologies (e.g., social media, online forums) are positioned to connect remote, isolated people, by providing space for like-minded people to connect. One such group that is vulnerable to loneliness is family caregivers. Due to the inordinate amount of time and energy spent taking care of ailing family members, caregivers can suffer from significant loneliness and social isolation, so websites with online forums are an important alternative for caregivers with limitations. Website forums were chosen because the threads and posts can offer more text space than social media and website forums can better target a specific population than social media. Even though online communication is an option for people to connect, it is unclear what type of social support websites actually provide for caregivers.

This study sought to identify how caregivers communicate loneliness on targeted websites, as well as examine the responses received. A content analysis was conducted on threads collected between August 2018 and January 2019 from AgingCare.com, a website dedicated to the needs of caregivers. An examination of threads tagged with the keyword "loneliness" helped determine how caregivers talked about feelings of loneliness and how other caregivers provided support.

The results from the content analysis indicated that while loneliness was being identified by caregivers, the loneliness appeared to be seen as a symptom of greater problems rather than the problem itself. While the online community provided space and attention for caregivers who needed to discuss their feelings, it was less clear if loneliness was being solved in online forums. Although this research helped identify how caregivers communicate about loneliness online, future research can shed light on the efficacy of online communication in alleviating loneliness.

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Introduction

Across diverse demographics, Americans are experiencing greater, more frequent feelings of loneliness. According to a 2018 survey by the American Association of Retired Persons (AARP), one in three Americans over the age of 45 is lonely, which is nearly five million more people who claim to feel lonely than in 2010 (Frank, 2018). In a recent survey conducted by Cigna (2018), nearly half of Americans report feeling alone, and one in five people report they rarely or never feel close to other people. One group particularly vulnerable to loneliness in America is family caregivers. These caregivers can be more isolated, have greater amounts of stress, financial strain, and less time to address their own needs than the average person (National Alliance for Caregiving [NAC] & American Association for Retired Persons [AARP], 2015). As loneliness becomes an increasingly prevalent mental health issue, it is seen as affecting social, psychological, physiological, and emotional health (DiTommaso & Spinner, 1997). Therefore, it is worthwhile to examine how caregivers communicate the need for social support. In recent years, communication technology has offered lonely and socially isolated people a place to connect to others. While caregivers can use online forums to make connections with peers, it remains unclear how caregivers are talking about loneliness and what kind of support they receive on the platform.

Weiss (1974) has made a direct link between the value of social relationships and a person's overall well-being. Emotional and social fulfillment requires the maintenance of multiple relationships that provide different needs such as guidance, nurturance, and reassurance of worth (Weiss, 1974). If these needs are not met, individuals can become

lonely and/or socially isolated, which can then lead to greater health risks such as heart disease (Knox & Uvnaas-Moberg, 1998), stroke (Valtorta, Kanaan, Gilbody, Ronzy, & Hanratty, 2016), and mortality (House, Landis & Umberson, 1988). People require *social support*, which is defined as participation in a social network, otherwise called social integration, or “the perceived availability of helpful persons or behaviors” (MacGeorge, Feng, & Burleson, 2011, p. 319). During a difficult time, such as caring for an ailing family member, people summon their personal networks to receive the social support needed (Ensel & Lin, 1991). If caregivers find that their existing social support networks are not sufficient some caregivers may try to seek needed social support online.

In this research, I attempted to answer the following research questions: How is loneliness reflected in caregivers’ online posts? What kind of public responses do they receive? Finally, how do caregivers respond to support? The questions were not developed from interviews or empirical testing. Instead, I began with these questions and refined them as I examined the threads. The questions highlighted the focus of the study, which was to understand how people are using the Internet to talk about the difficult subject of loneliness and whether or not people were getting support. Research has shown that the more communicatively skilled a person is at expressing feelings and emotions, the less stress and anxiety they feel (Buck, 1977; Buck, Miller, & Caul, 1974; Butler, Egloff, Wilhelm, Smith, Erickson & Gross, 2003). By understanding how people are communicating about loneliness, lonely people can learn how to get better social support and responders can learn how to provide it.

A content analysis of threads on caregiver forums allowed for a greater understanding of the way caregivers communicate about a stigmatized emotion (Groves,

Golub, Parsons, Brennan, & Karpiak, 2010). The person who starts the thread is called a proprietor and the people who respond to the proprietor's thread are called contributors. These threads consisted of user-generated content in which a proprietor occupied the head position and contributors commented on the proprietor's initial post (Walther & Jang, 2012). Threads are the basis for the content analysis performed in this study. The current study aimed to take a step toward understanding how self-identified lonely individuals—in this case caregivers—self-disclosed feelings of loneliness in an online forum. In addition, this content analysis provided more insight into how people respond to self-disclosures of loneliness online. Through the examination of online threads and posts, better understanding and guidance can be provided to lonely individuals seeking social support.

In this thesis, I provide a definition of loneliness and differentiate the concept from social isolation. Then, I discuss why lonely people can be stigmatized. Understanding how loneliness is stigmatized, explains why sharing those feelings can be understood as self-disclosure. Next, I justify the choice of caregivers as the population for the study. I explain how communication technology influences a person's ability to discuss personal feelings and experiences, particularly in a health context. I advance my methods and then present the results of the content analysis. Finally, I discuss the outcome of the study and suggestions for future research.

Literature Review

Loneliness is a harmful emotion, and research has shown that a lack of social connection detracts from an individual's ability to lead a healthy life (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; House, Landis & Umberson, 1988; Knox & Uvnas-Moberg, 1998; Valtora, Kanaan, Gilbody, Ronzi, & Hanratty, 2016). Therefore, to gain social connection, people need to engage in social participation (Berkman & Syme, 1979). When people experience stressful life events, such as caring for a sick family member, high levels of assistance from social networks lead to greater levels of happiness and health (Lakey & Cohen, 2000). Social support, or lack thereof, plays a critical role in the experience of loneliness (e.g., Cacioppo, Hawkley, Ernst, Burleson, Berntson, Nouriani, & Spiegel, 2006; Schmitt & Kurdek, 1985). Further, loneliness is a highly stigmatized emotion (Lau & Gruen, 1992; Rodin & Price, 1995; Rotenberg & Kmill, 1992; Rotenberg, 1998), so it may be challenging to communicate with others about the problem, even when social support is abundant.

Studies have shown that people are inclined to stigmatize loneliness and discredit individuals who show signs of loneliness (e.g., Lau & Gruen, 1992; Rodin & Price, 1995; Rotenberg, 1998; Rotenberg & Kmill, 1992). Rotenberg & Kmill (1992) found that college students were less accepting of a hypothetical peer who was described as lonely when compared to a peer that was not described as lonely. Lau & Gruen (1992) also found that college students were more judgmental of a lonely hypothetical peer and found them to be less competent and desirable as a friend than a person who was not described as lonely. Empathy for lonely people may increase as people mature and age, but the stigma is pervasive throughout the formative years, which can have a lasting effect (Lau

& Gruen, 1992). Stigmatized health conditions can result in social networks that avoid contact, express less empathy, and avoid conversation about the health condition (Hebl, Tickle, & Heatherton, 2000; Rush, 1998). For example, people who suffer from HIV can have exacerbated feelings of loneliness and stigma that affect the person's ability to communicate (Groves, Golub, Parsons, Brennan, & Karpiak, 2010). Groves and colleagues' (2010) research indicated that people generally see loneliness as an unattractive quality, and it is sensible to conclude that people may rebuff a lonely person's attempts for social connection.

Unfortunately, loneliness is a growing health and well-being epidemic that is difficult to ignore (Brody, 2017). According to a 2010 survey done by American Association of Retired Persons (AARP), low-income persons, separated, widowed, and never-married persons, and those with poor health are among the most vulnerable to loneliness (Wilson & Moulton, 2010). Loneliness tends to peak in adolescents and young adults, as well as senior citizens (Brody, 2017). Research has shown that loneliness was a strong predictor of poor health (Wilson & Moulton, 2010). Loneliness can cause erosions in physiological resistance, which makes people more susceptible to health problems (Hawkley & Cacioppo, 2007; Segrin & Passalacqua, 2010). Thus, finding solutions for people experiencing loneliness is important.

The current trend in the United States showed that both the quality and quantity of social relationships is decreasing (Killam, 2018). Some of the contributing factors to the decline in social relationships include "reduced intergenerational living, greater social mobility, delayed marriage, dual-career families, increased single-residence households, and increased age-related disabilities" (Holt-Lunstad, Smith, & Layton, 2010, p. 2).

Segrin and Passalacqua (2010) also found that “loneliness was more strongly associated with number of close relationships than with sheer contact with social network members” (p. 312). Put another way, feelings of connectedness, rather than number of connections or amount of communication, is the greater indicator of loneliness. Unfulfilled social needs can cause people to seek social networks online and the effectiveness of this strategy for connectedness is difficult to ascertain.

For many, the internet can be a helpful medium for finding connection because websites create virtual, social gathering places for individuals to find new people and engage in conversation (Walther & Jang, 2012). Nearly one in five adults in the United States have gone online for health-related peer support (Fox, 2011), and lonely people are more likely than non-lonely people to see the Internet as a place to share personal or uncomfortable information (Wilson & Moulton, 2010). Though interpersonal relationships are built more slowly online than in face-to-face interactions, there is potential to have the same depth of relationship online as in face-to-face communication (Walther & Tidwell, 1996). However, it is unclear if a person would be satisfied with more online relationships than face-to-face relationships or without face-to-face communication altogether. Furthermore, loneliness is an emotional and social state that requires interaction (Peplau & Perlman, 1981) to remediate, so it is valuable to explore how caregivers communicate loneliness online.

Defining Loneliness

Loneliness is a ubiquitous, subjective experience in which an individual lacks the number and/or quality of relationships (Zakahi & Duran, 1985). It differs from the similar concept of social isolation. While both loneliness and social isolation are associated with

poor health outcomes (e.g., Cacioppo et al., 2002) there is a distinction between the concepts (Cohen, 2004). Social isolation is an objective state that can be quantified by examining the social network size and amount of social contact (Weiss, 1973).

Loneliness reflects how an individual *perceives* their social connectedness with others, so it is more of a subjective state (Weiss, 1973). As such, having a small number of friends does not mean a person is lonely in the same way that having a large number of friends mean a person is not lonely. Furthermore, a person can be socially isolated but not lonely and a lonely person can have many social connections. Also, a person can be both lonely and socially isolated. Again, it is the individual's perception of the quality of those relationships, regardless of quantity that determines loneliness (Wenger, Davies, Shahtahmasebi, & Scott, 1996).

Humans need multiple relationships to fulfill all of the layered needs they require. As such, "loneliness is a global evaluation of relationships across all relational needs" (DiTommaso & Spinner, 1997, p. 417). Loneliness is described as an aversive psychological state when a person lacks the quality of social relationships in their life (Peplau & Perlman, 1981). If an individual evaluates their relationships and finds a gap in relational needs, they can feel lonely (DiTommaso & Spinner, 1997). Weiss (1974) found that individuals have six needs in a relationship, which include: attachment, social integration, reliable alliance, guidance, reassurance of worth, and opportunity for nurturance. It is unlikely that a single relationship can provide all of these, and therefore multiple relationships are necessary.

DiTommaso and Spinner (1997) found that lonely individuals experience different types of loneliness based on whether the loneliness stems from social or

emotional origins. Emotional loneliness and social loneliness can manifest in different ways. *Emotional loneliness* is expressed in “a sense of utter aloneness, anxiety, hyperalertness, oversensitivity to minimal cues, constant focusing on potential solutions to the problem, feeling of abandonment, vigilance to threat, nameless fear and constant appraisal” (DiTommaso & Spinner, 1997, p. 418). If an individual feels *social loneliness*, symptoms that might be expressed include: “boredom, depression, aimlessness, marginality, meaninglessness, and a drive to search and move among people, along with behavioral deviations such as self-talk and alcoholism” (DiTommaso & Spinner, 1997, p. 418). For example, if a caregiver’s loved one is diagnosed with dementia and cannot remember the caregiver, they might feel oversensitive to minimal cues and a sense of utter aloneness— this is emotional loneliness. However, if a caregiver is burdened every day by the needs of their loved one and cannot socialize with friends anymore, then that person may be feeling social loneliness.

Loneliness can also be situational or transitional as opposed to a chronic concern. An example of *transitional loneliness* may occur during a developmental change like going away to college or getting a divorce (Young, 1982). Rotenberg (1998) found that college students were more accepting of peers who experienced *situational loneliness*, which occur in circumstances that were not controllable by the individual. This research was consistent with other findings showing that a person receives more sympathy for loneliness and less stigma when others feel the circumstances surrounding the person’s loneliness is uncontrollable (Rotenberg, 1998). In that sense, people may have more sympathy for lonely caregivers than other groups of lonely people because their situation is beyond the control of the caregiver. Rodin and Price (1995) also found that people with

a history of loneliness (i.e. chronic loneliness) were more stigmatized than those who were transitionally lonely. As such, a caregiver may only be in the role of caregiver for a short period of time, such as if their partner has cancer or had surgery and may receive less stigma due to their loneliness being more transitional than chronic. I conducted this research using Zakahi & Duran's (1985) definition of loneliness, along with DiTommaso & Spinner's (1997) definitions of emotional and social loneliness, Young's (1982) definition of transitional loneliness, and Rotenberg's (1998) definition of situational loneliness.

Communicating Loneliness and Caregiving

According to a joint research effort by the National Alliance for Caregiving (NAC) and American Association for Retired Persons (AARP) Public Policy Institute, there are an estimated 43 million people in the United States providing unpaid care to an adult or child (National Alliance for Caregiving (NAC) & American Association for Retired Persons (AARP), 2015). Many of the caregivers were providing care to a parent or a spouse, which could shift the dynamic of otherwise strong interpersonal relationships (NAC & AARP). Nearly fifty percent of caregivers said they experienced emotional stress in taking care of a loved one (NAC & AARP). As these once strong relationships waned in reciprocity of emotional and social support, caregivers may have felt the need to extend their social support network to other people. Ensel and Lin (1991) found that people summoned their personal social networks for necessary social support during a difficult situation. However, a person, such as a caregiver, may lack a sufficient social network when their family member becomes ill.

Family members avoid substantial healthcare costs by providing personal care, but the stress and loneliness, can take a toll on the caregiver's health (Buck, 1977; Buck, Miller, & Caul, 1974). The longer a caregiver provides care to a loved one, the more likely the caregiver will report fair or poor health (NAC & AARP, 2015). Thurston and Kubzansky (2009) found that lonely individuals reported worse physical health and had a greater likelihood of developing serious health conditions than those who did not report loneliness. Jain, a healthcare industry leader in loneliness, has written extensively on the topic of loneliness in senior populations. He, along with many other doctors and clinicians believe that loneliness and the absence of social community impacts a person's physical and emotional health to such a degree that loneliness should be treated as a medical condition. Loneliness carries "a risk factor for cognitive decline, the potential progression of Alzheimer's disease, stroke and obesity" (Jain, 2017, para 2). Thus, even if caregiving evades some healthcare costs, the costs to the caregiver's personal health can be just as great.

While loneliness makes a financial impact on America's healthcare system, the symptoms of loneliness are complex and often masked, so treatment is rarely provided (Jain, 2017). Jain has encouraged clinicians to communicate with patients more and ask questions to help correctly diagnose and treat lonely and socially isolated patients. By communicating and diagnosing loneliness early, patients may be able to avert the development of a greater depressive state (Jain). However, starting a conversation about loneliness may be difficult for many people.

Stigma Communication

Loneliness is not only an aversive emotional and social state, but lonely people are associated with social deficiency. The inability to socialize within a community creates *stigma*, which is “a standardized image of the disgrace of certain people that is held in common by a community at large” (Smith, 2007, p. 464). Within stigma research, scholars employ the terms *public stigma* to refer to the stereotypes that have been normalized and proliferated throughout society (Rüsch, Angermeyer, & Corrigan, 2005). In Link and Phelan’s (2001) interpretation, stigma exists when certain components converge:

- (1) a difference is labeled and distinguishable; (2) the difference is considered undesirable and negatively stereotyped; (3) the labeled individuals are grouped to define the in-group and out-group or “us” and “them”; (4) the labeled group has a disadvantaged social status and is discriminated against which results in an outcome unequal to the non-stigmatized group; (5) those with power have the privilege of defining and constructing stereotypes (p. 367).

Thus, a lonely person being labeled, losing social status, and separated from the social center, is at risk for stigma. Now that it is clear what qualifies as a stigmatized concept, it is important to understand how people with stigma communicate.

Stigma communications are messages spread within communities to teach members how to recognize the disgraced people and react to them (Smith, 2007). To examine this Meisenbach (2010) created the Stigma Management Communication model that begins with a person receiving a stigmatizing message that triggers a need for a response. The model lays out specific strategies for addressing the stigmatized message

such as: accepting, evading responsibility, denying, and reducing offensiveness. In Meisenbach's model, stigmatized individuals are responding to incoming messages, but the model does not discuss how a person might begin communication about a stigmatized label. For example, if a caregiver wanted to open up about feeling lonely online, it would not be in response to a stigmatizing message. Rather, caregivers would start a conversation about their loneliness (stigma) with a group that appears similar and potentially empathetic.

When experiencing stigma people may turn to others with a perceived similarity, which encourages empathy and understanding (Rains & Wright, 2016) or those who have perceived credibility, which can be perceived competence or character (Wright & Bell, 2003). People seek advice from weak ties, individuals who are contacted within certain contexts but are not interpersonally close, because weak ties are perceived to be more objective and less emotional than strong ties, which are interpersonally close relationships (Wright, Rains, and Banas, 2010). The internet creates online support groups, which are "individuals interacting in groups using the Internet to exchange social support" (Wright, Rains, & Banas, 2010, p. 606).

Wright and Miller (2010) have found that seeking support from close ties, like family and friends, can be neither desirable nor practical in some contexts. Weak ties, or strangers, can provide more constructive and useful communication, particularly if someone is facing a serious health concern. If a person is feeling lonely, they may feel uncomfortable talking about that concern with close ties because it could seem to question the quality of their relationship. Additionally, lonely people may want to avoid feeling patronized, stigmatized or judged based on their feelings. Not to mention, if the

person is both lonely and socially isolated, there may be no available close ties in which to confide.

In some scenarios, as LaGaipa (1990) states, there could be a reciprocity failure when communicating with close ties, or an inability or unwillingness to reciprocate due to the confidant's own constraints. As such, weak ties can seem advantageous when the individual does not feel part of a close personal network or is facing a stressful situation like a health concern, and the weak ties can offer a diverse perspective (Wright & Miller, 2010). The advantages of a weak-tie network can be significant to a person seeking support.

The decision to open up about a stigmatized label with others, whether online or in person, is an act of bravery that risks a person being evaluated by others. It may appear to be ideal if a caregiver had a person or group of trusted allies to share with in person, but the caregiver's physical social network may be limited or lack understanding (Wright, Rains, & Banas, 2010). In fact, weak ties in online support groups provide: "(a) access to different viewpoints, (b) reduced risk, (c) access to objective feedback from others, and (d) reduced role obligations" (Wright, Rains, & Banas, p. 608). Online communication may be the best place for a lonely person to share and get helpful feedback from others with diverse viewpoints (Wright, Rains, & Banas). In order to receive that feedback, people need to share that personal information online.

Self-Disclosure

Self-disclosure is defined as "the expression of personal information that is of a descriptive, affective, or evaluative nature" (Roloff, 2009, p. 872). An act of self-disclosure can offer varying breadth and depth of information about a person and is

historically disclosed in face-to-face contexts (Roloff). Broadly speaking, any post on a social media site would be considered self-disclosure as a person is sharing personal thoughts and opinions to others (Lin, Levordasha, & Utz, 2016). In both face-to-face communication and online communication, highly intimate disclosures can be perceived as inappropriate (Bazarova, 2012).

Alternatively, people may see the self-disclosure of loneliness online as a jumping off point toward building a possible social connection. Altman and Taylor (1973) describe social penetration theory as a way for an individual to enact self-disclosure as a means to get another person to like them and build a relationship. Altman and Taylor posit that people like it when others disclose to them, and when a person discloses personal information to another person, it appears they like that other person. Self-disclosure is a means of relationship building that displays trust and honesty (Roloff, 2009). Often, there is an internal process that takes place when a person weighs whether or not to self-disclose with another person (Omarzu, 2000).

In 2000, Omarzu described a sequential decision-making process for self-disclosure in which an individual: (1) has a goal for disclosing information then; (2) makes a determination regarding whether or not a targeted confidant is right to disclose to; (3) determines if the time and location are appropriate and finally: (4) conducts a risk/reward assessment for the breadth and depth of information being communicated (Roloff, 2009). A person disclosing feelings of loneliness online is likely seeking information, objective feedback (Wright & Miller, 2006), empathy, and understanding (Wright & Rains, 2013).

Online Self-disclosure. Some evidence suggests that weak ties accessed via online communication can be valuable when strong ties are unwilling or unable to provide support (Wright & Rains, 2013). As individuals post personal information (e.g., opinions, health information) online, the definition of self-disclosure must be reframed to accommodate the context of communicating over the Internet. Computer-mediated communication (CMC) is any Internet-based and text-based communication in which dyads or groups interact (Rains & Wright, 2016). People can have one-to-one communication online (e.g., private messaging), but the communication in my research focused on information shared in a one-to-all context (Walker, 2019). People who communicate online have more control over certain nonverbal cues like appearance through the manipulation of photographs, the absence of a profile picture, or other visual identifiers (Kim & Dindia, 2011). As such, “online self-disclosure extends the traditional definition of self-disclosure (verbally revealing self) to include pictures of self and favorite links posted on the web” (Kim & Dindia, 2011, p. 156). Also, both the proprietor (the person who starts a thread) and contributor (the person who responds in a thread) of comments online may be unaware of the true identity of the other person. People who post online do not know the audience reading their posts and the readers do not know if the identity they see created is authentic. Furthermore, the goals of online self-disclosure are not clear either.

For example, Cho (2007) found in a study of Korean high school students’ online chatting experience with strangers that the three motivations people have for chatting online include entertainment, information, and the development of interpersonal relationships. Cho found that students who were motivated by the desire to develop

interpersonal relationships believed more online self-disclosure was required than those who were motivated by entertainment or information-gathering. Therefore, if a person seeks to build relationships online, sharing personal information may be the most effective way to start.

Brehm's (1966, 2008) psychological reactance theory added an insightful layer to understanding self-disclosure. The theory stated that individuals want to maintain freedom in their decision-making, and self-disclosure implied an obligation to reciprocate. Conversely, an act of self-disclosure was viewed as a plea for help. The process of self-disclosure can break down due to receivers' feeling that they have restrictions on their freedom of choice. So, if a lonely person confessed feelings of loneliness to another person face-to-face, the confidant may feel like an obligation has been put upon them to help alleviate that loneliness and/or to reciprocate with a disclosure of their own. Listeners may feel that the lonely person was asking for social or emotional connection by the act of self-disclosing an emotional state (Roloff, 2009).

When a lonely caregiver self-discloses online, however, there can be less pressure to respond and less of an obligation to reciprocate self-disclosure because of geographic dispersion and greater anonymity due to the text-based format (Walther & Boyd, 2002). For example, if a person reads a post on Twitter that self-discloses feelings, the reader has less pressure than if the person who posted the comment said it directly to the reader's face. If we take this even further, if the person reading a post online is a stranger, there is almost no obligation to respond unless the reader feels inclined to do so.

The timing of messages also influences the building of relationships. Most online communication occurs as asynchronous exchanges, which is communication that has

time between the content upload and the interaction with other people (Buxton, 2014; Hrastinski, 2008; Stein, Wanstreet, & Calvin, 2009). The time lapse in online communication can leave a space for cognitive and interactive pause (McQuillen, 2003). Also, online communication can be synchronous, which is communication with instantaneous feedback (Giesbers, Rienties, Tempelaar, & Gijsselaers, 2014; McBrien, Jones & Cheng, 2009). People may like the immediacy of a synchronous response when they are feeling lonely. On the other hand, with asynchronous exchanges, the lag time between responses can allow people more time to provide insightful responses (McQuillen, 2003).

Influence of Communication Technology on Health Communication

The Internet has the potential to shrink the distance between people in interpersonal interactions. However, as humans learn over and over again, tools and advancements in technology often encourage more autonomy and reduce the need for social gathering (McQuillen, 2003). A common criticism of online communication is the lack of socioemotional content, such as nonverbal cues, which can make communication more complex (Rice & Love, 1987). Though imperfect, online communication may be the best or only option for a person as deeper relational communication has the potential to take place.

Computer-mediated communication (CMC) is any Internet-based and text-based communication in which dyads or groups interact (Rains & Wright, 2016). CMC can develop deeper relational communication than some face-to-face relationships through hyperpersonal communication, or more personal interaction (Walther, 1995) and “foster topical discussions among large, dispersed groups” (Walther & Jang, 2012, p.3). CMC

seems to be a reasonable option for lonely caregivers to communicate with others and find connection.

However, people approach their online personas in ways that differ from an in-person identity. Online, some people present an idealized perception of the self, limiting their negative attributes. These limitations on a person's feelings and identity can hide negative emotions that someone may need to share and discuss. On the other hand, some people can be open with the personal information they share in the hopes that someone will read the content and find connection or guidance. People can be put-off by some personal topics (e.g., health and loneliness), so sharing requires a balance of honesty and self-protection. Nevertheless, it stands to reason that caregivers and individuals struggling with emotional issues would benefit more from an open approach to get the most helpful social support (McQuillen, 2003).

There are two outcomes of computer-mediated support: improving coping mechanisms and perceived support availability (Rain & Wright, 2016). People who turn to the Internet for support can better manage their stressors and perceive potential support from others (Rains & Wright, 2016). Communicating with support groups online has shown to have decreased rates of depression (Houston, Cooper, & Ford, 2002), and has empowered individuals to find information and meaning (Mo & Coulson, 2012). Despite that, online support has some drawbacks. Some people experience stress from hearing about other community members' difficulties (Holbrey & Coulson, 2013). Also, people can experience stress when comparing their own progress to others' progress (Malik & Coulson, 2008), or by focusing too much on the illness (Holbrey & Coulson, 2013). People can also experience frustration when the feedback is not immediate (Haberstroh &

Moyer, 2012), is negative or limited (Yli-Uotila, Rantanen, & Suominen, 2014), and lacks physical cues (Colvin, Chenoeth, Bold, & Harding, 2004). Caregivers who choose to self-disclose online have the potential to gain support from others in a similar position, but if the support provided and the support expected do not align, there can be a “support gap.” (Francis, 2017). Therefore, an examination of threads provides some additional insight into whether or not stigmatized individuals who self-disclose through online communication get social support.

Research Questions

Online communication can allow people to self-disclose more openly as there is greater anonymity compared to face-to-face communication, and the obligation to respond is less immediate and imposing on the receiver (Walther & Boyd, 2002). In addition, websites with computer-mediated forums can identify highly targeted groups who may be experiencing the same stigmatized issues as the lonely individual. This study seeks to identify how caregivers communicate loneliness online, and to interrogate how members of the online group respond to these messages concerning loneliness.

The research questions guiding this study are:

RQ1: How is loneliness reflected in caregivers’ online posts? There is evidence that the caregivers may discuss a lack of strong tie support or a need to connect with people who understand their unique situation (Wright & Miller, 2010).

RQ2: What kind of public responses do they receive? There is evidence to suggest that some people might respond by comparing their own progress to others’ progress (Malik & Coulson, 2008), focus too much on the illness than the caregiver’s emotions (Holbrey & Coulson, 2013), 2012), or may be negative or limited in feedback (Yli-

Uotila, Rantanen, & Suominen, 2014). Due to the ubiquity of caregiver loneliness and emotional stress – as nearly fifty percent of caregivers said they experienced emotional stress in taking care of a loved one – there may be some who also state feelings of loneliness (National Alliance for Caregiving (NAC) & American Association for Retired Persons (AARP), 2015).

RQ3: How do the caregivers respond to support? The evidence suggests that caregivers may experience frustration when the feedback is not immediate (Haberstroh & Moyer, 2012). Also, caregivers may be more responsive to feedback that offers information and objective feedback, (Wright & Miller, 2006), as well as empathy and understanding (Wright & Rains, 2013).

Methods

To answer the three research questions, I conducted a content analysis of the threads, which are sequential conversational posts regarding a single topic, in an online forum dedicated to the needs of caregivers. The goal is to understand how loneliness is communicatively expressed and what kind of public responses were received. Caregivers are a group vulnerable to loneliness and report having unmet needs for self-care support (NAC & AARP, 2015). Websites with interactive social support may be a good option for caregivers to talk about loneliness and other informational needs. As with any content analysis, the context of the texts analyzed are based on the interpretation of the communication analyst and do not represent a holistic interpretation of the texts (Krippendorff, 2004).

There are many websites with space dedicated to addressing the needs and inquiries of caregivers such as AgingCare (www.agingcare.com), American Association of Retired Persons (www.aarp.com), and Caregiver Action Network (www.caregiveraction.org). In this research, an examination was made of the content posted on the website AgingCare.com for the following three reasons. First, the website's site functionality and tagging features clearly identify which users are posting about loneliness. Second, the website is singularly dedicated to the needs of caregivers. Third, the forum is available to help caregivers share experiences, participate in group discussions, ask questions, and receive information regarding local and national service providers. Figure 1 shows a screenshot of some of the diverse topics on which AgingCare provides information to users.

Figure 1. Screenshot of AgingCare Topic Forum

The screenshot displays the AgingCare website's topic forum grid. The header includes the AgingCare logo, navigation links for FIND CARE, FORUM, and CARE TOPICS, a search icon, and a LOG IN button. The grid consists of nine topic cards, each with a title, a brief description, and a list of counts for articles, questions, and discussions.

| Topic | Description | Articles | Questions | Discussions |
|---------------------------------|--|----------|-----------|-------------|
| Liver Disease | Damage to the liver caused by genetics, virus, or substance abuse that leads to cirrhosis and can lead to liver failure. | 6 | 27 | 3 |
| Living Independently | The financial and functional ability to support living alone. | 31 | 801 | 60 |
| Living Trusts | Revocable trust: A legal document that identifies assets that are placed into a trust and remain under your control while living, then pass to a beneficiary upon death without going through probate. | 9 | 48 | 1 |
| Living Will | A legal document that communicates a person's wishes regarding lifesaving medical treatments. The document is often used when the individual can no longer communicate. | 11 | 18 | 0 |
| Loneliness | A feeling of sadness brought on by isolation or lack of companionship. | 25 | 115 | 27 |
| Long Term Care | A range of services and support which help meet both the medical and non-medical needs of people who cannot care for themselves for an extended period of time. | 38 | 123 | 6 |
| Long Term Care Insurance | A policy sold by a private insurance company to cover costs associated with long-term care that are not covered by traditional health insurance, Medicare, or Medicaid. | 20 | 45 | 0 |
| Long-distance Caregiving | Coordinating the care of another individual who needs support with activities of daily living while living a distance away from the care recipient. | 21 | 241 | 9 |
| Loss of Appetite | A decrease in appetite and lack of feelings of hunger, often leading to unintentional weight loss. | 8 | 43 | 1 |

In January 2019, Marquette University IRB approved the research plan. In November 2018, the website administrators at AgingCare granted permission for the content analysis to take place, but the information posted is open to the general public, so permission was not really necessary. The natural context of these open forums is ideal for the examination of latent content through a content analysis (Krippendorff, 2004). The unobtrusive nature of a content analysis is helpful when examining a stigmatized emotion like loneliness, because the posts are written authentically and without intervention.

The population consists entirely of current and former caregivers who have been active on the site between August 2018 and January 2019. The AgingCare site has a distinct section in which people can express feelings of loneliness and isolation. Figure 2 shows a screenshot from AgingCare's "Loneliness" topic forum page.

Figure 2. Screenshot of Loneliness Topic on AgingCare

The screenshot displays the AgingCare website interface. At the top, there is a navigation bar with the AgingCare logo, a search icon, and links for 'FIND CARE', 'FORUM', and 'CARE TOPICS'. A 'LOG IN' button is also present. The main heading is 'Loneliness in the Elderly'. Below this, there are three tabs: 'Questions', 'Recent Activity', 'Most Popular', and 'Needs Answers'. The 'Questions' tab is active, showing three posts:

- Post 1:** 'Hospice, it's lonely...' with 24 comments. The author is a user with a blue profile picture, and the post was replied to on Apr 6, 2019.
- Post 2:** 'My husband is only 51. He was diagnosed with early onset a yr and a half ago. I thought I was strong enough to do this. Depressed and lonely.' with 3 comments. The author is a user with a green profile picture, and the post was answered on Apr 6, 2019.
- Post 3:** 'How do you live your own life when caring for a 66 year old husband with dementia?' with 15 comments. The author is a user with a blue profile picture, and the post was answered on Apr 6, 2019.

On the right side of the page, there is a 'Find Care & Housing' section with a list of care options: Assisted Living, Memory Care, Independent Living, and Home Care. Below this list is a search input field for 'Your postal code or city' and a 'See My Results' button. At the bottom right, there is an advertisement for 'Simple Meds' with the headline 'THROW OUT THAT PILL BOX!' and the text 'No stress medication management. That's the Simple Meds promise.' and a 'Learn More' button.

The intuitive design of the website allows users to post questions or discussion topics and “tag” the content with keywords, such as “diabetes” or “Medicare.” These tags allow site users to search for a specific term that produces relevant results. One such tag found on the website is “loneliness.” This type of content addresses the emotional struggles that caregivers are going through and, at times, the emotional struggles that caregivers witness in their ailing family member. Through a content analysis of the loneliness-tagged contents, a determination can be made as to what type of communication is being used to discuss feelings of loneliness and the need for social support. Also, the responses posted by contributors can be analyzed to see what sort of emotional and social support is provided on the forum. Finally, the proprietors’ responses to contributors can be analyzed to see if conversation is occurring on the threads.

Data Collection

The conceptual content analysis quantified all of the threads posted under the loneliness topic theme, which are posts tagged using the keyword “loneliness,” over a five-month period from August 2018 to January 2019. This thread is designed by

AgingCare for users to discuss feelings of loneliness, isolation, or a lack of social support in caregiving. The content analysis will also provide a rhetorical analysis, which examines how messages are delivered (Krippendorff, 2004). Lastly, the content analysis had some elements of conversation analysis where applicable. The threads that caregivers created may include responses from contributors. The open conversations were examined to better understand the collaborative construction of loneliness and how people interact when speaking about the loneliness felt in their particular situation (Krippendorff, 2004).

This research aimed to define and describe a caregiver's real-life experiences with loneliness. As such, the approach for this research was an interpretative phenomenological approach (IPA), focusing on an individual, within a specific time and context to make sense of a personal, lived experience (Smith, 2011).

Data Analyses

To ensure reliability of the results, careful consideration was made in developing the codebook. The coded units are threads created by one proprietor and multiple contributors on the online forum. These threads consist of user-generated content in which a proprietor, the person who starts the thread, occupies the head position and contributors' comment on the proprietor's initial post (Walther & Jang, 2012). The proprietors' posts are cited using a two letter and number pseudonym (e.g., VR4). The "VR" is a pseudonym in place of the proprietors' screennames on the AgingCare website. The contributors' posts, or the comments that other caregivers post in response to the proprietor's post, are cited using the proprietor's pseudonym followed by "_Com" (e.g., VR4_Com). If there is more than one comment discussed from different contributors, the citation will have a number after "com" (e.g., VR4_Com_1). Proprietor comments are the

responses from the proprietor to the contributor. These responses from the proprietor are cited using the same pseudonym as the initial post and “_Resp” (e.g., VR4_Resp).

The threads were copied from the website and pasted into a Microsoft Word document for clearer coding, which yielded 146 pages of single-spaced content. The analyses occurred in January 2019. The total number of threads pulled was N=30, but not all of those threads were suitable for analysis. Upon review, 13 of the threads were determined to be unsuitable for the goals of the research as the focus of those threads was on a family member’s loneliness perceived by the caregiver and not personal loneliness expressed by a caregiver. For example, one caregiver started a thread about her father feeling abandoned and lonely in a nursing home while he was suffering from dementia. The caregiver was seeking advice on how to handle her father’s loneliness, not her own. While some threads offer some insight and support into alleviating loneliness for ailing family members, the research I focused on aims to understand the ways a person self-discloses loneliness online. If the proprietor discusses another person’s loneliness, there is no self-disclosure, which precluded those threads from this study’s goals. Therefore, n=17 threads, or 91 pages of single-spaced content, were determined to be suitable for the research goals, which was to examine how caregivers communicated feelings of loneliness, what type of responses were received, and how the caregiver responded to the support. The 17 threads examined in the research contained 248 responses from the AgingCare contributors, and 36 responses from the proprietor. Table 1 in the appendix shows a breakdown of the thread and response counts.

The threads from the AgingCare website were coded following specific guidelines using a deductive approach (Krippendorff, 2004). The proprietors' posts in the threads were coded for: (1) count of the terms "lonely," "alone," or "isolated"; (2) description of emotional loneliness (e.g., lack of empathy from others); and (3) description of social loneliness (e.g., lack of time and energy to socialize). The indicators of emotional and social loneliness were developed based on DiTommaso and Spinner's (1997) definitions. Further explanation of the code categories, including definitions and examples, can be found in Table 2 in the appendix.

My first research question was how is loneliness reflected in caregivers' online posts? There is evidence that the caregivers may discuss a lack of strong tie support or a need to connect with people who understand their unique situation (Wright & Miller, 2010). I used inductive reasoning to answer this question as the data I was reviewing was explicitly tagged using the keyword "loneliness." Therefore, all of the posts would be relevant to the topic of loneliness. Of course, some of the posts needed to be deleted from the data set because the proprietors spoke about the loneliness of a loved one and not their own loneliness.

My second research question was what kind of public responses do they [the proprietors] receive? Using deductive reasoning, I created four categories based on the literature and my reading of the thread data. The categories were: emotional support, information, personal stories, and questions. Through multiple readings of the data, I was mindful for other categories that may crop up. While there could be overlap in the categories, the overall context of the message was taken into consideration and a judgment was made as to what the statement was conveying. For instance, if a contributor

responds to a proprietor saying, “You sound just as exhausted as I was when my father went through chemotherapy. Try to get some rest” then this statement could be considered emotionally supportive and a personal story. Further explanation of the code categories, including definitions and examples, can be found in Table 3 in the appendix.

My third question was how do caregivers respond to the support? I also used deductive reasoning in framing this question and investigating the data. The literature suggested there would be a great deal of interest in caregivers seeking information and emotional support, but it was not clear whether or not caregivers would want the online relationship to extend beyond the web forum.

Results

Every thread examined was selected because the caregiver tagged the post with the keyword “loneliness.” Of the 17 threads examined, the proprietors were comprised of 65% women and 17.5% men, and 17.5% provided no gender description. No other demographic information could be determined such as age, income level, education, or ethnicity. In seven of the total 17 threads, the “loneliness” tag was the only explicit reference to the concept, which was just over 40% of the threads examined. In nine of the 17 threads, the caregiver used the words “lonely,” “isolated,” or “alone” only once in the body of their message, which was nearly 60% of the threads examined. There was only one thread among the 17 examined, in which the caregiver referenced “lonely,” “isolated,” or “alone” four times. The proprietors discussed symptoms of emotional loneliness (e.g., lack of empathy, disconnected) in 59% of posts and social loneliness (e.g., isolation, lack of time and energy) in 82% of posts.

How Loneliness is Reflected in Caregivers’ Online Posts

The first research question asked how loneliness is reflected in caregivers’ online posts. The proprietors reflected aspects of social loneliness and emotional loneliness (DiTommaso & Spinner, 1997) as well as transitional (Young, 1982) and situational loneliness (Rotenberg, 1998).

Social and Emotional Loneliness. The comments regarding social isolation stemmed from family members and friends distancing themselves from the caregiver and their ailing loved one after diagnosis. For example, one caregiver posted “I literally don’t have any other family to ask for help or advice from” (CH13, AgingCare, 2019) and another said, “I miss the company of others” (CL17, AgingCare, 2019). I considered

comments like this to focus more on the objective absence of social support than the perceived absence of emotional connection.

The caregivers also discussed other aspects of social loneliness such as a lack of time, energy, and isolation created by the illness. Often in these situations, the caregiver became the single or main resource for the ailing family member with many others not taking responsibility. Caregivers described that burden in such ways as:

Long story short now with dad gone the care of mom has fallen totally on me. I'm the oldest of three daughters. My two younger sisters are completely absorbed in their own lives even though we all live within a five minute or less drive of each other. (KT2, AgingCare, 2019)

In some situations, friends distanced themselves when the caregiver had to reprioritize their life: "She also was my business partner for 30 years. We were always good, but I had to give it up to take care of hubby. It's like I disappeared out of her life" (SQ14, AgingCare, 2019). In one case, a caregiver who spent a lot of time caring for a parent was dumped by her significant other: "My significant other left me, via text, after 13 years" (LM4, AgingCare, 2019).

Elements of time and energy were discussed as reasons why the loneliness existed. One caregiver discussed how balancing priorities left her little time to spend with her significant other: "We tried to spend time together, but my mother was my obsession I think and I lost myself. Trying to maintain two careers and her too" (LM4, AgingCare, 2019). This example highlights how the tasks of caregiving draw a person away from the social network they need. Often the energy lost is due to overexertion and a burden of responsibilities, such as: "I'm doing everything from bathing and dressing her and I have

to feed her. I'm not sleeping all night. Sometimes she stays up all night those days are the hardest" (BM8, AgingCare, 2019).

In addition to an overextension of self, the caregivers referenced feelings of anxiety in caregiving, which depletes vital energy through loss of sleep and stress to the body. One example came from a caregiver who had a young child as well: "To add more anxiety we now have a toddler together and it has been the toughest time I have ever experienced" (SA10, AgingCare, 2019). Even though the caregiver had a husband, she was so busy caring for ailing loved ones and children that she felt she had no extra time for social interaction after caring for her toddler, working, and taking care of an ailing family member.

Proprietors discussed emotional loneliness by conveying a perceived inability to talk about their emotions like loneliness, frustration, and anger, or feeling that no one understands the day-to-day struggles of caregiving. In one such case, a caregiver mentioned feeling unable to communicate with her children and friends for different reasons of empathy and propriety: "It is inappropriate to talk to my kids and my friends all have well spouses so they don't understand" (CM16, AgingCare, 2019).

For some caregivers, the AgingCare site was an entryway into finding others who can understand their unique set of circumstances and they used the opportunity to ask for guidance: "Anyone aware of elderly support groups dealing with loneliness, anxiety, and depression?" (TA12, AgingCare, 2019). Another caregiver mentioned the usefulness of the site for people struggling with the same set of issues: "I've reached a point to where it would just be nice to hear others feel similar to the way I do" (CC15, AgingCare, 2019).
Ok, but how are you tying this to loneliness?

Comments regarding social and emotional loneliness were framed differently in the threads. The discussion of social loneliness used more straightforward language about feeling lonely and lacking strong tie support. In one case, a caregiver wrote “I am alone in a retirement community” (MM5, AgingCare, 2019) while another caregiver wrote “I need to have a social life to help” (AN3, AgingCare, 2019). Emotional loneliness was expressed more often in questions rather than declarative statements. For instance, one caregiver framed her emotional loneliness as seeking advice: “[H]ow do you stay connected to your husband when it feels that the only reason he chose you, is so you can help him run his errands?” (SA10, AgingCare, 2019). Another caregiver asked for advice on how to handle the loss of a relationship: “How do I handle rejection from my male friend that’s 74?” (JE9, AgingCare, 2019). In these examples, caregivers portrayed a proactive approach to solving their loneliness by seeking advice on how to handle their loneliness.

Loneliness expressed in these threads was often paired with other emotions such as sadness and anger. In one case, the proprietor shared that she had been diagnosed with clinical depression: “I felt worthless and scared. I cry a lot. I got diagnosed as having situational depression” (CM16, AgingCare, 2019). Another proprietor wrote “I’m hurt, sad, angry and alone” (EN1, AgingCare, 2019). This example highlights how many caregivers feel more than just lonely, but also sad and angry.

One caregiver expressed more anger toward the people in their life who have disconnected and shown no empathy: “What do you do when you find yourself angry when friends don’t even ask how my husband is doing...I’ve heard her say in past everyone has problems. Seems cold to me?” (SQ14, AgingCare, 2019). Some caregivers

appear angry at the lack of help in caregiving, while also feeling alone and lonely. One caregiver said, "I get angry because I have no help and am alone in a retirement community," (MM5, AgingCare, 2019), or another stated, "I'm angry, resentful, and lonely as H*LL" (CM16, AgingCare, 2019). In these examples, feelings of loneliness and emotions such as anger and sadness are expressed simultaneously.

Transitional and Situational Loneliness. The caregivers on these threads discuss loneliness stemming from the unique situation of being a primary caregiver for an ailing loved one, which is situational loneliness. These circumstances are beyond the control of the caregiver, so there is a greater sense of empathy (Rotenberg, 1998). The caregivers talk about the responsibility of caregiving eating up their opportunity for a social life. Often caregivers reference losing friends due to the caregiving experience with such comments as "no friends left due to disease. I need to have a social life" (AN3, AgingCare, 2019). Another caregiver discussed her concerns that her husband's progressive dementia, which has caused him to be disruptive and rude at times, will cause her friends to stop socializing (JC7, AgingCare, 2019). For some, caregiving is not only a time-consuming task that leaves little space for socializing, the illnesses can also drive some friends away.

Transitional loneliness can be expected when a loved one passes away, a person goes through a romantic break-up, or when a person moves to a new place. Some caregivers expressed transitional loneliness due to moving to a new location, such as a retirement home. Also, some caregivers express a feeling that they are "losing [a person] every day" when they suffer from dementia or Alzheimer's disease (BM8, AgingCare, 2019).

What Kind of Public Responses Caregivers Receive

The number of responses in each thread varied. Ten of the threads had fewer than 10 responses by contributors and six of the threads had more than 20 responses; one thread had 12 responses. The most responses on a single thread had 52 posts from contributors and the fewest responses on a single thread had 1 post from a contributor.

The second research question asked what kind of public responses the caregivers receive. There is evidence to suggest that some people might respond by comparing their own progress to others' progress (Malik & Coulson, 2008), focus too much on the illness than the caregiver's emotions (Holbrey & Coulson, 2013), 2012), or may be negative or limited in feedback (Yli-Uotila, Rantanen, & Suominen, 2014). Based on the threads, the contributor responses fell under four general themes: (1) emotional support; (2) personal anecdotes; (3) information; and (4) questions.

Emotional Support. Proprietors who pose questions on AgingCare and tag the post with "loneliness" are likely looking for compassion and empathy in the responses they receive. At times, the contributors did not have specific advice, but wanted to offer encouragement. One caregiver was lamenting that her birthday dinner was encumbered by the presence of her ailing mother, but she stated that her family failed to understand her perspective. A contributor replied by saying "hope you had a good birthday whatever you decided to do. I understand where you are coming from" (EN1_Com, AgingCare, 2019). The contributors also provided empathy by way of confirmation for the exhaustion the caregiver might be feeling: "It is so hard like you said to juggle it all" (KT2_Com, AgingCare, 2019) or "it sounds to me like you are onto something when you wrote:

‘when it feels that the only reason he chose you, is so you can help him run his errands’” (SA10_Com, AgingCare, 2019).

The emotional support could also be action-oriented. Many contributors urged the proprietor to do what they want or what is healthy for them. In one case, a caregiver discussed having to leave college in order to attend to two ailing relatives. Contributors rallied behind the caregiver: "Definitely don't give up on your life...Your life is just as important as theirs, and you need to take care of yourself" (CH13_Com, AgingCare, 2019).

Many other examples of emotional support included urging the proprietor to not feel bad about their emotions: "Guilt?? Dear young lady - you have nothing to feel guilty about. You have willingly, lovingly, sacrificed your time and emotions for your parents - and you know in your heart, that it's time to take care of you" (CC15_Com, AgingCare, 2019).

Overwhelmingly, the community of caregivers on the forum was quick to provide general comments of empathy and kindness. For some, it was a direct expression of sympathy like “sympathy to both of you” (TH6_Com, AgingCare, 2019) or “I’m sorry that this is happening to you” (JC7_Com, AgingCare, 2019). Another caregiver was feeling lonely after her best friend and other friends stopped coming around when her husband fell ill. Commenters said specific things to recognize the pain in these situations like “I'm sorry people can't be more sensitive" (SQ14_Com, AgingCare, 2019) and “It must hurt to be treated that way by a friend” (SQ14_Com, AgingCare, 2019). However, much of the emotional support was encouragement to take care of themselves. One

proprietor expressed loneliness and sadness for having a male companion “reject” her, so a contributor wrote “Look after your heart. Xxx [kisses]” (JE9_Com, AgingCare, 2019).

Personal Anecdotes. Personal anecdotes are meant to provide solutions and information to those who are struggling. Often, contributors provided their past experiences in posts, too. Some contributors were able to provide emotional support through a connection to their own personal story:

I know firsthand how mentally draining it is to care for an elderly parent. I also know how frustrating it is when siblings come from out of town to visit and want to go out, then add mom on to the equation. Same as you I just want time with them and away from mom so I can vent. (EN1_Com, AgingCare, 2019)

At times, the personal story acted more as a back-up to the primary post claim: “My father did the exact same thing with my mother, then died in 2015 and here I am, the only child, in charge of doing everything for my mother who's 92” (KT2_Com, AgingCare, 2019). In these circumstances, the contributor offered a firsthand account as a means of support.

In one case, the contributor was not only sharing their own personal story about her love life: “I remarried 2 years before dementia arrived on the scene... mine is wonderful, supportive and in spite of the hardships, steadfast. Yes, they do exist ladies... and I'm just affirming that partners like that are out there” (LM4_Com, AgingCare, 2019). In this situation, the contributor was responding to a proprietor’s disclosure that her significant other just left her over a text message.

This forum is targeted for caregivers, so many of the responses come from people who are struggling as much or more than the proprietor. At times, the contributor's anecdotes and stories are about negative, personal experiences:

I have been caring for my mother for 6 years now alone. Sometimes I feel like I could die and [a] kind word would really heal my heart. My best friend told me she was tired of hearing about my mom and the issues. It stresses her. So I say nothing in order to keep a friend. I have lost all my other friends they are tired of my texts from the ER. We just have to accept this is your life and everyone else is just living theirs. (SQ14_Com, AgingCare, 2019).

Information. Proprietors often asked for advice or posed a question for the forum to respond to, so many contributors provided concrete solutions to the issues at hand. For loneliness, contributors would often recommend using local resources to find support: "Sounds like you could use a few more supportive adults in your life. Maybe you could look into a caregiver support group? People on this site will have good suggestions" (EN1_Com, AgingCare, 2019). When proprietors discuss feeling lonely, a frequent suggestion was to get involved with more activities, so many of the responses are ideas for things to do: "Getting out of the rut is the first step - go to the library, the mall, a coffee shop or seniors centre where people hang out, even if it is just to sit on the edge of the crowd and people watch" (AN3_Com, AgingCare, 2019).

More often, contributors responded more indirectly about feeling lonely during caregiving. Instead of providing ideas on how the proprietor could meet people, the contributors shared resources for taking care of the ailing family member, so the caregiver can get more time to focus on their own life. For example, government

organizations were frequently cited: "Contact Medicare/Medicaid to ask about in-home health aides. Contact the Society for The Blind to see if they have a senior program Mom could attend" (MM5_Com, AgingCare, 2019) or "Contact your county's Area Agency on Aging (sometimes it has a slightly different name) regarding grandpa and see if they or someone else can direct you regarding dad" (CH13_Com, AgingCare, 2019). Lastly, even if the response was not a suggestion of helpful programs or ideas for things to do, the contributors motivated proprietors to open up and discuss their feelings with friends and family: "Tell them directly how you feel and ask for their help in some way" or "You must tell them exactly how hurt you are" (SQ14_Com, AgingCare, 2019).

Questions. Contributors often asked follow-up questions to the proprietor's thread. For the most part, the questions asked in the thread were specific to the proprietor's circumstances such as: "Are there any dementia support groups in your area?" (BM8_Com, AgingCare, 2019). At times, those questions could appear to be too personal to respond to on an online forum such as: "Can you afford homecare?" (BM8_Com, AgingCare, 2019). Mostly, people are unwilling to discuss finances with strangers. In other cases, the contributors appeared to be eager to have a conversation with the primary post caregiver:

What do you want advice on? Do you want your SO back? Are you wondering how to move on without your SO? Or are you just trying to get your life back together? Did your SO tell you why she left? (LM4_Com, AgingCare, 2019).

In one case, the contributor even wrote: "There are so many things I want to discuss with you" (LM4_Com, AgingCare, 2014).

How Caregivers Respond to Support from Others

The evidence suggests that caregivers may experience frustration when the feedback is not immediate (Haberstroh & Moyer, 2012). Based on the findings, there were no comments made by proprietors regarding the lack of immediate responses. In fact, the proprietors did not engage very frequently or consistently with contributors. The contributors averaged 14.5 posts per thread with a median of 5 posts. This shows that proprietors were consistently getting some kind of feedback on their threads. For the most part, the questions asked by contributors were appropriate and not intrusive of the proprietor's privacy. However, proprietors were not responding and creating conversation in most of these instances. In fact, proprietors only responded to, on average, 17% of contributors. For many proprietors, the responses were only a simple "thank you." In a few cases, the proprietor would post a comment saying "thank you" to all contributors rather than respond to each person.

Based on previous research, it seemed likely that caregivers may be more responsive to feedback that offers information and objective feedback, (Wright & Miller, 2006), as well as empathy and understanding (Wright & Rains, 2013). If proprietors did respond more than a "thank you," the response was typically a response to the information provided by the contributor. In one case, a contributor suggested that the proprietor "have a heart to heart with your sister and tell her you need one on one time with just her to vent and recharge. I am sure she just doesn't get how hard it is" (EN1_Com, AgingCare, 2019). The proprietor responded:

I did tell her that I was excited because it would just be her and I, without kids, husbands or my mom. But she already knew I wanted it to be just us then she asks

again about bringing the kiddo. I suggested she take mom and the kiddo and leave me home, she didn't want to do that. (EN1_Resp, AgingCare, 2019)

Only one proprietor asked follow-up questions to the contributors who responded to their thread. In each case, the proprietor showed an empathic response to the contributor's personal story and asked for more detail from the contributor. For example, one contributor shared that their husband died and there was a lack of acknowledgement from many friends. The proprietor responded: "OMG!!! I'm so sorry. That would kill me but i [sic] guess i [sic] should prepare in my head for that, How long was he sick? may i [sic] ask?" (SQ14_Resp, AgingCare, 2019). It stands to reason that proprietors created threads about loneliness in an effort to initiate and maintain social connection with other caregivers. However, very little conversation occurred on the threads with many contributors' comments going unacknowledged on the threads.

Discussion

This study indicated that caregivers on the threads pulled from the AgingCare website were feeling lonely and socially isolated. Other emotions such as sadness and anger were expressed in the threads as well. The contributors provided social support to proprietors by showing emotional support, providing information, commiserating with personal stories, and asking follow-up questions. The responses in the threads did not always elicit further comments from proprietors. There are many possibilities as to why more proprietors did not respond to contributors, but a definitive answer could not be confirmed.

The first research question asked how loneliness was reflected in AgingCare's loneliness threads. The threads show that social and emotional loneliness are addressed simultaneously by the caregivers. Often, the illnesses of their family members caused caregivers to be overburdened, stressed, and isolated from their normal lives, which led to feelings of loneliness. Family members' illnesses were a disruptor in caregiver's lives, and the illness reprioritized the activities caregivers were able to focus on. The absence of friends, family, and activities caregivers once loved could leave caregivers feeling lonely and feeling a sense of loss for social connections that have weakened or waned. Though loneliness was discussed, often other emotions, such as sadness, anger, guilt and frustration, were more focused on in the posts.

For example, many caregivers expressed both sadness and loneliness when their friends and family stopped communicating and socializing with them after their loved one was diagnosed with an illness. Some caregivers expressed anger and loneliness at other people's lack of understanding or empathy, and some caregivers were angry at

family members for not taking better care of themselves. More often than not, loneliness was reflected in subtle ways. Caregivers expressed sadness and anger more demonstratively than loneliness.

Beyond the thread tag, there was often only one mention of the words “lonely” or “alone;” perhaps this was due to the fact that most people mis-identify loneliness as other emotions or that loneliness co-occurs with other emotions. As previous research has found, loneliness can be confused with social isolation (Cohen, 2004) or people can feel the emotion differently based on emotional and social loneliness (DiTommaso & Spinner, 1997). In effect, loneliness is a nuanced and complex emotion that can manifest itself in different ways. In stressful situations, such as caring for a sick loved one, people will go through emotional regulation strategies to modify their reaction to the stressor (Marroquín, Czamanski-Cohen, Weihs, & Stanton, 2016). People can cope by focusing on loneliness as problem and look for ways to manage their environment better, or people can focus on loneliness as an emotion and try to adjust their expectations for social interactions. At times, people cope by drawing on beliefs and values to make meaning out of their experience (Schoenmakers, van Tilburg, & Fokkema, 2015). This complexity leads to loneliness communication that can appear scattered or wrapped up in other emotions, which can lead others to focus on more familiar and less stigmatized emotions like sadness, anger and frustration.

In the second research question, I asked what kind of public responses the caregivers receive. Based on the data, the caregivers were given a great deal of empathic support through sympathetic remarks and affirmations of the pain they were experiencing. The caregivers were also provided a lot of information for improving their

day-to-day experiences with caregiving with such advice as resource recommendations or ways to communicate with others. If specific information was not offered, the caregivers tended to provide a glimpse into their own experiences as a way to commiserate with each other. At times, online communication gives people the anonymity to be blunt and rude (Turner, 2017). Blunt honesty is perceived in different ways, so one person may see a response as harsh while another might see it as sincere and helpful. In sum, the support offered can be harmful and inadequate when people write judgmental things (Shoebottom & Coulson, 2016), when people feel rejected from a lack of responses, and when the content can be too unpleasant to read (Turner, 2017). Even if support is available online, the communication can be counterproductive.

Based on this research, it appears that the AgingCare community makes a sincere effort to be a helpful resource to caregivers who are going through similar difficult circumstances. Every thread had at least one response, and most had at least five responses from contributors. The social network is certainly active. Based on the many references made by caregivers on these threads, this site is a lifeline of sorts; a helpful salve for many caregivers who have lost social connections in their lives and need extra support.

In the third research question, I asked how the caregivers responded to support. In this, I can unpack the crux of the problem. All of the threads created on the forum were answered by at least one contributor. Any response, of course, does not guarantee a helpful response, but there was at least one contributor communicating with every proprietor. However, there was a low response rate from the proprietor back to contributors. In fact, proprietors only responded to, on average, 17% of contributors. For

many proprietors, the responses were only a simple “thank you.” In a few cases, the proprietor would post a comment saying “thank you” to all contributors rather than respond to each person. It stands to reason that proprietors would have a higher response rate if they were seeking social support online.

Conversely, perhaps the proprietors wanted to hear words of support or insights from contributors but had less of an interest in engaging with them. There are many more reasons as to why the proprietor may not have responded to the comments: too busy, did not like the responses, did not want to share more detail, or resolved the issue on their own. Online health forums are most effective when users write engaging content, so proprietors and contributors alike need to contribute to the conversation (Gopalsamy, Semenov, Pasiliao, McIntosh, & Nikolaev, 2017). Regardless of the reason, the proprietors did not appear to have made meaningful interpersonal relationships with contributors in their thread. The caregivers may have been communicating more in other places or taking their communications to private messaging, but there was no way of confirming that within the threads.

Furthermore, the AgingCare website appears to have offered a supportive community of people offering insights and affirmations. The website created an opportunity for caregivers to experience a one-to-many relationship dynamic more readily than a one-to-one relationship dynamic because threads are public and seek input from any contributor. This type of relationship can be useful when other relationships lack support, but it may not be a substantial enough resource to provide the total necessary support people need. The optimal matching theory suggests that social support has the best outcome when the received support matches the goals one has for support

(Cutrona, 1990). If the support provided and the support expected do not align, there can be a “support gap.” Also, when people seek support, they can make a choice as to who to seek support from, so people should choose those who can best achieve the goals they have in mind for social support such as information or emotional support (Francis, 2017). However, in this research, the social support sought by caregivers was online, so the target for support could only be narrowed to topic, not matching support goals *per se*. Instead, the caregivers could respond to messages on the thread that suited their goals and skip over messages that provided social support they did not want.

The AgingCare website—and other websites that target specific groups of people—are helpful for information and emotional support, but communication technology may not solve the problem of loneliness in this context. The asynchronous communication of a website can be improved with technology such as instant messaging and video communication (McQuillen, 2003), but this may be challenging to accomplish on a consistent basis. Instead, these problems may be better solved on a localized basis, so people are able to make contact with people in their own community who can readily address particular needs (Matsaganis, Golden, & Scott, 2014). Technology may not be the ultimate solution to providing social support, but it can be paired with a larger emotional support strategy if people want to diminish feelings of loneliness. Of course, a person may be unable to find local solutions, so technology can be that supplemental resource until other solutions can be found.

Limitations

Not all of the data examined were relevant for the purposes of this study, which caused a smaller data set than desired. Nearly half of the posts pulled from the website

dealt with a caregiver discussing concerns of loneliness for their ailing family member instead of a caregiver expressing personal feelings of loneliness. Furthermore, while the data provided some insight into the way caregivers approached loneliness and what type of verbal support was provided to the proprietor, there is no way to measure if loneliness was actually diminished after the proprietor started a thread. By self-disclosing feelings of loneliness on the forum, some caregivers may feel some relief and connection, but such a revelation cannot be confirmed.

Future studies are encouraged to widen the breadth of data examined and dedicate more resources to the research process. With more coders working on a content analysis, the sample set could have been expanded to a longer timeframe or to more websites so that more examples could be examined. Also, future studies could try to get access to private messages exchanged on the websites to determine if caregivers are communicating further outside of threads. I could not determine if the comments exchanged on the threads led to private conversations and personal relationships, but there was no evidence that these relationships were being created. In addition, the content analysis could have been paired with a survey or interpersonal interviews to round out the information gleaned from the content analysis.

The content analysis does have some limitations due to the inherent nature of interpretation of meaning without full context. As with any content analysis, the context of the texts analyzed are based on the interpretation of the communication analyst and do not represent a holistic interpretation of the texts (Krippendorff, 2004). For example, some of the content categorized as supportive could be interpreted differently by another person. In one case, a contributor wrote: "I remarried 2 years before dementia arrived on

the scene... mine is wonderful, supportive and in spite of the hardships, steadfast. Yes, they do exist ladies... and I'm just affirming that partners like that are out there”

(LM4_Com, AgingCare, 2019). One could argue that her comment was meant to provide hope by urging her to believe that decent partners are real, but my interpretation was that the contributor appeared smug and like she was rubbing the proprietor's nose in her good relationship. There are multiple ways to interpret a comment like that, which highlights how helpful nonverbal cues and vocalics could help clarify the tone. As the sole coder for this research, there was only one interpretation of the data.

The data examined were created by people online, so nonverbal communication and contextual information was not there to round out the full interpretation of the written analysis. Furthermore, cultural and individual differences could create an unconscious bias or inaccurate view of the sentiments expressed on the website. For example, my lack of caregiving experience, my age, and my socioeconomic background could subconsciously affect my understanding of the communication posted online.

Suggestions for Future Research

The content analysis was a useful exercise to see how a population vulnerable to loneliness communicated those feelings on a computer-mediated forum, but there are many ways to build on this research. A quantitative survey sent to the caregivers on these sites would be helpful to understand if the forum provides social and emotional support or to what extent, if at all. A qualitative interview of caregivers or other populations vulnerable to loneliness (e.g., single, low-income, rural residents) would be helpful as well to understand the unique challenges people face in communicating loneliness and alleviating loneliness.

Specifically, one possible trend I noticed in the research was that a significant proportion of proprietors and contributors on these threads dealt with the caregiving of a loved one with dementia or Alzheimer's disease. Alzheimer's disease is the main cause of dementia, which is defined as "memory impairment and executive dysfunction interfering with daily life activities" (Scheltens, Blennow, Breteler, de Strooper, Frisoni, Salloway, & Van der Flier, 2016, p. 505). Caregivers discussed the fear and anxiety people have about dementia and how much the topic is avoided by their social networks. A lack of social support can affect any caregiver, but it seems that caregivers of loved ones with Alzheimer's and dementia may be the most isolating. In future research, caregivers of family members with Alzheimer's and dementia may be a good population to target.

The content analysis was one step in what could be a more dynamic and holistic study of loneliness. More interpersonal and qualitative research could expand on the budding ideas of this research, particularly among caregivers and other lonely populations. Furthermore, I would like to see more research being translated into practical advice for the public so lonely individuals can ask for and receive more social support.

When the proprietor looked at the whole, they were satisfied, but no one was enough to make them strike a relationship or move forward. If you look at all together, they get all the needs satisfied.

Conclusion

Loneliness is an aversive state that can affect a person both physically and mentally. It differs from social isolation in that social isolation is an objective state while loneliness is a subjective state, but the two may occur together. Certain populations, like caregivers, are more vulnerable to both loneliness and social isolation. Through an analysis of posts to AgingCare.com, a website dedicated to the needs of caregivers, I was able to examine communication by caregivers about their loneliness in an online setting designed to support their needs. The resulting analysis showed that while loneliness was discussed by caregivers, it appeared to be seen as the symptom of other problems rather than the problem itself. Caregivers were seeking support, but I could not confirm if the support provided addressed and alleviated the caregivers' loneliness or simply provided a platform for caregivers to speak about loneliness and receive empathic responses from others. Online communities provide space and attention for caregivers who need to discuss their feelings and issues, but it was less clear if problems like loneliness are being solved in online forums. This research can serve as a stepping stone for future research aimed at improving loneliness communication online and in face-to-face settings.

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Appendix

Table 1. Data from Threads for Loneliness on AgingCare.com between August 2018 and January 2019

| Proprietor Post | Contributor Post | Proprietor Responses | | |
|-----------------|------------------|----------------------|-------------------------------|------|
| 1 | 20 | 7 | | |
| 2 | 5 | 1 | | |
| 3 | 2 | 1 | | |
| 4 | 45 | 12 | | |
| 5 | 5 | 0 | Total Proprietor Posts | 17 |
| 6 | 32 | 2 | Total Contributor Responses | 248 |
| 7 | 16 | 2 | Total Proprietor Responses | 36 |
| 8 | 3 | 0 | Mean (Contributor) | 14.5 |
| 9 | 5 | 3 | Median (Contributor) | 5 |
| 10 | 5 | 1 | Mode (Contributor) | 5 |
| 11 | 5 | 0 | Min (Contributor) | 1 |
| 12 | 1 | 0 | Max (Contributor) | 52 |
| 13 | 5 | 1 | Mean (Proprietor Responses) | 2.1 |
| 14 | 21 | 5 | Median (Proprietor Responses) | 1 |
| 15 | 23 | 1 | Mode (Proprietor Responses) | 0 |
| 16 | 52 | 0 | Min (Proprietor Responses) | 0 |
| 17 | 3 | 0 | Max (Proprietor Responses) | 12 |

Table 2. Codebook for Proprietors in Threads

| Codebook Category | Description | Example |
|-----------------------------------|---|--|
| Uses terms in post (count) | The caregiver uses the terms lonely, alone, or isolated | 2 tags: lonely, alone |
| Describes emotional loneliness | The post discusses feeling disconnected from those around him or her | <i>I have received no help, no emotional support, no understanding</i> |
| Describes social loneliness | The post discusses not having a sufficient number of friends and family in their interpersonal life to feel togetherness. | <i>I literally don't have any other family to ask for help or advice from.</i> |
| Describes situational loneliness | The post discusses not having sufficient social support due to circumstances beyond their control. | <i>My friends have their own lives and barely call anymore now that my husband is sick.</i> |
| Describes transitional loneliness | The post discusses not having sufficient social support due to a life change such as moving, a break-up, or death. | <i>I am alone in a retirement community.</i> |
| Other emotions | | |
| Describes sadness | The caregiver describes sorrow or lack of joy | <i>I seem to be very sad all the time.</i> |
| Describes anger | The caregiver describes feeling annoyed, displeased, or hostile | <i>I can feel my blood pressure rising! At this point I feel angry that I didn't protect myself from this soon enough!!!</i> |

Table 3. Codebook for Contributors in Threads

| Codebook Category | Description | Example |
|--------------------------|---|--|
| Emotional support | Contributor provides emotional support such as empathy, sympathy, or validation | <i>Loneliness, depression and anxiety go along with caregiving, you are not at all unusual, it happens to all of us.</i> |
| Information | Contributor provides ideas and information to help the problem | <i>Take vacations without him. Don't feel guilty going out to dinner with other couples. Keep involved with friends and things you like to do.</i> |
| Personal story | Contributor shares a personal experience related to caregiving or similar life circumstances. | <i>My mom will say mean and hurtful things, but I have to remember that it's the dementia.</i> |
| Questions | Contributor asks questions for caregiver to follow-up on and creates an opportunity for a conversation to begin | <i>Tell us more about dad. How old is he? Does he have any medical issues? Does he still work?</i> |