ALZHEIMER'S FACEBOOK SUPPORT GROUPS: USES, GRATIFICATIONS AND PERCEPTIONS OF INFORMATION ACCURACY FOR CAREGIVERS

by

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Abstract

This study was designed to explore how Alzheimer's caregivers use Facebook support groups. Specifically it describes what kinds of activities caregivers engage in when in Facebook support groups, explores the motivation behind participation, and details perceived advantages and disadvantages of the groups. Whether Facebook support groups are considered a primary and accurate source of disease information was also explored.

The study was qualitative in nature and consisted of 20 caregiver interviews, conducted via phone and Skype. Guided by uses and gratifications theory (Katz, Blumler & Gurevitch, 1974), the study employed six research questions to fully explore the experiences of caregivers in Facebook support groups. Generally speaking, the study identified the primary theme of community, and three subthemes including context, advice and emotional release/support. There were also significant findings on the primacy and accuracy of information. The ability to more fully understand these themes in the context of the caregiver experience will provide health care professionals with a foundation on which they can build effective ways to tap existing Facebook support groups and bolster support as the Alzheimer's epidemic grows exponentially between now and 2050.

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Chapter 1 - Introduction

A greater number of people are becoming affected with dementia with current estimates at 35.6 million globally, though by 2050 this number is expected to triple (World Health Organization and Alzheimer's Disease International, 2013). Alzheimer's disease is one of the primary forms of dementia, and in the United States alone it is the sixth leading cause of death among all adults, presently affecting 5.3 million people (Alzheimer's Association, 2015). As baby boomers age in the U.S., the threat posed by Alzheimer's disease is expected to grow to as many as 16 million people by the year 2050 (Theis & Bleiler, 2011).

Due to the expense of health care, the inadequacy of social security funding and the practice of keeping the elderly at home as long as possible, the responsibility of caring for those with Alzheimer's often falls to family. In 2010 family members and other unpaid caregivers provided $202 billion in care for those with Alzheimer's and other forms of dementia (Theis & Bleiler, 2011). With the projected growth in the number of those afflicted by Alzheimer's, it is likely that familial caregiving will continue to be the norm. The need to ensure that these familial caregivers receive proper training and have an adequate support network will become more than evident, particularly since the caregiving experience has a great emotional and psychological toll (Beinart, Weinman, Wade & Brady, 2012; Knickman & Snell, 2002), and even more so in the case of adult children providing care (Diwan, Hougham & Sachs, 2004).

Support groups are one way to provide both the latest health-related information and emotional support to this audience. For some though, there can be barriers to participation in face-to-face groups. Research has detailed challenges including the inability to find reliable transportation to meetings, difficulty making time to participate, a perceived lack of confidentiality, or not knowing of existing groups (Biegel, Shafran & Johnsen, 2004). Tanis, Das

and Fortgens-Sillman (2011) also found that caregivers are often reluctant to admit they need help and that they have trouble leaving their charges, even for short periods of time. The virtual nature of online groups gives participants the ability to take part when they have time, to get information when they most need it, to respond and offer support to others at their convenience, and do so with relative anonymity thanks to the computer screen (Colvin, Chenoweth, Bold & Harding, 2004). Social media platforms like Facebook have great potential to help familial caregivers meet the challenges they face by providing social community. Also, use of Facebook by those aged 50 and older is on the rise at a greater rate compared to other age groups (Madden, 2010). This statistic is notable as the average age of those providing care to the elderly is 48-years-old, according to the National Alliance for Caregiving (2009).

Research has also tied social media usage to emotional and social well-being, aligning with some of the potential needs of Alzheimer's caregivers. The Pew Research Center's Internet and American Life Project found that making friends correlated with feelings of social support, and that updating one's status was connected to feelings of emotional support (Hampton, Goulet, Marlow & Rainie, 2012). The act of writing, in general, has also been historically tied to positive emotional outcomes (Pennebaker, 1997). Health communication is also increasingly taking place online and via social media, which is why social networking sites like Facebook have become a virtual breeding ground for online support groups and information related to health (National Research Corporation, 2011; Fox & Jones, 2009).

Given that the online environment is becoming more influential in the realm of health, and the fact that the caregiving demographic is already active, this venue would seem a natural place to provide support and information to a group that will increasingly need both.

Problem Statement

As baby boomers age, more families will be faced with the dilemma of providing care for their ailing elders. Because of the devastating impact of Alzheimer's disease and the increasing demand on families (Beinart, et al., 2012; Schulz & Martire, 2004), more caregivers will turn to the internet and social media for health information and emotional support. However, there is limited understanding of how Alzheimer's caregivers use Facebook support groups, what compels them to participate, and whether the accuracy of information presented in these groups matters.

This purpose of this study is to examine how Alzheimer's caregivers use Facebook support groups. It describes what kinds of activities caregivers engaged in as part of Facebook support groups, explores what motivates caregivers to take part in the groups, and details the perceived advantages and disadvantages of the groups. Whether Facebook support groups are considered a primary and accurate source of disease information is also explored.

Support groups, whether online or off line, can act as a community based on common experience, as well as an information resource (Tanis, et al., 2011). Content wise, studies have parsed the activity taking place in these groups into categories including experience sharing, advice on disease management and network-building, in addition to commercial promotion and pure health education (Greene, Choudry, Kilabuk & Shrank, 2010; Heller, Roccoforte & Cook, 1997). The benefits of story sharing online are also many (Gooding, et al., 2011; Ziebland & Wyke, 2012), though these sometimes very personal stories are often shared via open platform. Alzheimer's support groups hosted via social media offer both social support and health information, and the opportunity to tap into the expertise and experiences of others to become a better caregiver, whether by dealing with the emotional toll or by training on the latest methods of care. Overall, researchers agree that positive outcomes result from social support. The sharing and educational roles of face-to-face support groups clearly have a

psychological, if not a resulting physical impact, on health and health care (Uchino, Uno & Holt-Lunstad, 1999; Spiegel, Bloom, Kraemer & Gottheil, 1989; Goodwin, et al., 2001; Ziebland & Wyke, 2012, Beinart, et al., 2012). This is why it is so important to study the needs of caregivers and how social media support group participation might gratify them.

However, social media support groups are also largely unmonitored by trained health officials or medical experts. Also judging the quality of information, prolific though it may be, can be problematic since social media users are both consumers and producers of information. How well group participants understand the openness of online groups also varies depending on a number of demographic factors – like age, education, gender, and cultural background (Joinson, Reips, Buchanan & Paine Schofield, 2010), in addition to health literacy considerations. In fact after assessing health literacy levels of paid caregivers for seniors, Lindquist, Jain, Tam, Martin and Baker (2010) found that health literacy was inadequate in around 40 percent of cases, and that as a result these individuals typically made more errors when performing duties like giving medicine. Bostock and Steptoe (2012) also noted that doctors often overestimate the health literacy of their patients and caregivers. If health care professionals are to effectively tap into these groups, they must adapt how both offer support and information within this context.

Through the lens of uses and gratifications theory (Katz, et al., 1974; Urista, Dong & Day, 2009), this study clearly describes how a subset of the caregiving population uses Facebook support, what motivates them to take part and what participation looks like, what they see as the plusses and minuses of the groups, and whether they consider information shared to be accurate. Uses and gratifications theory is an audience-focused theory that deals with how an active audience chooses the most satisfactory gratification source(s). The theory is known for focusing on what people do with media, as opposed to how media affect them. With a growing number of online support groups related to

Alzheimer's, it is important to understand what needs are being gratified, why users decide to join these groups, and what they perceive as the benefits of participation. Knowing this information will assist health care professionals and communicators as they look at whether and how this medium may be employed to improve health outcomes for Alzheimer's patients and caregivers.

Justification

With the aging of the baby boomers, the pure number of people in the U.S. suffering from Alzheimer's disease is expected to more than triple by 2050 (Theis & Bleiler, 2011). Combine that with the prohibitive cost of health care (Alzheimer's Association, 2015) and the cultural practice of keeping the elderly in their homes as long as possible, and a largely unpaid and overworked class of familial caregivers emerges. In the face of this trend, one that will levy a psychological toll (Knickman & Snell, 2002; Beinart, et al., 2012), a deeper understanding of how social media support groups benefit caregivers will help health care professionals develop more effective online support for caregivers.

Though there is literature touting the benefits of social media for health and calling for hesitant health professionals to jump on the social media bandwagon (Hawn, 2009; McNab, 2009), how those in the health care industry can tap into the organic activity that is already happening on social media platforms like Facebook has been largely ignored. Understanding more deeply what motivates social media support group participation, and how it enables caregivers to better perform their duties has yet to be explored in detail in the literature. Given the current state and anticipated growth of Alzheimer's disease, doctors, nurses, psychologists, counselors and other medical and psychological professionals could use Facebook to provide the latest and greatest information about Alzheimer's. However, to do this well, one must clearly understand the needs of caregivers and how they are being met in this venue. Out of this study, the researcher will provide health care practitioners and communicators with a strong foundation on which to build best practices on how to engage with Facebook support groups to improve

health related outcomes for those afflicted with Alzheimer's and those who care for them.

Thesis Organization

Following this introduction, the thesis is organized into four consecutive chapters. Chapter 2 is a comprehensive review of the relevant literature, and includes the theoretical framework and proposed research questions. Chapter 3 details the methodology around qualitative interviews and describes the study's participant pool, method of sample recruitment, in addition to study design and data collection and analysis. Chapter 4 describes the study's key findings and Chapter 5 includes a thorough discussion of the study's conclusions, practical and theoretical implications, plus recommendations for future research and limitations.

Chapter 2 - Review of the Literature

This review of literature addresses the prevalence of Alzheimer's disease, the burden placed on familial caregivers, use of the internet and social media for health information and emotional support, in addition to information accuracy in the online space. This chapter also describes the theoretical framework of the study, which is guided by uses and gratifications theory (Katz, et al., 1974).

The Growing Alzheimer's Epidemic

Every 67 seconds someone in the U.S. develops Alzheimer's disease and two-thirds of those afflicted are women (Alzheimer's Association, 2015). As American baby boomers grow older, the threat posed by Alzheimer's disease is expected to grow to as many as 16 million by 2050. This drastic increase is related to not only the sheer number of baby boomers, but also the number of life-extending medical advances made over the last half a century (Theis & Bleiler, 2011).

Alzheimer's disease is the most common form of dementia, accounting for up to 80 percent of dementia cases in the U.S. Alzheimer's disease typically starts with memory loss and confusion concerning recent events, but instead of being the occasional bout of forgetfulness the symptoms persist (Alzheimer's Association, 2015). Those with Alzheimer's disease may ask questions repeatedly, struggle with the concept of time, and may forget the names of everyday things and people that should be familiar to them (Mayo Clinic, 2014). The development and progression of the disease varies from individual to individual, but it can also result in depression, personality changes, sleeping related trouble, loss of inhibitions and mood changes. The root cause of these symptoms is damage to and the death of neurons in the brain. Research

has connected the disease's onset with the development of protein plaques and twisted proteins in the brain. Age, family history, genetics, education, and one's mental and social activity are all risk factors for the disease (National Institute on Aging, 2012).

At the core of the Alzheimer's crisis is the fact that though clinical medical research has enabled Americans to live longer, the health care infrastructure needed to support a certain quality of life has not kept up. The economic strain of Alzheimer's disease on the U.S. economy and health care system is also significant. In 2015 along, Medicaid spending on Alzheimer's and other dementias was expected to be $41 billion. Payments supporting overall health care, plus hospice and long-term care were also projected to climb to $1 trillion in 2050 for those with Alzheimer's disease, up from an estimated $226 billion in 2015. What these figures don't include is the 18 billion hours of unpaid care provided by millions of family members in the U.S. (Alzheimer's Association, 2015).

In addition to the financial impact, the emotional and psychological strain experienced by familial caregivers is costly. More than paid caregivers, familial caregivers experience severe levels of emotional stress and depression (Beinart, et al., 2012; Diwan, et al., 2004; Knickman & Snell, 2002), which can impact their physical and emotional health. This also ultimately impacts their ability to care properly for their loved ones. Due to the devastating impact of Alzheimer's disease and the increasing demands placed on family, ensuring that caregivers are properly trained and have adequate support is emerging as a critical issue. Having the latest medical information in addition to effective coping mechanisms will enable caregivers to better deal with the challenges of caring for a deteriorating family member.

Online Health Communication and Social Media

Eng (2001) provides an accessible definition of eHealth as "the use of emerging information and

communication technology, especially the internet, to improve or enable health and health care" (p. 1). Research has supported many times over the notion that the internet is a popular place to seek health information (Eysenbach, 2003). Fox (2011), in particular, noted that 80 percent of users turn to the internet for health information and that activity was third only to emailing and search engine use. Of those seeking information on chronic conditions, more than a quarter of internet users have seen or read about someone else's health-related experience and 16 percent tried to locate others with a similar condition (Fox & Duggan, 2013). Individuals seek information on a variety of afflictions and believe that what they find is as good, or better, than information received from trained medical providers. In addition, many go online to seek second opinions, do not share the information with their doctors and are motivated to do so because they believe their doctors are too busy (Diaz, et al., 2002).

For social media specifically, a 2011 survey by the National Research Corporation revealed that one in five Americans used social media specifically for health care information. Facebook was reportedly the most popular platform, followed by YouTube, Twitter, MySpace and Foursquare. Though respondents in that survey said hospital websites were still the most reliable source of health information, one in four claimed that social media was "likely" or "very likely" to influence their health care decisions (NRC, 2011). Work by Duggan and Smith (2014) supported this trend, showing that 71 percent of online adults use Facebook, though 42 percent of that same research pool reported using two or more of the five social media sites examined – Facebook, Twitter, Instagram, Pinterest and LinkedIn.

Social media is being used more and more for health education according to Gorham, Carter, Nowrouzi, McLean and Guimond (2012). Web 2.0 has created the ability to not only share information widely, but to have others interact with and share messages, in addition to creating new and unique content. For health communicators, it is no longer enough to disseminate information to the masses – one must establish a meaningful dialogue. The Health Communicator's Social Media Toolkit from the

Centers for Disease Control (2011b) notes that social media has expanded the reach of health

information and is a powerful tool that has created broader access to up-to-the-minute scientifically

backed health information. McNab (2009) describes social media for health as instant and without

borders, stating plainly that it has the power to spread information "faster than any influenza virus" (p.

566). Social media for health, however, isn't without a negative side.

When examining the types of health information shared and behaviors within social media

groups, researchers have found experience sharing and group support makes up the majority of health-

related activity (CVS Caremark/Harvard, 2010; Greene, et al., 2010). Advertising was next in line, most

notably testimonials endorsing unofficial products and remedies. Greene and colleagues dissected the

content of diabetes-related Facebook support groups into four types of user behavior: promotion,

support, recruitment for research, and queries about non-traditional forms of disease management. This

research also acknowledged the sometimes questionable nature of online health information and the lack

of organized regulation. This study also revealed that sensitive information not likely to be shared with

medical professionals was imparted in the Facebook support groups they studied. Unequal access to

computers and inadequate levels of health and technological literacy can also impact one's ability to get

to, seek out and discern whether health information online is helpful or potentially hurtful. This is why

Collins and Lewis (2013) argue that health care providers should provide a list of vetted online health

resources to their patients.

Public health agencies in the U.S. have tackled this problem by investing heavily in their own

interactive presences. For instance, the National Institute of Health's National Library of Medicine

offers a mobile version of MedlinePlus (http://m.medlineplus.gov), marketed as "Trusted Health

Information for You." Users may interact with MedlinePlus using a wide variety of channels including

RSS feeds, weekly podcasts, Twitter, and others. The AIDS.gov website, managed by the U.S.

Department of Health and Human Services, also features a variety of interactive options (www.aids.gov). Corporations have also realized the value of mHealth – or mobile health – and are developing apps intended to engage audiences and provide a service, though there are both challenges and promise when it comes to mobile technology's potential to better public health via broad application (Istepanian, Jovanov & Zhang, 2004).

Beyond basic access, the way in which the information is presented is also important. This is particularly true when it comes to cultural considerations and one's ability to understand and use the information provided (Talsma, 2012). For mobile platforms in particular, applications can be a popular and effective way to engage health care consumers. Further, this has been recognized by the marketplace. Research2Guidance, a market research firm, estimated in 2010 that 500 million people – one in every five worldwide – will be using healthcare apps of some sort by 2015 (Mikalajunaite, 2010). Smartphones also bring users closer to their online social networks, providing increased access without physical boundaries. In 2012, comScore reported that Facebook's mobile app was the second most popular download in the U.S. for smartphones (Radwanick, 2012). Being that 85 percent of U.S. adults own a cell phone and that 45 percent own smartphones, these statistics are highly relevant, especially since searches for health information are becoming increasingly more mobile (Fox & Duggan, 2013).

Health information consumers will be further attracted by technology's ability to personalize the user experience and provide interaction at a consumer's fingertips (Cline & Haynes, 2001; Neuhauser & Kreps, 2003). Not only are these powerful marketing concepts, they are key characteristics of successful social media platforms (Boyd & Elison, 2008). Information presented as personally relevant is more likely to influence behavior, the ultimate goal of many if not all health communication campaigns (Kreuter, Farrell, Olevitch, & Brennan, 2000).

The Digital and Literacy Divides

When online the search for health-related information is one of the most popular past times, with 80 percent of internet users taking part (Eysenbach, 2003; Fox, 2011). However, access to the hardware used to search the internet is not equal, nor is the capacity to understand and use the information. When considering how best to employ the online venue as a communication tool, one must account for both access and literacy levels.

When it comes to access, there are documented disparities in computer ownership between Caucasians and African Americans, and others (Gibbons, 2005; Lenhart, 2003). Though technological access is central to the digital divide (Gibbons, 2005; Spooner & Rainie, 2000), that access is rapidly changing with the availability of mobile hardware. In 2011, Livingston found that African Americans' use of the mobile internet was growing at a rate faster than any other ethnic group, and that access to phones with mobile internet capabilities was on the rise for Hispanics/Latinos. That study noted that 6 percent of Hispanics/Latinos and African Americans, compared to 1 percent of Caucasians, reported accessing the web from a cell phone and had no other internet service at home (Livingston, 2011). This isn't surprising since of those owning cell phones in the U.S., nearly 65 percent now have internet capable smartphones (Nielsen, 2013).

Access aside, the ability of individuals to interpret and use the health information they find to improve their health is another key factor. This concept is also known as health literacy and is defined by the CDC (2011a) as the "degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions." Though technology enables people to efficiently connect, interact with and create health information, this does not mean that all can decode and utilize it equally. The usage piece is often referred to as functional health literacy, defined as one's ability to apply

the skills of literacy to health related tasks and information (Nutbeam, 2000; Parker, Baker, Williams & Nurss, 1995).

Like with technological access, education, income level, language and culture, are the most often cited influences on one's ability to effectively utilize health information (Cashen, Dykes & Gerber, 2004). According to the 2003 National Assessment of Adult Literacy, those who could benefit most from health interventions often don't have the capacity to understand the information. That study uncovered that only 20 percent of adults with low literacy got health information from the internet, compared to 60 percent with high literacy (Baur, 2008). Likewise, children from lower income homes, and whose parents have a high school diploma or less education are far less likely to use a computer to find health information (Brodie, et al., 2000). In a study of whether patients used a diabetes-focused patient portal, African Americans, Latinos and Filipinos were less likely to use the portal, as were those with lower education levels (Sarker, Schillinger, Lopez & Stone, 2010).

For caregivers specifically, functional health literacy is central to providing excellent care. In assessing health literacy levels of paid caregivers for seniors, Lindquist and colleagues (2010) found that health literacy was inadequate in around 40 percent of cases, and that these individuals typically made more errors when dispensing medication. This study, in addition to work by Bostock and Steptoe (2012), note that doctors often overestimate the health literacy of their patients and caregivers. Presumably, these caregivers have received more formal training than a familial caregiver.

Bodie and Dutta (2008) argue that one's ability to interpret health information and take action can also be influenced by how messages are targeted and tailored. Further, knowledge and understanding can be increased depending on how the messages are delivered. To meet the needs

of those with lower health literacy, Sarker et al. (2010) called for more visual website design, in addition to highlighting the need to consider social and cultural barriers, and to develop targeted messaging. As the U.S. becomes more diverse, these studies also highlight the importance of accounting for demographic factors and cultural differences when presenting health information on the internet. According to the U.S. Census's website, 73 percent of the population was Caucasian on 2010, down from 75 percent in the 2000 U.S. Census. The number of African Americans also grew from 12.3 percent to 13 percent, while the Hispanic/Latino population grew from 12.5 to 15 percent of the U.S. population. Between 2007 and 2012, the poverty rate also grew to 15 percent, from 12.5, and overall education levels are on the rise (www.census.gov). All of these factors have been tied to the ability of individuals to locate, interpret and use health information. Therefore, cultural, social and economic factors should be considered when developing the best ways to accomplish health communication within the context of social media.

Strategic Use of Support Groups in Health Communication

Research has documented the positive impact of support group participation on physical, emotional and psychological health. Improved physical health and longer life for patients has been linked to participation in face-to-face support groups (Uchino, et al., 1999). Positive correlations between social support and the ability to cope (Baum, 2004; DuPertuis, Aldwin & Bosse, 2001) and an increased ability to manage pain related to illness have also been found (Goodwin, et al., 2001). Pector (2012) cited Irvin Yalom's major therapeutic factors related to online support groups, claiming that group participation brings about "hope, universality, cohesiveness, catharsis, information attainment, interpersonal learning, and helping others" (p. 20), adding that these benefits can be realized both in person and online. Lepore, Buzaglo,

Lieberman, Golant and Davey (2011) also found positive psychological effects related to the act of providing support to others. In other words, participants seeking relief felt better because they were also able to support others. Overall, researchers agree that positive outcomes can result from social support, but whether how the audience is engaged makes a difference has yet to be fully defined by the literature.

In addition to the emotional rewards of support group participation, such groups can also be a critical information resource. Heller et al. (1997) view support groups as a venue within which the latest information about a disease is presented, particularly since face-to-face support groups are often facilitated by trained moderators. For Barak, Boniel-Nissim and Suler (2008), information and knowledge acquisition is a key aspect of participant empowerment, which they argue is the ultimate purpose of support group participation. Other empowering aspects of online support group participation noted by Barak and colleagues include catharsis via writing about experience, the recognition and validation of emotion, and increased feelings of belonging. The immediacy of social media, therefore, should be attractive when it comes to sharing the latest health information on Alzheimer's disease and care.

Despite the many benefits of support groups, there are also barriers that deter participation. Face-to-face groups are designed to provide a safe environment where people facing similar issues can share their experiences and gain knowledge in an effort to help them cope with the challenges of the situation at hand. A study of face-to-face support groups catering to those caring for mentally ill family members noted many of the above benefits, in addition to barriers (Tanis, et al., 2011). Primarily, those barriers dealt with lack of time and access. Tanis and colleagues also noted that caregivers were conflicted about leaving their charges, even temporarily, and that in many cases they were often reluctant to admit that they needed support. Because online groups are virtual they have the potential to provide access and

interaction when convenient for the end user, thus directly removing some of the most significant barriers to participation. Similarly, Urista and colleagues (2009) found the ability to respond to posts, comments, and questions at a convenient time was a benefit noted by young adults when asked why they used social networking sites. Other noted benefits of online support groups include anonymity provided by the computer screen (Colvin, et al., 2004) and the ability to write about one's experience, which has proven cathartic effects (Barak, et al., 2008; Pennebaker, 1997). The ability to share of oneself in these groups can also lead to what Barak and colleagues call the disinhibition effect, where one is able to create a sense of intimacy and bonding more readily with group members.

Though anonymity is an often cited benefit of online support groups, it can also be troublesome. Among the limitations of online support groups, Pector (2012) lists the possible misinterpretation of comments due to the lack of physical cues. The inability to effectively intervene in a crisis was also noted as a limitation. Other potential downsides addressed elsewhere in this thesis include limited access for those without a computer, smartphone or the ability to afford paid internet service, and the impact of health and technological literacy on one's ability to reap the benefits of available emotional and informational support.

Some research has explored the kinds of activities in which online support group participants engage. Support groups, whether online or off line, act as a social community, as well as an information resource (Tanis, et al., 2011). Content related studies have identified experience sharing, advice on disease management and network-building taking place in these groups, in addition to commercial promotions and health education (Greene, et al., 2010; Heller, et al., 1997).

Alzheimer's support groups hosted via social media offer both social support and health information, both of which have great potential to empower caregivers. The study examines how and why caregivers use Facebook support groups and the kinds of activities they take part in, in addition to

the reported advantages and disadvantages, and the role of information accuracy.

Accuracy of Online Health Information

When seeking information online, determining how accurate it is can sometimes be a challenge, particularly on social media platforms. Due to the nature of social media, where users are both information consumers and producers, individuals are forced to make judgements about what is and isn't accurate and these judgements are influenced by several factors. Literature to date has broadly examined what influences perceived credibility.

Greer (2003) examined how online news was judged, finding that how closely the information was affiliated with a recognizable news brand was key. Other influential characteristics identified were spelling, grammar, URL, professional visual presentation, perceived bias, plus source authority indicators like credentials, contact information and currency of information posted. Other indicators of authenticity included how individuals heard about a site, such as from friends or family, how high it was ranked by search engines, and whether it appeared to be backed by an authority (e.g. by a university). Greer's study stopped short, however, of examining information consumption and accuracy. Diaz, et al., (2002) identified university or medical society sponsorship as key factors indicating source reliability, while Lederman, Fan, Smith and Chang (2014) claimed that short of a source's authority, those seeking health information online will seek out corroboration for scientific information and look for consensus regarding others' experiences. In Diaz and colleagues' study (2002), patients reported that they considered the information they found more reliable only after discussing it with their physician. More than one study called for physicians to identify good online sources for health information (Collins & Lewis, 2013; Diaz, et al., 2002; Hawn, 2009), concluding that patient use of these outlets was inevitable.

On social media platforms, determining what is accurate or reliable is complicated by the fact that users also create or share existing content. Flanagin and Metzger (2011) studied how

information presented via user-generated Wikipedia is perceived compared to Encyclopedia Britannica, in addition to a lesser-known online encyclopedia. While they found that credibility lies in the "idea of expert-generated (or vetted) content" (p. 371), user-generated content was deemed as credible under certain circumstances.

Theoretical Framework

Uses and Gratifications Theory

How web-based venues are used to deliver online health information and why individuals seek it there is best explained by uses and gratifications theory (Katz, et al., 1974). Contrary to the notion that media influences the masses, this theory focuses on an active media consumer who is motivated to engage with media, and who has particular needs gratified as a result. Briefly, the theory is "concerned with: (1) the social and psychological origins of (2) needs, which generate (3) expectations of (4) the mass media or other sources, which lead to (5) differential patterns of media exposure (or engagement in other activities), resulting in (6) need gratifications and (7) other consequences, perhaps mostly unintended ones" (Katz, et al.,1974, p. 510). Specific media are intentionally chosen to fill very particular needs and the various mediums compete to become the top gratification source (Katz. et al., 1974).

This study concerns itself with how Alzheimer's caregivers use Facebook support groups. It describes what kinds of activities caregivers take part in when engaged in Facebook support groups, explores what motivates caregivers to take part in the groups, in addition to detailing the perceived advantages and disadvantages of the groups, and the role of information accuracy.

Much of the early uses and gratifications research was developed with news media in mind, particularly of the print variety. The body of work then expanded to television and other media types (Katz, et al., 1974; von Feilitzen, 2004; Palmgreen, Wenner & Rosengren, 1985).

Given the participatory nature of social media – where those using it are both consuming and producing content – studying why and how this venue is used by Alzheimer's caregivers, what needs are fulfilled as a result, and the function of gratified needs is a compelling application.

Urista et al. (2009) used this theory to examine why young adults used MySpace and Facebook and found efficient and convenient communication, popularity, and relationship formation among the top motivators. The ability for social media users to repost existing online content (i.e. citation) can facilitate interpersonal communication about various health topics, in addition to making such information seem more valuable. Gorham, et al., (2012) noted the ability to create a timeless dialogue via social media, which allows those online to use social media to cater to specific needs.

Palmgreen et al. (1985) drew a distinction on the gratifications side of the theory, noting the difference between gratifications sought and gratifications obtained. This distinction has been recently applied in comparing the use of Facebook versus instant messaging (Quan-Haase & Young, 2010), with a focus on which characteristics of particular online mediums motivate individuals to choose and, ultimately, reinforce that choice. Motivators identified by Quan-Haase and Young (2010) that apply to online support group participation by Alzheimer's caregivers include: the ability to share problems, sociability and social information. This is directly in line with Katz and colleagues' (1974) original research that examined how the gratifications of one media source set it apart from others. Other research has looked into how social media use is also driven by emotional and habitual need (Wang, Tchernev & Solloway, 2012), further supporting the notion that the reasons for participation could be connected to the specialized needs of Alzheimer's caregivers for quick and convenient access to both information and social support.

Von Feilitzen (2004) developed functional groups into which gratifications could be categorized: entertainment and emotional; information and cognitive; social; non-social and escapist; and mode of consumption. These groupings guided the researcher's coding of survey participant's responses on questions delving into gratifications sought and received from group participation. Due to the ability of Facebook to facilitate customized interaction, they are also well-equipped to meet an individual's particular need at practically any point in time. This is true regardless of what kind of gratification an individual is seeking. In the case of Facebook- based support groups for Alzheimer's caregivers, users can log on to look for information and ask questions (information), can view or contribute funny stories and inspirational content (entertainment), can share their own experiences and psychological struggles (personal identity) and receive emotional support or offer support to others (social support and escapism). They can also do so at any time, which ties into von Feilitzen's functional group of mode of consumption (2004). Via uses and gratifications theory, this study analyzes the reported functions of social media participation for Alzheimer's caregivers, in addition to what gratifications motivate participation.

Research Questions

This study employs the following six research questions to fully explore the experiences of Alzheimer's caregivers in Facebook support groups as it relates to the key components of uses and gratifications theory – needs, uses and gratifications – in addition to describing whether Facebook support groups are perceived as an accurate and primary source for health information related to the disease.

RQ₁: What motivates Alzheimer's caregivers to seek out and take part in Facebook support groups?

RQ₂: What kinds of activities do caregivers participate in when in Facebook support groups?

RQ₃: What are the benefits of Facebook support groups for Alzheimer's caregivers?

RQ₄: What are the perceived disadvantages of Facebook support groups for Alzheimer's caregivers?

RQ₅: Are Facebook support groups considered by caregivers to be a primary source for information about Alzheimer's disease?

RQ₆: Is the information presented in these groups perceived to be accurate?

Chapter 3 - Methodology

This overarching purpose of this study is to develop a thorough understanding of why Alzheimer's caregivers take part in Facebook support groups and to more fully describe their experiences with group participation. Uses and gratifications theory (Katz, et al., 1974) was employed for this analysis.

This chapter details the study's approach to answering the six research questions outlined at the end of Chapter 2. It describes why a qualitative approach was deemed appropriate, followed by a detailed description of sample recruitment, interview design, data collection and analysis.

Qualitative Approach

Typically, studies in the health communications realm choose either a quantitative or qualitative approach to collecting data. Both have their strengths and weaknesses. Quantitative studies collect numerical data that can be statistically analyzed to indicate trends and correlations to answer hypotheses, while qualitative studies collect objects like words and images that can be analyzed to indicate "the diversity of ideas" on a particular topic or research question (Creswell & Plano Clark, 2007, p. 6). For this study of Alzheimer's caregivers a qualitative approach was chosen in order to explain more deeply the full experiential context of the study's subjects in their own words. Because there is little research on Facebook support group usage, there were also many basic questions to be answered. According to Lindlof and Taylor (2010), qualitative approaches are also often employed and are effective for health communications research.

Chesebro and Borisoff (2007) outline five commonly shared elements of all types of qualitative research. Incorporated into this study's design are "natural setting," "researcher as

participant," "subject-based communication" and the "pragmatism" of the approach (p. 9). Since the environment in which the subjects interact is online and via Facebook, subjects were recruited from this space for phone interviews, though video interviews were conducted when possible. This was to preserve that natural setting as much as possible. Dillman, Smyth and Christian (2009) also argue that the online venue allows researchers to recruit participants from a wider geographical range. The researcher's limited experience as an Alzheimer's caregiver also gave her valuable insight, which also allowed her to delve more deeply into some topics during interviews.

Sample Description and Recruitment Method

Research participants were recruited from Facebook support groups and pages focused on caregiving for Alzheimer's patients. The researcher joined the online support groups or liked group pages to gain access. Private messages were sent to group and page organizers to ask permission to recruit. Once approved, recruitment messages were posted. The message included pertinent study details as well as a sentence about the researcher's personal experience with Alzheimer's. The latter was included to gain credibility within the group. The participation target was 20 and entry into a drawing for a $100 Amazon gift card was offered in exchange for study participation.

Caregiver demographics

In November and December of 2014, 20 caregiver interviews were conducted by phone or Skype; 18 of the interviews were ultimately analyzed. The interview pool's demographic characteristics were as follows:

- All were women.

- The vast majority (83 percent) were Caucasian.

- The average age was 50.2, with a range of 32 to 60 years old.

- All completed at least a high school level education, with 28 percent also
  earning an associate's degree and 34 percent having completed a bachelor's
  degree or higher.

- Five study participants had some sort of formal nursing or caregiving
  education, or had worked in a nursing home prior to caring for their loved one.

- The group hailed from 14 U.S. states including Arizona, Arkansas, California,
  Florida, Illinois, Kansas, Michigan, New York, North Dakota, Ohio
  Pennsylvania, South Carolina, Texas, and Virginia, and the federal district of
  Washington, D.C.

The characteristics of this interview pool fall in line with national caregiver
demographics provided by the Family Caregiver Alliance (2012).

Caregiving situation

Just over half of those interviewed (10 participants) provide care for their mother; this
was by far the most common arrangement. Two participants care for grandparents, two for a
spouse or partner, and three cared for a father figure (i.e. father, father-in-law, and stepfather).
All provided care for a member of their immediate family, though this was not a requirement of
inclusion in the study. This was not surprising given that the vast majority of U.S. caregivers –
83 percent – are familial caregivers (Family Caregiver Alliance, 2012).

In addition, the average duration of care was 3.8 years, with a range from 6 months to 10
years at the time interviews were conducted. Sixteen of those interviewed were providing care at
that time and two had provided care in the past as their charge had recently passed away.

Living arrangements were also probed. Of the 18 participants interviewed, 10 lived with their charge to provide around-the-clock care, whether in their own home or in the ward's. In four cases the patient lived in their own home with the caregiver coming in to provide care or otherwise coordinating care with paid aides. The remaining four patients either lived in nursing homes or assisted living facilities.

Study Design

This study utilized an interview guide built around uses and gratifications theory (Katz, et al., 1974). The guide was constructed to ensure each interview covered the same key topics, while also allowing the interviewer to probe deeply into what motivates caregivers to use the Facebook groups and what they get out of the transactions taking place within the groups. The researcher ordered the guide so that the flow was smooth and logical (see Appendix A for the full guide).

To describe how Alzheimer's caregivers use Facebook support groups, the study employed six research questions to determine what needs motivate caregiver participation in Facebook support groups, what kinds of activities caregivers take part in, and the perceived advantages and disadvantages related to group participation. Questions were also asked about whether the Facebook support groups were considered a primary and accurate source for health information related to Alzheimer's disease.

Procedures

Following approval by Kansas State University's Institutional Review Board (IRB) for research involving human subjects, private messages seeking permission to recruit were sent to the organizers of active Facebook support groups and pages focused on Alzheimer's caregivers. Once permission was granted an initial recruitment message was posted, followed by a reminder

message roughly a week later. The researcher was able to recruit 20 participants exclusively

from the Facebook support groups. Consent forms were provided via email and interviewees

consented to be interviewed by either email or verbally. Each interview was also recorded after

permission was granted by each interviewee. Audio files were then transcribed for analysis. Of

the 20 interviews, 18 were viable; two files had technical issues. To maintain confidentiality,

only participant initials were used in the transcriptions and were eliminated after responses were

sorted. Demographic data were also kept in a separate spreadsheet. Following transcription, the

audio files were to be destroyed.

Data Collection

Survey instrument

Data were gathered during interviews conducted via phone or Skype, using an interview

guide built around uses and gratifications theory (Katz, et al., 1974). The guide consisted of 31

content-related prompts and four qualifying prompts. After the qualifying questions, the guide

walked through the individual's caregiving experience, support mechanisms employed, the

specifics of Facebook participation and health information, wrapping up with demographic

questions (see Appendix A for the full interview guide). In order to gain the richest data, a

majority of the questions asked were open-ended, though some closed-ended questions were also

utilized. Typical interviews were 30-45 minutes.

Motivation for participating in Facebook support groups

The motivation behind participation in social media support groups is related to how

useful they are to the participant, or put another way: what needs they are attempting to gratify.

After all, a very active user of media is central to uses and gratifications theory (Katz, et al., 1974).

First, participants were asked to indicate which support mechanisms they took part in outside of Facebook. The list included: one-on-one counseling, face-to-face support groups, formal caregiving or nursing training, print-based materials including newsletters and books, online articles, blogs and website subscriptions, and online support groups including, but not limited to, social media. This question was designed to get a broad idea of how many mechanisms caregivers used, which is indicative of not only which venues they prefer but what level of support they might be searching for. Similarly, they were also asked to describe their day-to-day support network, so as to ascertain how much external support they already had. Interviewees were also asked to detail why they joined the groups and what they expected prior to joining. These questions lay the groundwork for understanding the nature of the needs caregivers are seeking to gratify via support group use, in addition to beginning to explore how they utilize the groups to satisfy their needs.

Interactivity within Facebook support groups

Several prompts were employed to examine what kinds of activities caregivers were taking part in and how they were utilizing both the medium of Facebook and the support groups themselves. Study participants were asked broadly how they used the groups, in addition to how the information found in groups was used. Specific to the mechanics of the Facebook platform, they were also asked what they did when in the groups (e.g. read items, liked others' content, commented, or posted content). Frequency of use was also probed.

Perceived advantages and disadvantages of Facebook support groups

Aside from the needs of a given caregiver and the way they reportedly use Facebook support groups, whether they are actually satisfied by group participation and return to use the group again are relevant questions. Repeated use would indicate a conscious choice is being made by an active audience, a la uses and gratifications theory (Katz, et al., 1974).

The researcher probed both gratifications sought and gratifications received by asking which of the support mechanisms employed were best for information about Alzheimer's disease. A similar question was asked with regard to emotional support. Group participants were also asked to cite the most important thing they received out of group participation and explain why it was significant. General advantages and disadvantages of the groups were also detailed. This line of inquiry allowed for a detailed analysis of the types of gratifications which will shed more light on motivation.

Participant perceptions regarding information accuracy

When considering social media support groups as a venue through which to share the latest in Alzheimer's information, the degree to which group members trust information presented in this venue could be highly relevant. Those interviewed were first asked where they went for truthful and accurate information about Alzheimer's disease. Regarding Facebook support groups and primary care doctors, study participants were then asked to rank truthfulness and reliability on a 1 to 10 scale, with 10 being the highest possible ranking. They were also asked to what degree they verified information they found about Alzheimer's disease. These questions were designed to gauge where Facebook support groups lie on the hierarchy of needs gratification.

Data Analysis

Though initial themes emerged during the transcription process, the data were sorted by interview question so a line by line analysis could be conducted. Using grounded theory as a guide, open coding was employed to determine broad categories of meaning, while axial coding was used to identify any significant relationships between categories. Excerpts were pulled from the transcriptions to illustrate the key themes and sub themes resulting from the analysis (Dutta & Basu, 2007; Glaser, 1978; Lindlof & Taylor, 2010). As needed, the data were subjected to analysis using NVivo software. The resulting analysis and discussion is covered in Chapters 4 and Chapter 5 of this thesis.

Chapter 4 - Results

This purpose of this study was to develop a deeper and more meaningful understanding of why Alzheimer's caregivers take part in Facebook support groups, and to more fully describe their experiences with Facebook group participation. This research is descriptive in nature and was designed to explore what motivates caregivers to take part in Facebook support groups, to understand how Facebook support groups are used, in addition to detailing the perceived advantages and disadvantages of the groups. Whether caregivers consider Facebook support groups to be a primary and accurate source of disease information was also probed.

The primary theme that emerged from this study was caregivers' desire for community based on common experience. Subthemes that emerged included the ability to gain context on the caregiving experience, the seeking of and provision of advice, the need for emotional release and support. There were also meaningful results related to information primacy and accuracy.

Common Experience and Community

Both the literature and this study's own data reflect that geriatric caregiving, particularly for homebound Alzheimer's patients, can be a lonely and challenging experience (Beinart, et al., 2012; Diwan, et al., 2004; Schulz & Martire, 2004). Therefore, belonging to and engaging with a community of others who have similar experiences and needs can be comforting. It's also a documented benefit of support groups.

Bringing Context to the Caregiving Situation

Of those interviewed, seven mentioned that their Facebook groups provide them with a needed frame of reference for their own caregiving experience.

You don't feel like you are the only one going through some of those things. You're like 'I don't have it so bad,' and you read others and you're like 'Why are you whining?' It's just kind of a support system to see that I am pretty lucky because we are not that far into it.

Caregivers consistently reported that they were comforted by the idea that they weren't alone and that they could compare experiences. One participant described the feeling this way: "It's like 'Wow, people are going through the same thing.'" Another summed it up succinctly when she said the group: "reminds me that I'm human and that I know what I'm feeling is okay, and that I'm not alone." This was reinforced by another who said "knowing we're all in the same boat, that it's not just me" was the most important thing she gleaned from group participation.

Caregiving is a lonely, lonely job. You give, give, give and have very little time for a relationship, so it made me see that I am not unique. There are other people who feel lonely, and who get depressed … other people feeling the way I was feeling, isolated.

Others said that the Facebook support groups helped orient their experience: "It gives you a base to locate is this normal, is that normal."

This context, of course, is developed through group interaction. When it came to the motivations for group participation, some simply noted they needed an outlet: "When you get to the end of your rope and you're already banging your head against the front door, you need somebody to talk to." Others took that a step farther expressing interest in only connecting with those who would intimately understand what they were going through. One study participant said she couldn't just talk to anyone – she needed experienced caregivers so that:

When I say I resented his presence they aren't going to think I'm a horrible person.

They're going to get it and they aren't going to tell me that I have to get rid of him,

or that I can't do it. They'll talk me through it instead of out of it.

Another caregiver said "For me personally it's the affirmation and guidance that other people who have 'been there, done that, got the t-shirt,' can offer." Another said she sought out the Facebook groups because she was looking for "a group of people who would finally get what I had been trying to say to other people who've never been in this situation." Of the caregivers who had day-to-day, in person support from nearby family or friends, several noted that those individuals didn't always fully appreciate the demands of caregiving, nor did they understand why the loved one shouldn't be placed in a nursing home or assisted care facility. One caregiver addressed the latter notion this way: "(This is) the right thing to do. He literally has no one else … If I didn't do this he would be in a county home and he's not bad enough to be in any facility right now."

Facebook support groups were also described as a "lifeline" and as a place where caregivers could get a glimpse of what's next for their charge as the disease progresses.

To Receive and Give Advice

In addition to providing a broader context for individual caregiving experiences, caregivers' need for advice was also gratified by group participation. For instance, reasons cited for joining support groups included the search for information or new ideas they hadn't tried. The terms "advice," "hints," "ideas" and "information" were used frequently during interviews. One caregiver explained it this way: "I would use it for advice, great hints, what you do if they say 'No.' What you do if they get agitated. There's a lot of people that do offer very sound advice." Another said the information provided by those who had been caregiving longer was

"priceless" because of their broader experiences. More than one interviewee mentioned that the groups were best for practical advice: "It's a good place to see how other loved ones have reacted to things … (and it) is kind of a good way to judge some things, though by no means am I learning truthful medical stuff." A majority of caregivers said they use the groups for information or new ideas on how to care for their charge. The most popular way caregivers participated in groups was by reading information, or curating it for later use.

Aside from receiving advice, others noted the benefits of providing advice and helping their fellow caregivers. Many of those interviewed said that they've made friends in the groups and said they spend time supporting others. On the latter, one caregiver said: "I am not dwelling on my situation … just wanting to help, and that's helpful when you're outside your own day-to-day drama and possibly helping someone else. It's just not all about you, right?" One caregiver took it as far as to say that she used the group more for helping others rather than helping herself: "I've probably used it, honestly, more for … giving them advice, or help, or emotional support than I do for myself." Notably, there are documented benefits for those offering support as well as those benefiting from the support (Lepore, et al., 2011). Another caregiver equated group participation to listening to her cohorts: "I do a lot of listening, which benefits me and the person who's making the post. It's kind of like collecting, I don't know, little nuggets of wisdom and putting them in a basket for later."

Caregivers also wanted to protect their community. Some addressed bad advice shared in their groups, going as far as to suggest that group organizers should regularly monitor the groups for bad information: "I've seen some people get themselves in a little bit of a bind because you can't trust Facebook to provide you with the best legal information." This level of concern is indicative of the high value caregivers place in this organically grown community of common experience.

The Need for Emotional Release and Support

With a sense of community also comes a certain level of comfort and security. These concepts were particularly relevant for caregivers related to emotional release. Several caregivers mentioned that they were looking for a place to "rant" or "vent," with some mentioning the need to do so privately so as to avoid family drama. One caregiver described an experience she had when she first joined her open Facebook support group:

> When I first posted I posted a big long story of some things that I was going through and I was complaining about my family in the post not helping me, not stepping up … within two minutes of posting it my phone is ringing off the hook because, when you post in an open group everything you post goes directly into your newsfeed for all your friends to read … If I was ever referring someone to a support group like that I would suggest that they look for a closed group if they don't want everybody to know their business.

She went on to relay that she then sent the group moderator a request to close the group. The moderator quickly obliged and hadn't realized the full consequences of an open group. Another interviewee stressed both the community and confidentiality concepts: "It's kind of like AA (Alcoholics Anonymous), except we're dealing with old people."

Some negative aspects of emotional support were also discussed when those interviewed were asked about the disadvantages of Facebook support groups. Issues cited included the negative or rude attitudes of some group members. This prompted at least two study participants to suggest that these groups needed an official moderator to set the emotional tone: "Someone should really be monitoring these comments because you are speaking to people who are in very sensitive situations, and when you're a caregiver and you're stressed out it takes one thing to

push you over the edge." Another caregiver lamented: "I think sometimes people don't think before they start typing and one thing could really damage someone who's already in a tough place."

Despite concerns about privacy and negativity, caregivers still reported that Facebook support groups were the best for emotional support. Those interviewed were asked to describe what kinds of support mechanisms they used as a caregiver. The interviewer provided six categories to guide the conversation: one-on-one support, face-to-face support groups, formal caregiving or nursing training, print-based materials, online resources or Facebook support groups. Most caregivers utilized more than one of these support mechanisms. In the interest of determining which was most meaningful, they were asked to choose the best mechanism for emotional support. The results are summarized in Table 1.

Table 1:
Best Support Mechanisms for Emotional Support

Support Mechanism	Responses	Percentages
One-on-One	2	13%
Traditional Support Groups	1	6%
Formal Caregiving/Nursing Training	0	0%
Print-based Materials	1	6%
Online Resources	1	6%
Facebook Support Groups	11	69%
Totals	16	100%

As shown in Table 1, Facebook support groups were reported to be the best emotional support mechanism by nearly 70 percent of respondents. One of those interviewed said she chose the Facebook support group because:

I feel it is a place I can go to be validated, you know with my feelings and my experiences and my knowledge. I never thought about it that way until it came out of my mouth, but that's basically what it boils down to.

Another said "without a doubt" the Facebook page was the best for emotional support. She went on to relay a recent experience:

A week ago I had been up and was dealing with some issues with my Mom. I had seen her and it was a very poor visit for me with her in the nursing home. I left and I got on my phone and I posted, 'You know, I just hate this disease. I hate that it's stolen my mother and replaced her with a woman that is mean and nasty, and I hate the way I sometimes respond to this new woman.' (There was a) flood of support within a matter of minutes that was responding specifically to my post, to my concerns, and giving me encouragement and support and permission to be human.

Other support mechanisms didn't rank anywhere close to Facebook as being best for emotional support.

Facebook as a Primary Information Source

Access to information about the disease can impact an Alzheimer's caregiver's ability to provide proper and effective care. Information could be made available within a community of common experience and, better yet, it may have been vetted by practical experience. However, whether caregivers considered the groups to be a good, accurate source of information needed to be explored.

To determine how Facebook support groups were ranked when compared to other sources of information, caregivers were asked which of the list of six support mechanisms they believed was best for information. The results are summarized in Table 2.

Table 2:
Best Support Mechanisms for Information

Support Mechanism	Responses	Percentages
One-on-One	0	0%
Traditional Support Groups	1	6%
Formal Caregiving/Nursing Training	2	12%
Print-based Materials	2	12%
Online Resources	5	29%
Facebook Support Groups	7	41%
Totals	17	100%

Of the six mechanisms considered, Facebook was cited most often as the primary way to get information, with online resources ranked a close second. The two combined made up 70 percent of caregiver responses.

One caregiver cited Facebook's accessibility, describing it as "quick and handy to get to. I always have my phone and I can get online and I can go look things up." Another noted the asynchroneity of Facebook as a benefit:

If I get up at 3 o'clock in the morning, someone is always up. There's always somebody online … it's like calling your girlfriend up and you got that somebody's going to tell you something, and if they're not up you better believe by 6 or 7 you're going to get more hits, more posts about whatever question that you post, no matter

what time it is. I like that and I can post and … before you know it you've got about

ten people chiming in.

Another cited the attractiveness of information vetted by more experienced caregivers

when describing her participation in a specific Facebook group, the Alzheimer's Reading Room:

It felt like I was speaking with someone who really knew what I was going through,

who gave helpful hints. He attached different like white papers and I really liked

the guy. He would attach different links to his website and you'd be able to read

different links on Alzheimer's … and he was an Alzheimer's caregiver and wasn't

someone just preaching, he was someone who understood. I used a lot of the hints

he suggested.

The need for information also motivated caregivers to seek out and join Facebook support

groups: "I just hoped to get information to help me understand her condition and how to deal with it,"

said one caregiver. Some described the Facebook support groups as a starting place for information and

said they relied on subsequent research or practice to validate what they found.

Several also mentioned that it was a place to seek and save information for future use. For

example one participant stated: "I'm there to see what other people tell them. I'm saving that

information for a future time." Another reported: "I weed through just to try to find something that

might be pertain to us or to know in the future. If I need something this would be somewhere I could

turn."

Facebook as an Accurate Information Source

Second to whether Facebook support groups were considered a primary information

source, was whether they considered the information presented to be truthful. To determine this,

caregivers rated two scenarios for information accuracy on a 1 to 10 scale, with 10 being the

most accurate. The first scenario was information presented in their Facebook support group; the second was information presented by their Alzheimer's patient's primary care doctor.

Information presented by a doctor was considered only slightly more accurate (average ranking of 8.17) than that presented in a Facebook support group (average ranking of 7.14). This assessment was not without any challenges, however. Not all rated both the group and doctor, which was taken into consideration upon calculating the averages. Also, some participants rated both the primary care physician and neurologist, with some arguing that the neurologist was really primary given the stage of the disease they and their charge were dealing with. The interviewer allowed study participants to choose which doctor to rate and if they insisted on ranking both, an average was calculated.

While there was little discussion offered on why those interviewed rated Facebook in the above manner, there was extensive discussion surrounding the role of the doctor. Overall ratings were high for doctors, presumably based on their medical education and expertise. Most of the concerns noted had to do with lack of adequate time with doctors and poor bedside manner. One caregiver described a recent visit to the doctor:

> He asked me 'Does he (her charge) ever hallucinate?' And I said 'Oh yes, yes he has.' And he said 'How?' and I said, 'Oh, I kind of wish I had written it down. I'm not sure.' He threw his pen in like disgust down on the desk … I didn't have the information at the ready and it disgusted him because I couldn't come up with anything.

Of the whole group interviewed, a majority either had neutral attitudes or were positive toward their doctor. The role of the doctor in support provision is clearly an area for future research.

Those interviewed were also asked where they generally went for truthful information about Alzheimer's disease. Online resources were most often reported and included Alz.org, internet searches and the Facebook group, though the latter was only mentioned by two of those interviewed. One caregiver said they go to Alz.org:

Because I know that is put out by somebody who knows what they are talking about … there's one link, to another link, to another link … you just keep reading the next thing you know you are reading about something else then. It's a helpful tool.

Another interviewee mentioned the timeliness of the information provided by the association in general: "The material that they've given out to the caregivers support group meetings is the most up to date information in research and reality and the stages of Alzheimer's. To me, it's proven to be trustworthy."

Those that mentioned online searches also said they were careful about the sources they used. This caregiver's sentiments summarized why:

The internet has a lot of BS on it and you have to be aware of that. I don't think any of us would 100 percent trust the internet and it needs even more scrutiny when you're talking about something that affects … a loved one.

Multiple caregivers said they look for websites backed by medical institutions or the government. Examples given were sites organized by the Mayo Clinic, WebMD and the National Institutes of Health. Another said she looks for sites with a .org in the url or another nonprofit designation:

(You) get better information from a .org than you do from a .net or .com site, because you're dealing with someone who is there strictly in the interest of offering what they can … you've pretty much devoted yourself to that topic."

What was clear from caregiver interviews was that many use what they can get access to and cross check between sources, though some level of judgment based on experience is necessary. Some also wait for a consensus to develop:

There were a lot of people who talked about coconut oil (in the Facebook group) … and I kind of watched those posts for a while and after time I could see that it probably was just a placebo effect, and I did a little more research on it and I found there really is no real basis for it.

This is consistent with a study by that found online seekers of health information will actively look for agreement among multiple sources (Lederman, et al., 2014).

Chapter 5 - Discussion, Implications and Conclusions

This purpose of this study is to thoroughly examine the use of Facebook support groups by Alzheimer's caregivers. This study's results describe what motivates caregivers to take part in Facebook support groups, how the groups are used by caregivers, as well as exploring the perceived advantages and disadvantages of the groups. Whether caregivers consider Facebook support groups to be a primary and accurate source of disease information was also explored.

This chapter includes a detailed discussion of each research question, and the study's findings and literature, where relevant. The study's limitations and future research is also discussed, particularly since this research produced foundational knowledge that will be useful to future researchers and those in the health care profession who are ultimately responsible for bolstering support for the growing caregiving population.

Caregiver Motivation to Participate in Facebook Support Groups

Uses and gratifications theory (Katz, et al., 1974) explains how consumers choose media outlets and what they get in return. Prior to discussing how media are chosen, however, the needs of the consumer must be vetted due to their critical influence on motivation. RQ_1 sought to determine which factors motivate Alzheimer's caregivers to both seek out and take part in Facebook support groups.

Overall, those interviewed revealed the need for a community of common experience as the plight of the Alzheimer's caregiver is a lonely one. Caregivers reported that the Facebook community gave them context for their individual experience, the ability to timelessly receive and give advice, in addition to and resulting in emotional release and support. The Facebook

support groups were also considered primary and accurate enough to motivate repeated group participation.

What one expects from joining a social media support group, and whether those needs are met, can also influence participatory behavior. According to Katz and colleagues, needs generate expectations (1974). When caregivers were asked what they expected to gain from Facebook support groups, six said they didn't have any expectations, four said they expected emotional support, three noted that they were looking for practical advice, and one noted emotional and informational expectations equally. In addition, four of those interviewed only noted whether their expectations were met, not what they were or whether they had any prior to group participation. Three said the groups were too negative and caused further emotional distress. Another was disappointed and a little worried that her fellow caregivers were not very knowledgeable about Alzheimer's disease.

Regardless of expectations, all caregivers interviewed continued to participate in the groups. This is likely due to the many ways the Facebook support groups can be used to gratify widely varying needs. Facebook users can create a truly individual experience. Caregivers can take or leave whatever content is most relevant their needs and customize the level of interaction. For example, the caregiver concerned with the knowledge of her peers took that as an opportunity to begin mentoring group members and also redirected negativity within the group. Notably, this particular caregiver was among the more experienced of the group interviewed. Others wanted to passively sit back and peruse the experiences and information provided as they needed.

Due to the many ways Facebook support can be used, the diverse needs of caregivers can be met. Consistently gratified needs will cause an active user of media to continue using a

preferred outlet. This is consistent with literature on the adaptability of social media and its current role in health (Cline & Haynes, 2001; Gorham, et al., 2012), and falls nicely into line with uses and gratification theory (Katz, et al., 1974). Though there is ample research on the benefits of support groups, both on and off line, previous work does not fully examine the experiences of Alzheimer's caregivers on Facebook. This study therefore extends previous lines of research on the health-related impacts of emotional and informational support via Facebook.

Caregiver Use of Facebook Support Groups

After identifying and fully describing caregivers' needs, the study then turned to how caregivers use the groups and usage's link to needs gratification. To examine how Facebook support groups are used, RQ_2 simply asked: What kinds of activities do caregivers participate in when in Facebook support groups? Understanding how caregivers use this two-way social medium should influence how health care professionals utilize Facebook to provide caregiver support.

The majority of caregivers interviewed said they read information and experiences shared, with some even curating content for later reference. One caregiver equated her reading activity with listening to her cohorts. Commenting on posts and creating posts were the next most popular activities, with liking reported least frequently.

Reading about the experiences of others allows caregivers to passively tap into this community of common experience and gain perspective on their situation. Multiple caregivers reported that reflecting on others' situations made them thankful and provided them with a look into the future. This ties directly into the sub theme of context that emerged from the study overall. Because of the isolation associated with caring for an Alzheimer's patient, caregivers said they often wondered if they were providing the best care possible or if there were other

ways they could help their charge through daily activities. By reading Facebook content,

caregivers were gratified by information new to them and were generally reassured about the

quality of care they provide. Having their doubts addressed has emotional value and getting new

information has value in the day-to-day practice of caregiving. Both kinds of experiences

perpetuate group participation by gratifying caregiver needs.

Literature on support groups clearly indicates that they are a resource for both emotional

support (Baum, 2004; DuPertius, et al., 2001; Lepore, et al., 2011; Pector, 2012) and

information (Heller, et al., 1997), and that group participation can be an empowering experience

for caregivers (Barak, et al., 2008). Clearly, caregivers are out to satisfy a mixture of needs

related to their situation, their background and experience, their relationship with their charge,

and other factors. Considering that all caregivers interviewed said the Facebook groups were

useful and emotionally gratifying, though to varying degrees, it seems to be one more tool that

can be employed by those in the health care profession who are obligated to bolster support. This

is even more compelling given that caregiver demographics align with the fastest growing group

using Facebook (Madden, 2010; National Alliance for Caregiving, 2009).

Advantages of Facebook Groups for Alzheimer's Caregivers

To more deeply explore gratifications, caregivers were asked to describe the pros and

cons of Facebook support groups. While the prior section describes how specific uses resulted in

gratified needs, this question was designed to get caregivers' broader perspectives on what they

were getting from the experience. RQ$_3$ therefore asked: What are the benefits of Facebook

support groups for Alzheimer's caregivers?

Benefits reported by those interviewed included learning practical tips from other

caregivers and learning how others cope with the caregiving experience. One caregiver with a

medical background noted that she still needed the practical advice, further highlighting the subtheme of context. Another advantage noted was the ability to have a readily accessible outlet for emotional release, another subtheme identified in this study. In addition, the ability to access it at any time was noted and this mention of immediate gratification as an aspect of social media usage was consistent with work by Urista and colleagues (2009).

Facebook support groups for Alzheimer's caregivers provide a way for caregivers to share their problems, stories, encouragement and advice with one another, which was consistent with prior literature on support groups (Baum, 2004; DuPertuis, et al., 2001; Lepore, et al., 2011; Pector, 2012). The end goal in all cases was to provide quality care to their loved one, and to survive the experience mentally and emotionally. A majority of the caregivers interviewed for this study did not have formal training or experience in nursing or other caregiving activities and, therefore they needed information and best practices, or at the very least to know if what they were doing was correct.

Disadvantages of Facebook Groups for Alzheimer's Caregivers

This study also looks at the reported disadvantages of group participation as an indicator of gratifications not received. RQ4 therefore asked: What are the perceived disadvantages of Facebook support groups for Alzheimer's caregivers?

Caregivers reported that they did not like the negative or poor behavior of some group participants, as well as the presence of misinformation – though the latter was almost always described as well intentioned. This reinforces that caregivers are motivated by what they judge to be good, solid information and positive emotional support. Multiple caregivers also noted the need for an authority figure to manage those behaving badly and to correct misinformation.

Uses and gratifications theory holds that the needs of individuals generate expectations of media, and that through media exposure needs are gratified or not gratified, which influences whether the user chooses to stay with the same source or move on (Katz, et al., 1974). Notably the caregivers interviewed for this study spent more time and were more forthcoming when it came to talking about the advantages of group participation versus the disadvantages. One could conclude that this means they were very much gratified by group participation and perceived that the positive effects far outweighed the negative ones. Further, when describing the disadvantages they had strong opinions on what should be done to correct the issues they identified. This illustrates the perceived value of the support groups.

Primacy of Facebook Support Groups as an Information Source

For information about Alzheimer's disease, there are multiple sources and many formats available. But because those caring for Alzheimer's patients are socially isolated and pressed for time, some sources are likely more accessible than others. RQ_5 asked whether Facebook was considered a primary source of information about Alzheimer's disease.

To support this line of inquiry, those interviewed were first asked where they went for truthful information about Alzheimer's disease. Online resources were most often cited, and of the 14 mentions, two specifically noted Facebook support groups first in their responses. This was not surprising as most caregivers are essentially homebound with their charges, and the internet addresses this and many of the documented barriers to traditional support group participation. Among the barriers noted in literature were lack of time and caregiver hesitancy to leave their charges or admit they need support (Tanis, et al., 2011). It is one thing to make time, schedule temporary care for their charge and physically travel to a face-to-face support group, and quite another to passively read the experiences of others and any tips they might share. And,

in fact, reading others' content was noted as the most gratifying activity for caregivers taking part in Facebook support groups. Because this same passive reading activity can take place in the general online space, it was not surprising that this venue is a primary source of informational gratification, and that caregivers returned to the online space again and again.

Though primary, caregivers did indicate that the legitimacy of their online resources was important. Several mentioned the Alzheimer's Association's official website, and noted that other reliable sites were endorsed by medical institutions, the government or other nonprofit organizations. This is consistent with literature on how internet users judge websites and their content to be credible (Diaz, et al., 2002; Greer, 2003).

In addition, this study pitted more traditional information authorities (i.e. doctors) against social media to determine how gratifying Facebook support was to Alzheimer's caregivers. Caregivers were asked to rank both information gleaned from Facebook groups and that provided by doctors. Surprisingly, information presented via Facebook came in only slightly lower than that provided by doctors. This can be explained, in part, by some negative attitudes toward doctors, as described in Chapter 4. However, it was clear that the medical profession is still considered a factual authority when it comes to a clinical understanding of the disease.

Though online information sources were noted as primary when it came to Alzheimer's information, the Facebook support groups were described more as a starting place for caregivers who use many sources to cross check and verify what they receive. This is consistent with literature showing that the search for health information is a primary activity for a great majority of internet users (Fox, 2011) and that social media is becoming more and more influential when it comes to health (Gorham, et al., 2012; NRC, 2011).

One thing to note: additional exploration is needed to probe what caregivers consider to be factual information, and how it differs from practical advice and emotional support. When asked about information during interviews, it was clear that the term meant various things to caregivers. This may be an area for future study and clarification.

Accuracy of Information in Facebook Support Groups

Determining what to believe in the online context can be a challenge, particularly on social media platforms like Facebook where users can be as much information producers as they are consumers. So while Facebook may hold promise as a tool for health care providers to connect with caregivers needing support, whether information presented in this venue was believed to be accurate is a valid question. Therefore, caregivers were asked to elaborate on their perceptions of information presented to determine whether that characteristic was compelling in some way. RQ_6 asked whether information presented in these groups was believed to be accurate.

Caregivers were first asked whether they verified information received in the Facebook groups. Though there were varying definitions of what it meant to verify, the overall response was a resounding "yes." Many reported that they cross checked online information in various ways, which is consistent with literature (Lederman, et al., 2014). Some also said that in the Facebook support groups they waited for a consensus to develop over time before deciding if a piece of information had value.

More than one caregiver took verification to mean whether what they learned worked in practice. This further highlights the need for practical information on dealing with the day-to-day duties of caregiving. This also ties back into the study's subthemes of context and advice.

Just because the caregiving demographic appears to be part of the fastest growing group on Facebook is not reason enough to assume this tool would work well to provide medical information to caregivers. Information provided needs to be relevant and it may be possible that practical tips are more important in the day-to-day context than medical information. That's not to say that medical facts aren't important, but they don't appear to be a primary motivator driving group participation. This finding will be useful as those in the health care profession develop best practices to effectively utilize Facebook support groups to provide informational support.

Though this study clearly supported the notion that emotional gratifications were motivating and perpetuated group participation, the same wasn't necessarily true for factual information. Caregivers had a hard time separating emotional support from informational support. Notably, the receipt of needed information has emotional benefits. Future studies should better parse information and emotional gratifications so that the implications of gratification levels can be more clearly defined.

Conclusion and Implications

As baby boomers age, more families will be faced with the burden of providing care for their ailing elders. Caregivers will turn to the internet and social media for critical health information and emotional support, though until now there has been a limited understanding of how Alzheimer's caregivers use Facebook support groups. The purpose of this study is to describe what kinds of activities caregivers engage in in these groups, explore what motivates caregivers to participate, and detail the perceived advantages and disadvantages of the groups. Whether Facebook support groups are considered a primary and accurate source of disease information is also discussed.

Caregivers describe Facebook as a highly-valued and accessible community. This community

has reported emotional benefits as well as practical ones, all of which seem to overcome any perceived disadvantages. Uses and gratifications theory was useful in exploring the varied facets of Facebook support group participation, particularly when it came to motivation. Clearly, if an individual is getting what they need from a particular social transaction, they will continue participating. Emotional support and practical advice was reportedly more motivating than factual medical information, which was a unique finding that also bears further research.

These are all salient points for health care professionals, who some believe are reluctant to interact with patients via social media outlets like Facebook (Hawn, 2009; McNab, 2009). Due to this criticism, it would appear that this is a perfect opportunity for the health care industry to dip its toe into the social media waters. There is also some urgency to this given that Alzheimer's disease is expected to triple by 2050. It is incumbent on health care professionals to plan now how they will engage with caregivers to provide support and information. Facebook not only already hosts support-related activities, the medium overcomes several significant accessibility barriers unique to this caregiving population. This reality further emphasizes the need to take support to the caregivers instead of making them come to it. A dynamic online community already exists – it just needs to be tapped.

Providing an information authority may be one way health care professionals can tap into these groups. However due to the presence of some negative attitudes toward doctors, the way that they participate will need to be carefully constructed as one of a knowledgeable partner, so that caregiver participation continues. After all, if gratification stops and caregivers feel they are being criticized or addressed in a condescending manner they could move on to another group or support mechanism.

Recommendations for Future Research

By describing the nature of the Facebook-related experiences of this small sample of Alzheimer's caregivers, this study gives health care professionals a place to begin figuring out how best

to use existing Facebook support groups to engage with and provide support to this population. The next logical step is to develop best practices to effectively engage with Facebook support groups in a way that creates meaningful two-way dialogue between caregivers and health care professionals. This study provides a theoretical foundation on which to build these best practices.

This study was descriptive in nature and, therefore, identified several potential future lines of inquiry. Already noted was the need to delve deeper into separating emotional and informational support with the purpose of more clearly discerning the impact of gratification levels on group participation.

Additional areas for future study include:

- Whether health literacy impacts caregiver perspective on gratifications received and influences participation.

- Whether the strength, or quality, of relationships within the support groups influences perceptions of information accuracy.

- Whether length of group membership influences participant perception of gratifications received, and whether that impacts motivation.

- More clearly defining the role of the doctor in providing support. Multiple caregivers criticized the help they received from doctors. A deeper exploration of this phenomena will be useful in developing best practices for tapping Facebook support groups, but could also have the potential to enhance overall medical and emotional support for Alzheimer's caregivers.

- Whether the themes identified in this study would resonate on the international stage. Alzheimer's is, after all, a global epidemic.

- Whether there would be any differences in gratifications reported when comparing urban and rural populations.

- What kinds of technological devices are used for Facebook support group participation, and whether there is any influence on perceived gratification.

Study Limitations

Like most studies, this one was not without limitations. Since the data were self-reported and collected via interview, some of it may be subjective in nature. Also in this study 20 interviews were conducted, only 18 of which were usable due to technical difficulties with two of the audio recordings. This study was descriptive and exploratory in nature, and with such a small sample size cannot be generalized to the experiences of all Alzheimer's caregivers who use Facebook. Another limitation was that a majority of the interviews were conducted via phone, when the original intent was to capture video. Many of the caregivers did not already have video conferencing capabilities and though the researcher attempted to coach some interviewees through installing Skype, requiring video would have likely reduced participation levels. Although one of the final interviews was conducted via Skype, audio files were transcribed across the board so as to mitigate any concerns about the consistency of the data.

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Appendix A - Interview Guide

Interview guide
Facebook Support Groups for Alzheimer's Caregivers

> *LEGEND*
>
> <u>Interviewer instructions will be underlined and preceded with >></u>
>
> **Interviewer script will be bold**

Consent Form: Y/N

Recording: Y/N

<u>>>Begin with an introduction:</u>

Thank you for agreeing to take part in this interview. Our hope in conducting this study is that your information can help others. Let's begin.

Prompt: **Are you an Alzheimer's caregiver? Y / N**

Probe: <u>>> if NO/unsatisfactory:</u> **Are you spending time caring for someone with Alzheimer's?**

Probe: <u>>> If YES to above probe ask:</u> **Approximately, how many hours a week?**

Prompt: **Do you use Facebook support groups for Alzheimer's caregivers? Y / N**

Probe: <u>>> if NO/unsatisfactory:</u> **Do you use Facebook at all?**

Probe: <u>>> if YES to above prompt:</u> **Do you use Facebook to talk with others who are caregivers to Alzheimer's patients?**

<u>>>*Note to interviewer: If more than 20 hours a week AND they talk to others who are caregivers, they are still eligible for the study.</u>

Qualifies	Does not qualify
Continue	Skip to exit statement

Ok, now I am going to ask you to share some specific information on your caregiving experience.

Prompt: **How many years have you been providing care for someone with Alzheimer's disease?**
Probe: >> Use dates (i.e. years and months). Also record any details shared about the patient's symptoms and condition that prompted care.

Prompt: **During that time have you been caring for the same person or have you cared for more than one person?**
>> Mark below and note time elements if multiple
_____Same individual
_____Multiple individuals

Probe: >>If 'multiple individuals" ask:
How many people have you cared for? >> Record number: _____
Probe: **Please tell me about their relationship to you.**
Probe: **How long did you care for each?**
>> Note each individual's relationship to caregiver and length of care below

Thank you for those details. Now I'd like to talk about the Alzheimer's patient you have most recently cared for.

Prompt: **Are they a relative?** Y / N
Probe: >> If YES: **How are they related to you?** _____

Prompt: **Where do they live?** (i.e. with you, in their home or in a nursing home, etc.)

Prompt: **How did you come to care for this person?**
Probe: >> If elaboration is needed ask: **Can you tell me more?**

Prompt: **Are you paid for the care you provide?** Y / N
Probe: **Is it enough?** Y / N

Prompt: **Next I have a list of support mechanism in front of me. I'm going to run through this list and ask you to tell me whether you've taken part in them as an Alzheimer's caregiver?**

>> As you go through the list below mark a "Y" for YES and an "N" for NO.

____One-on-one counseling
____Face-to-face support groups
____Formal caregiving or nursing training
____Print subscriptions such as newsletters, or other literature
____Online news, blogs or other website subscriptions
____Other online support groups, on or off social media

Prompt: **Of the support mechanisms I listed** (>>repeat options they take part in)**,**
which do you find the most useful (>> add emphasis) **for information?**
>> Wait long enough to allow a response. If not provided by interviewee, PROBE for one answer related to "most useful for information."
Probe: **Why do you feel that** (>>insert what they said in response to "most useful for information") **is the most useful** (>> add emphasis) **for information?**

Prompt: **Of the support mechanisms I listed** (>>repeat options they take part in)**, which of the above do you find the most useful** (>> add emphasis) **for emotional support?**
Probe: **Why do you feel that** (>>insert what they said in response to "most useful for emotional support") **is the most useful** (>> add emphasis) **for emotional support?**

Prompt: **What does your day-to-day, face-to-face support network look like?**
>>If more information is needed, you have the option of asking the following:
Probe: Does your spouse live with you?
Probe: Do your children live nearby?
Probe: Do you have any siblings, other family who live within a 20-mile radius of you?

>>Transition:
Now I'd like to talk to you about Facebook support groups, ok?

Prompt: **First, can you tell me how many Alzheimer's Facebook support groups you belong to?** (>> write number) _____

Prompt: **Tell me a little bit about why you joined these groups?**
Probe: >> If elaboration is needed ask: **Can you tell me more?**

Prompt: **When did you join these Facebook support groups?**

Probe: >> *If elaboration is needed ask:* **Can you tell me more?**

Prompt: **Was there a specific event that convinced you to join these groups?**

Probe: >> *If elaboration is needed ask:* **Can you tell me more?**

Prompt: **What did you expect when you joined these groups?**

Probe: >> *If elaboration is needed ask:* **Can you tell me more?**

Prompt: **How do you use Facebook support groups?** >> *Record the order of what they say.*

Probe: >> *If elaboration is needed ask:* **Are there other ways you use these groups?**

Prompt: **What would you say is the most important thing you receive from Facebook support groups for Alzheimer's caregivers?**

Probe: >> *Ask:* **Why is that important to you?**

Prompt: **What would you say are the benefits of Facebook support groups?**

>> *Record the order of what they say.*

Probe: >> *If elaboration is needed ask:* **Can you tell me more?**

Prompt: **What would you say are the disadvantages of Facebook support groups?**

>> *Record the order of what they say.*

Probe: >> *If elaboration is needed ask:* **Can you tell me more?**

Prompt: **When in these Facebook support groups what kinds of activities do you participate in?** >> *May need to rephrase:* **What kinds of things do you do?**

Prompt: **How often do you log on to Facebook?** _____

Probe: >> *If elaboration is needed ask:* **How many times a week?** *Or* **How many times a day?**

>> Transition:

Let's discuss health information now, ok?

Prompt: **Do you consider yourself to be knowledgeable about the facts of Alzheimer's disease?**

Y / N

Probe: **How did you become knowledgeable?**

Prompt: **Where do you go for truthful and accurate information about Alzheimer's disease?**
Probe: **Why?**

Prompt: **How do you use the information you find?**
Probe: **Can you tell me more?**

Prompt: **How truthful and accurate is the information provided in your Facebook support group(s)?**
Probe: **Please rate on a 1 to 10 scale, 10 being the most truthful/accurate.**
(>> Circle one)

1   2   3   4   5   6   7   8   9   10

Prompt: **How truthful and accurate is the information provided by your charge's primary care physician?**
Probe: **Please rate on a 1 to 10 scale, 10 being the most truthful/accurate.**
(>> Circle one)

1   2   3   4   5   6   7   8   9   10

Prompt: **Do you verify information you get on Alzheimer's disease?** Y/N
Probe: >>If YES, ask: **Why?**
Probe: >> If YES, ask: **How?**

>>Transition:
Thank you. We are just about done. I only have a few demographic questions left, ok?
Prompt: **How old are you?** (>> Write out in years) _____

>> Mark gender (do not ask)
_____ Male
_____ Female
_____ Unknown

Prompt: **Did you graduate from high school?** Y / N
Prompt: **Did you graduate from college?** Y / N
Probe: **If yes, what is the highest degree you completed?** _____

Prompt: >> Premark race/ethnicity.

Would people in your household describe your ethnicity as:

___ Caucasian/White

___ Hispanic/Latino

___ Black/African American

___ Native Hawaiian/Other Pacific Islander

___ American Indian

___ Alaskan Native

___ Asian

___ Choose not to reply

>> That's it! Thank you very much. I really appreciate the time you spent with me today. Do you have any questions of me? Share researcher's contact information.

Appendix B - Approval Letters from the Institutional Review Board

KANSAS STATE | University Research Compliance Office
U N I V E R S I T Y

TO: Nancy Muturi   Proposal Number: 6891
    Journalism & Mass Comm.
    217A Kedzie

FROM: Rick Scheidt, Chair
      Committee on Research Involving Human Subjects

DATE: 10/21/2013

RE: Proposal Entitled, "Alzheimer's Facebook Support Groups: User Gratification and Perceptions of
    Information Accuracy Among Caregivers"

The Committee on Research Involving Human Subjects / Institutional Review Board (IRB) for Kansas State
University has reviewed the proposal identified above and has determined that it is EXEMPT from further
IRB review. This exemption applies only to the proposal - as written – and currently on file with the IRB.
Any change potentially affecting human subjects must be approved by the IRB prior to implementation and
may disqualify the proposal from exemption.

Based upon information provided to the IRB, this activity is exempt under the criteria set forth in the
Federal Policy for the Protection of Human Subjects, **45 CFR §46.101, paragraph b, category: 2,
subsection: ii.**

Certain research is exempt from the requirements of HHS/OHRP regulations. A determination that
research is exempt does not imply that investigators have no ethical responsibilities to subjects in such
research; it means only that the regulatory requirements related to IRB review, informed consent, and
assurance of compliance do not apply to the research.

Any unanticipated problems involving risk to subjects or to others must be reported immediately to the
Chair of the Committee on Research Involving Human Subjects, the University Research Compliance
Office, and if the subjects are KSU students, to the Director of the Student Health Center.

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TO: Nancy Muturi
         JMC
         217A Kedzie Hall

FROM: Rick Scheidt, Chair
         Committee on Research Involving Human Subjects

DATE: 10/29/14

RE: Proposal #6891.1, entitled "Alzheimer's Facebook Support Groups: User Gratification and
         Perceptions of Information Accuracy Among Caregivers."

         A MINOR MODIFICATION OF PREVIOUSLY APPROVED PROPOSAL #6891,
         ENTITLED, "Alzheimer's Facebook Support Groups: User Gratification and Perceptions of
         Information Accuracy Among Caregivers"

         New survey

The Committee on Research Involving Human Subjects at Kansas State University has approved
the proposal identified above as a minor modification of a previously approved proposal, and has
determined that it is exempt from further review. This exemption applies only to the most recent
proposal currently on file with the IRB. Any additional changes affecting human subjects must be
approved by the IRB prior to implementation and may disqualify the proposal from exemption.

Unanticipated adverse events or problems involving risk to subjects or to others must be reported
immediately to the IRB Chair, and / or the URCO.

It is important that your human subjects project is consistent with submissions to
funding/contract entities. It is your responsibility to initiate notification procedures to any
funding/contract entity of changes in your project that affects the use of human subjects.

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