A CASE STUDY ANALYSIS OF MEDIATED COMMUNICATION

INTEREST AT END-OF-LIFE

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DEDICATION

This thesis is dedicated to the San Diego hospice patients I have had the honor of knowing and serving. I would like to especially thank Ms. Ellaine LaCourse, Ms. Donna Kennedy, Mr. Burke Belknap Jr. and Ms. Kim Kirkpatrick. I can only hope that this piece of research may begin to open a door to the increased study of improved mediated communication opportunities for persons at the end of their life journeys.
ABSTRACT OF THE THESIS

A Case Study Analysis of Mediated Communication Interest at End-of-Life

by

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The growth of new media has become integrated into all aspects of everyday life, even for populations with little or no prior experience using the Internet. As the population ages and technology advances, online communication for health-related purposes becomes an area rich for exploratory research. Though many have studied access and use in terms of older generations of Internet users, very few have sought to understand whether dying persons, specifically, are in need or want of mediated communication opportunities.

The following piece of research employs case study analysis to assess the level of Internet interest among three San Diego hospice patients. Using both questionnaires and in-depth interviews, and with corroborated feedback from social workers and primary care physicians, the study seeks to understand whether patients could benefit from the integration of new media into their assisted living facilities. The study is structured by the traditional communications concepts of uses and gratifications and self-efficacy.

Initial findings indicate that interest does exist among patients, although convenient access does not; also, that variables such as prior technology use and patients’ assessment of their own physical health decline can mediate subsequent Internet interest among these dying persons. Future research might consider larger implications, such as modifications within the healthcare industry’s infrastructure, as a whole, which would allow patients at end-of-life improved opportunities to access new media from their facilities.
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CHAPTER 1

INTRODUCTION

BACKGROUND AND STATEMENT OF THE PROBLEM

This research project is highly exploratory. As such, the problem is broad and multi-faceted in hopes of keeping the process inductive, rather than deductive. At this time, limited literature exists exploring the technology use of dying persons. The research that does exist is generally directed towards individuals who are living their last days at home. In order to further examine the potential for communication improvements at end-of-life, this research project was directed towards hospice patients dying in facilities—including nursing homes and assisted living facilities. The “problem,” then, is the question of whether these persons have any interest and/or could benefit from the further integration of mediated communication tools (i.e. the Internet) within said facilities.

The research project was guided by two theoretical concepts: motivations for technology use and self-efficacy. The first of these sought to evaluate patients’ current need for opportunities to emotionally disclose, find health information and receive social support. The second of these concepts enabled the primary researcher to understand patients’ feelings of autonomy and control, both in terms of learning new skills—including technology—as well as in regards to their own health and healthcare.

The following research questions are proposed as a guide for this project:
RQ 1: Are San Diego VITAS hospice patients interested in Internet access?
RQ 2: If San Diego VITAS hospice patients are interested in Internet access, what are they most interested in using it for?
RQ 3: Do San Diego VITAS patients feel as though they have control over their own healthcare?
RQ 4: Do San Diego VITAS patients feel as though they could use the Internet?
RQ 5: Do patients feel as though access to the Internet could enable them to exert more control over their own healthcare?
Along with these questions, the primary research hopes descriptive, contextual information will be gleaned from patients, regarding potential environmental factors which may affect their attitude towards and access to technology in the past and present. These inquiries are malleable and will be integrated into patient interviews as appropriate.

**SUGGESTIONS FOR FUTURE RESEARCH**

By using an exploratory research model, this project discovered new concepts that were not outlined in its initial research questions. The differentiation between cognitive and physical Internet self-efficacy is a valuable one; future research might explore these two concepts as stand-alone variables and integrate the antecedent variable of prior Internet use. Future researchers will benefit from a Baby Boomer population with years of experience online; many e-patients will have already sought out health information, found social support, and disclosed emotions via blogs and chat rooms and other web forums. As they age, these experienced web-users will, inevitably, also experience declining physical and cognitive health capabilities. This will create a larger and richer population from which to study mediated communication interests and behaviors.

Other populations of interest might include service men and women, who return from combat with changed physical and cognitive abilities, whether due to lost limbs and bodily injury or issues like PTSD and memory loss. Future research in this area might seek to understand how the dual-nature of Internet self-efficacy can enable veterans to utilize the Internet in a way that satisfies their unique needs.

Future research should also seek to quantify some or all of the variables from this study and structure them in an empirical sense. By identifying relationships and consequently creating a structured model among concepts like patients’ physical health assessments and Internet self-efficacy, new theoretical paradigms might emerge. Ideally, these paradigms will lead to propositions for tangible, improved online communication tools in assisted care facilities, senior centers and VA hospitals.

**PURPOSE OF THE STUDY**

As indicated above, this study extends existing research on technology use at end-of-life. Current literature has shown hospice patients dying at home are interested in and use the Internet for a variety of purposes. And the proliferation of e-patients is only growing (Rainie,
The present study examines a very specific population, which has been evaluated for its communication needs. This population, however, has not been offered a solution or opportunity to fulfill this need via new technologies. This research is significant, then, in its exploration of interest for Internet use among hospice patients. It is also significant in its integration of self-efficacy theory, which posits that persons will not attempt to utilize new skills or tools or technologies if they do not feel empowered or able to do so. This combination of concepts (motivations for use and self-efficacy) has not yet been used to evaluate this particular research topic.

The present investigation is significant in that it examines a specific population that has been evaluated some for its communication needs, but not enough in its communication solutions.

**Theoretical Bases and Organization**

The uses and gratification approach to communication indicates media use is rooted in the satisfaction of specific needs or goals. It originated with mass media research, and continues to find popularity there (Herzog, 1942; Palmgreen, Wenner & Rosengren, 1985), but has also been used to study interpersonal relationships and the accompanying devices which assist in the upkeep of such communiqué (Charney & Greenberg, 2001; Keller, 1977; Leung & Wei, 2000; O’Keefe & Sulanowski, 1995; Wei & Lo, 2006). Most recently, U&G has sought to address Internet use (Kaye, 1998; Lin, 1999; Morris & Ogan, 1996). Some, however, have identified ways in which traditional U&G must be adjusted in order to apply to this new medium (Ferguson & Perse, 2000; Korgaonkar & Wolin, 1999).

LaRose, Mastro & Eastin (2001) suggest that current U&G media research excludes important elements from social-cognitive theory, including the idea of self-efficacy. Self-efficacy (Bandura, 1997) is the belief in oneself to complete a certain task or “execute a particular course of action” (LaRose et al., p. 400). If a person is highly efficacious in reference to a particular task, they often invest more effort into achieving its successful completion. Those with low self-efficacy may either not attempt to complete the task or will not persist in the face of perceived barriers. Therefore, the following study will employ both of these underlying theoretical bases—U&G and Self-efficacy—in order to provide the most comprehensive and inclusive analysis.
No hypotheses have been formulated for the following study, as its methodology necessitates the proposition of only patterns and communication themes. Therefore, the five distinct research questions will be used as a means of identifying these patterns and communication themes among patients, as well as describing relationships between the theory-based variables involved.

**LIMITATIONS OF THE STUDY**

Significant limitations exist for this exploratory study. First and foremost, there was very limited time to study the population of interest due to rapidly declining physical health among participants (all participants were given a six month maximum life-expectancy). Furthermore, many patients, who were physically capable of completing the questionnaire, were unable to participate due to declining mental capacities. Fifty-two percent of the population of interest had either a primary or secondary diagnosis of Alzheimer’s or dementia. Treatment team members were given liberty to remove these patients from the participation pool.

These two limitations inevitably created a third: the transition of this research from a quantitative to a qualitative project. That is, with a questionnaire return rate of only 3.5%, it was impossible to statistically analyze the data, let alone generalize to a larger hospice population. Even a pilot study structure could not have been attempted with such a low number of participants. Therefore, as the research progressed and the population of interest quickly decreased, the primary researcher was forced to adjust research goals and methodology to promote and preserve validity. The initial survey project was transitioned into a dual-part case study, employing a questionnaire followed by in-depth interviews. The VITAS database and patients’ social workers were used as additional information sources.

Because this project is qualitative in nature, it is limited by its inability to ensure external validity. Instead, the primary researcher made every attempt to assure internal validity and to corroborate all information through a triangulation of sources. The primary researcher understands, however, that some data—specifically information gleaned from patient reports—is not entirely accurate. Non-verbal cues and other speech attributes were not considered in the evaluation of patients’ in-depth interview, so the absence of descriptive validity is noted as a limitation of this study.
DEFINITION OF TERMS

The term “VITAS” will be used in this study as shorthand for VITAS Innovative Hospice Care, the company wherefrom all study participants were recruited.
CHAPTER 2

REVIEW OF LITERATURE

The Internet has truly permeated the emotional and intellectual infrastructure of most world industries. Whether in sectors of education or government, the medical or entertainment communities, there is little that cannot be created or implemented online. As of 2009, nearly 80% of adults in the U.S. were using the Internet—half of whom were using wireless to navigate the net. From dubbed “digital collaborators” to “mobile newbies,” Internet users are varied in their demographics and also in their online activity. But perhaps the industry experiencing the most infrastructural shift, as its consumer base increases exponentially is healthcare. Last year, nearly 50% of adults using the Internet were online to get information about doctors or other healthcare professionals; 40% found hospital and medical facility information via the Web.

The following review will provide a detailed overview of existing literature related to the present study. It will first examine primary motivations for communication and their relation to health, including the need to self-disclose, seek out information and find social support. These elements will then be examined in terms of their online potential—how do users seek to fulfill these needs or pursue these end-goals via the Internet? Each variable will also be discussed in terms of their relation to the healthcare industry, at large. Self-efficacy theory will be introduced, as it complements traditional U&G studies. It will also be discussed as a predictor and mediator for both technology use and healthcare maintenance. And finally, this review will provide an overview of current opportunities for patients seeking online communication tools.

SELF-DISCLOSURE

There is little question among scholars of psychology, medicine and communication, that links exist between emotional disclosure and health. Studied widely in Western culture, researchers have found that “the disclosure of traumatic and emotional experiences can promote physical and psychological” well-being (Pennebaker, 2002). Writing about these
types of trauma can improve immune function, decrease physician visits for illness, and lead
to better performance at work and school (eg. Esterling, Antoni, Fletcher, Margulies &
Schneiderman, 1994; Pennebaker, 1993; Spera, Buhrfeind, & Pennebaker, 1994). The failure
to talk, out or at least acknowledge significant experiences has been associated with
increased health problems and autonomic activity (eg. Rime, Mesquita, Phillippot, & Boca,
1991; Wegner, 1992). Other experts in cognition and memory have found these processes to
be significantly affected by traumatic experiences—challenging patients’ abilities to
construct coherent narratives of the events (Freyd, 1993; Mahoney, 1991). Disclosure allows
for greater elaboration of a patient’s “network of meaning,” which often leads to “greater
processing of the traumatic event” itself (Borkovec, Roemer, & Kinyon, 1995).

According to Pennebaker (1989) and other disclosure researchers, this network of
meaning has been created and stored by individuals who have faced trauma. And the access
and verbal re-experience of these internalized truths could be very effective methods of
reducing the toxic presence of worry and anxiety within them. Pennebaker noted that the
behavioral inhibition required to prevent natural and healthy disclosure, could actually cause
strain on the body. Others have supported this notion physiologically and found increased
levels of anxiety among patients who suppressed thoughts, whether they were neutral or
negative in subject matter (Roemer & Borkovec, 1994; Wegner, Shortt, Blake, & Page,
1990).

With such strong physiological data, it is not surprising that the medical community
has taken particular interest in the very tangible benefits of disclosure for patients. Research
has found that frequent stress and “habitual inhibition” can weaken immunity and encourage
the development of myogenic pain (Traue, 1989). For the terminally ill then, whose primary
care is often palliative care through pain management, perhaps disclosure becomes even
more important. Prior research indicates the presence of worry to be oriented specifically to
future, possible events (Borkovec, Robinson, Pruzinsky & DePree,, 1983). With all future-
oriented issues hanging in the balance for this population, it is reasonable to assume that the
terminally ill are particularly susceptible to feelings of anxiety and worry. If we understand
emotions as “[responses] to environmental stimuli or as [acts] to control the
environment”(Traue, 1989), then we know the terminally ill may struggle with emotional
inhibition and their own expressions of trauma. Researchers know that communicating
uncertain health test results can lead to increased psychological distress for some patients (Maissi et al., 2004); and also that a relationship exists between uncertainty and the development and continuity of anxiety disorders (Dugas & Ladouceur, 2000).

And restrictions on individuals’ emotional expression not only affect their own health, but may result in negative social consequences. Research has shown the presence or absence of community can significantly affect the physical wellness of those struggling with illness.

**SUPPORT GROUPS**

Inhibited expression affects and is affected by successful social support networks. Of course, it is difficult to maintain, let alone create new relationships when disclosure is not offered by one or both parties. Research shows a social support system to be a “stress buffer” (Traue, 1989, 170); some hospice patients even wish to hasten their own death, should they feel they have low levels of social support, low family cohesion, or believe themselves to be a burden upon others (Kelly et al., 2002). Patients satisfied with social support perceive their health more positively and report fewer physical symptoms (Sammarco, 1987). And as the terminally ill often isolate themselves at end-of-life (Chapman & Pepler, 1998; Kelley et al., 2003; Rodin et al, 2007), communication and social interaction may be more important for improved quality-of-life. In 2000, Lang found that older adults who felt near death became closer to family and people who supported them emotionally but decreased closeness and deliberately discontinued relationships with others with whom they felt less close. The most important factor for intimate disclosure at end-of-life, then, may be for patients to feel as though they have maintained and developed close, as opposed to peripheral, relationships (Zech, Rime & Nils, 2000).

And yet, communication and relationship development seems to be especially difficult for the terminally ill, as well as for those who seek to support and treat them. As the field of medicine, itself, is oriented at the prolonging of life, death conversations are often avoided. The presence of a dying person is perceived to be highly threatening on both an individual and on a larger social level (Littlewood, 1992). Many experience communication apprehension when interacting with the terminally ill (Hayslip, 1986). Physicians may struggle to communicate with a dying patient, feeling the need or want to offer hope when
there may be none to give (Wenrich et al., 2001). Hines, Babrow, Badzek and Moss (1997) found that doctors “avoided discussing life threatening conditions as long as possible and discussed them as minimally as possible, leading to treatment decisions that were unnecessarily rushed, to the point that the patient was too seriously ill to give consent” (as found in Planalp & Trost, 2008). Hospice nurses have even reported diverting conversations with patients about patient illness or feelings because they are unsure of what to say and/or didn’t want to “upset patients” (Maguire et al., 1996). At a time when “stakes are highest for our interpersonal relationships—a time when there are better ways to communicate…particularly in those contexts we tend to avoid,” even healthcare professionals shy away (Foster, 2005, 144). These findings indicate a need for purposeful change in the interpersonal infrastructure of the medical community.

Of course, this is not to suggest doctors and nurses are always at fault for patients’ limited communication opportunities. Whereas 30 years ago, nearly 9 out of 10 doctors reported that they would not reveal a terminal diagnosis to the patient, today almost all physicians say they would inform patients of their impending death (Miller & Knapp, 1986). Physicians face significant time constraints, which can limit their actual face-to-face time with each patient; this can prevent the creation and continuation of trusting and meaningful relationships between patients and staff. It can also prevent many doctors from communicating disease and treatment information to patients adequately. As well as opportunities for self-disclosure and increased social support, research indicates this information seeking to be a primary concern for patients (Leydon et al, 2000; Sutherland et al, 1989). If dying persons feel unable or unwilling to communicate or seek support from their caregivers, opportunities for information seeking—in terms of their own health status, treatment options and prognosis—become even more important for their quality-of-life.

**INFORMATION SEEKING**

As worry is often birthed from the unknown and the possibility of future pain and trauma, information-seeking becomes a crucial coping strategy for many sick and dying patients (Brashers, Goldsmith, & Hseih, 2002; Radin, 2005;). Fear, confusion and depression are commonly experienced by patients and their families in anticipation of impending loss (Keeley & Kellas, 2005; McQuellon & Cowan, 2000; Planalp & Trost, 2008); and these
feelings only increase as a patient’s illness progresses, making the terminally ill the most susceptible to difficult emotional experiences. In Cegala et al.’s (2008) study of prostate patients and their information-seeking activity, individuals became increasingly more dissatisfied with their communication as they continued to live with the after-effects of their treatment. The researchers note that this could be because patients became more “critical of their ability to communicate with physicians as they continued to have experiences for which they had little expectation or understanding” (67). That is, as patients felt as though they were losing control of their own health and lacking in information to adequately process the experience, communication between them and their healthcare team worsened. How can a patient articulate their needs and wants when s/he doesn’t know what to ask? Others echo Cegala’s findings, noting that “better informed patients may ask better questions, manage their disease more effectively, and even monitor and intervene to improve their care” (Gustafson et al, 2002). However, patients must first feel willing and able to become informed, which introduces the concept of self-efficacy.

Patients’ communication self-efficacy—that is, whether they feel empowered to communicate with their physicians—is linked with emotional wellbeing and symptom distress (Gustafson et al., 2001; Maliski et al., 2004). Some researchers believe this link warrants “more attention…to patient communication skills training in decision aids designed to help…patients learn about their disease” (Cegala & Broz, 2003). In other words, a patient’s overall wellness is intimately connected to their ability to communicate with their healthcare team and seek out information on their condition.

Of course, information seeking is not only important for patients post-diagnosis. Very recent cancer research has shown the benefits of communication and health information seeking for oncology patients, including increased prevention behaviors, such as screening (Sullivan & Rutten, 2009). This area of health research has become so important, in fact, that scholars are attempting to develop new strategies to enable and encourage cancer-prevention-information-seeking for patients of varying ethnicities, ages, and disease progression (Eheman et al, 2009; Longo et al, 2009; McMillan & Macias, 2008; Waters, Sullivan, Finney Rutten, 2009). Even modest interventions, on the part of doctors or nurses, along with the provision of communication opportunities, have been shown to have significant impact on
key patient behaviors such as asking questions and verifying information” (Cegala & Broz, 2003).

As mentioned above, information seeking at end-of-life is strongly associated with self-disclosure and social support. Scholars now understand providing opportunities for one of these factors often has residual effects upon the others; when patients are receiving unclear or incomplete information, concerning prognosis or possible treatment options, there must be openness for their emotional response to the uncertainty (Rosen & Knauper, 2009). Studies have found links between emotional disclosure and social support as it affects the immune system (Esterling, Antoni, Fletcher, Margulies, & Scheiderman, 1994; Petry, Weems & Livingstone, 1991). And when patients do not feel as though they have adequate opportunity to self-disclose and/or receive social support, the act of information-seeking can provide them with feelings of hope and control (Radin, 2005).

THE INTERNET AND SELF-EFFICACY

Patients need and want more information. In fact, nearly half of adults using the Internet last year were online to get information about doctors or other health professionals (Rainie, 2010) and nearly 40% reportedly used the Internet to find information about hospitals and other medical facilities. In fact, research has found that 42% of adults and 60% of e-patients say they were helped by following medical advice or information they found online. These same e-patients were more likely than other Internet users to engage in social media and blog creation and contribution. So, although physicians continue to be the primary source of health-related information, the Internet is becoming a wide and growing resource for patients seeking that information, as well as for those looking to self-disclose and experience social support (Bernhardt & Hubley, 2001; Brodie, Kjellson, Hoff, & Parker, 1999; Cotten & Gupta, 2004).

Radin (2005) argues a larger point, insisting that the Internet has become a natural promoter of a structural shift in healthcare, by essentially fulfilling all three of the patients’ needs explored above. She first describes the Internet as a “global collective memory”, which allows patients to contribute, story and annotate their own disclosure. A large body of literature supports this point, indicating that online support groups and other forms of e-emotional support have very measurable medical benefits (Roter & Hall, 1997, 179; Spiegel,
Kraemer, Bloom & Gottheil, 1989). Online communication and support can encourage disease prevention, build deep relationships, and promote intimacy (Coulson, Buchanan & Aubeeluck, 2007; Trenholm & Jensen, 2000). Lee and Hwang (2006) suggested that online communication services are a vital resource for social and emotional support. Gallagher et al (2002) supported these findings, saying that communication services provide patients with the opportunity to exchange experiences, and that doing so via computer-mediated communication systems may “protect patients from the deleterious effect of stress as well as enhance their self-efficacy,” in terms of expressing their feelings and providing support to others. Not only does online sharing help the individual who is actively disclosing, but patients can feel empowered and valuable by listening to and supporting fellow patients.

The mediated online environment is also characterized by two crucial elements that the healthcare industry at large is generally lacking: affordability and consistency. One practicing physician, who is also a cancer survivor, describes the familial nature of these online groups. Ferguson (1996) notes:

> Online self-help networks are like surrogate families. Members share common problems, help each other toward mutual goals and support each other through good times and bad. The support they provide is available for free, and in most cases, around the clock, as needed. (p. 41)

Furthermore, the advantage of anonymity is incredibly conducive to levels of involvement many sick or dying patients would not offer in face-to-face communities. That is, participants in “the online world [have] fewer ways to differentiate themselves, contributing to a sort of egalitarian atmosphere that promotes trust because people appear to be very much the same” (Radin, 2005). At a time when illness and disease can make patients feel alone and different, this sameness in community is crucial (Shaw et al., 2000; Winzelberg et al., 2003). And as indicated earlier, many terminally ill patients feel guilty for troubling loved ones with their care and/or emotional distress. Online access allows patients to “freely express their concerns without fears of burdening their [real life] social support network” (Lee, 2006). More tangibly, the Internet can help patients by removing geographic, time, and financial barriers, which may prevent them from participating in or seeking out other social support options (Gustafson et al., 2008).

Radin (2005) also indicates the readily apparent capabilities of technology for information-seekers. She describes the Internet as a “massive expert database, wherein
patients can find information on disease prevention and palliative care”. As of 2006, 80% of adult Internet users were estimated to have used the Web for health purposes, and today that number is even higher (Rainie, 2010; Sarasohn-Kahn, 2008). Numerous studies have sought to understand how and how much patients are using the Internet to learn about their own illnesses and treatment options (Brant, 2003; Street, Gold & Manning, 1997). Many find patients are using the Internet to seek out health information that will expand or clarify their understanding of their disease and allow them to participate more fully in managing their treatment (Bass et al., 2006; Gustafson et al., 2008). And patients are using the Internet both pre- and post- doctor’s visits, to diagnose themselves, as well as to find answers to very basic care questions (Broom, 2005; Diaz et al., 2002; Nettleton et al., 2004; Williams et al., 2003).

Radin believes this subsequent shift in the medical community has given patients more control over their treatment; making patients consumers of their own healthcare. And if patients are now consumers, they can be empowered to compare and contrast “the goods and services they’re being sold by their healthcare providers;” they can use the Internet as a “global broker.” However, in order to participate in and utilize this online marketplace, patients must first feel willing and able to consume (use technology). The concept of self-efficacy can be found, then, at the foundation of patient participation in their own online health management.

Self-efficacy involves someone’s belief in her or his own capabilities to accomplish something and how that belief actually changes her or his behavior. Self-efficacy in the healthcare setting has been studied extensively, particularly as it influences the behavior of cancer patients. Research has explored attitudes toward screening, preventative behaviors, survival, psychosocial adjustment, and overall quality-of-life (De Nooijer, et al., 2004; De Vries & Lechner, 2000; Eiser et al., 2000; Jackson & Aiken, 2000). Patients’ perceptions of their own self-efficacy are “critical to determine how much effort and persistence [they are] willing to put forth towards a certain thought-process or task” (Rains, 2008, p. 3). Gallagher and colleagues (2002) found that patients with high negative emotion would not even seek out information online if they did not feel as if they had control over their situation. If these patients’ self-efficacy can be influenced, they can more effectively change their own behavior and gain confidence in adhering to that change. For example, an increase in self-
efficacy could enable a patient to feel as though they remain in control of their own health management, despite sudden or extreme shifts in prognosis or treatment.

Self-efficacy research is especially relevant to healthcare online due to the opportunity for both patients and healthcare professionals to participate in Radin’s global marketplace. That is, unlike “passively receiving information” via other mediums, the Internet allows an individual to play an active role in managing their own health. Patients control the information they see and digest, control the way in which they acquire information specific to their health situation, and control the pursuit of alternative perspectives or treatment options (Rains, 2008, 13). Researchers have already looked at how patients use the Web to seek out medical information, as well as to evaluate the effectiveness of health-related searches online (Nettleton et al, 2004; Rains, 2004). And literature supports the notion that information acquired online can lead individuals to feelings of empowerment in approaching and managing their own health (Bass et al., 2006; Broom, 2005; Fox & Rainie, 2000). Internet self-efficacy is an important predictor of not only using the Web, but also general attitudes and perceptions of the technology (Busch, 1995; Eastin & LaRose, 2000; Igbaria & Ivari, 1995; Taylor & Todd, 1995). It has been linked to an increase in confidence for patients attempting to maintain their independence, as well (Bass et al., 2006; Fox & Rainie, 2000). This is an important factor for those at end-of-life, who are often suffering from deteriorating physical and mental abilities, which require them to rely more heavily upon loved ones and members of their healthcare team.

Although the Internet is ripe with opportunity, there are barriers to its use—particularly for populations with less technological experience and/or interest. Ten years ago, there were nearly 100,000 Website offering health information (Cline & Hayes, 2001; Eysenbach, Sa, & Diepgen, 1999) and the number is only growing. Navigating these sites, as well as attempting to evaluate the quality of the information provided, can be an uphill battle for both patients and healthcare professionals (Huh & Cude, 2004; Rains, 2007; Rains & Karmikel, 2009; Usher, 2009). The initial use of a computer can be, in and of itself, a great barrier for a number of patients. One must know how to turn on and run certain hardware, before even attempting a search task (Zeng et al., 2002).

Furthermore, understanding information written in medical jargon can dissuade and/or confuse patients—even those with full mental capacities still in tact (Wolfe & Sharp,
2005). Studies indicate self-efficacy and these types of barriers affect one another significantly. Individuals with high technology-related self-efficacy are often more successful at navigating the Web. And those who say they do not have a positive “relationship” with technology, indicate that it is because they “perceive that they lack the appropriate skills” to use it (Hong, 2006; Nettleton et al., 2004, p. 538). As one might imagine, simply having access to the Internet does not ensure patients or healthcare professionals will have a positive experience online or find the information they need and want (Gustafson et al., 2008; Rains, 2008, p. 13). If the Internet is truly going to shift the healthcare industry and improve communication for patients and professionals in a meaningful and relevant manner, technology self-efficacy must be evaluated and encouraged in all patients.

WHAT CURRENTLY EXISTS

Despite scholarly calls to action (Gallagher et al., 2002 & 2008; Lee & Hwang, 2006) and research touting the emotional, social and informational benefits of computer-based personal health support systems for patients (Fogel et al., 2002; Gustafson et al., 1999 & 2008, 2001; Lindermalm, 2005; Liberman et al., 2003), the medical industry has created very few; even fewer have been successfully utilized. One of the most extensively studied computer-based system, in terms of use and subsequent patient quality-of-life, is called the Computer Health Enhancement Support System (CHESS). CHESS is an integrated, non-profit system, created to address the information and support needs of breast cancer patients and their families. It includes three distinct content areas: Information services, including a library, consumer guide, directory and Web links; Communication services, including discussion groups, expert advice and personal stories; and Decision services, which include assessments, health charts and action plans (Gustafson et al., 2008). Despite the fact that evaluation of this system has been limited to individuals with HIV and women with breast cancer (Gustafson et al., 1999; Gustafson et al., 2001; Shaw et al, 2000), initial findings indicate patients can benefit greatly from access to these types of online resources.

As far as online communication opportunities and hospice patients, technology has just begun to bridge the gap. Though the government and the terminally ill, themselves, would prefer death at home (Dunlop et al., 1989; Townsend et al., 1990), this is often not possible. Whether due to advanced palliative care needs or a family’s or patient’s lack of
resources, many dying persons end up living their last days in some sort of assisted living facility or nursing home. In fact, in a study by Brown University, researchers estimated that nearly 40% of Americans will die in a nursing home by the year 2020. The healthcare industry has noticed this trend, and in response—whether out of bottom line or altruistic motives—has begun to explore the concept of e-hospice (Kuzieumsky, Jahnke & Lau, 2006). E-Hospice enables hospice patients living at home to communicate with their healthcare teams online, as well as the opportunity to view electronic records of provider visits and medicines. This online approach is becoming more attractive to healthcare companies both economically and as a means of social responsibility or “going green” (Bose, 2003).

Mediated communication tools such as videophones are also an area of interest for providers and researchers, who see potential for disease management in at-home hospice settings (Oliver et. al, 2006).

Barriers to technology use are, of course, higher for hospice patients. Though age is a significant factor, and health concerns and problems increase with age, older persons are using the Internet in increasing numbers (Nussbaum & Coupland, 2004). In 2005, more than 20% of those aged 70+ were online. Many are looking for new ways to stay connected and be informed (Kiel, 2005, 19). Seniors are searching health-information online like drug information, cancer and heart disease (Fox & Madden, 2005; Lorence, Park & Fox, 2006; Voelker, 2005). Some are also attempting to build and contribute to community online; in 2010 6% of people 65+ had created their own social networking profile (“Millenials”, 2010).

**Motivations for Use**

Rooted in this internal shift of the medical community, which has positioned patients as active and independent health consumers, is the uses and gratifications (U&G) approach to communications research. This traditional perspective focuses on how individuals use different forms of media and communication to fulfill their psychological needs and wants (Cantril, 1942; Katz et al., 1974; Rubin, 2002). U&G studies can be analyzed parallel to self-efficacy theory, as it seeks to understand the motivations for media among patients who may or may not feel empowered and capable of using technology. In fact, scholars suggest that self-efficacy is an integral part often excluded from research on motivations for media use. LaRose and his colleagues (2001) believe self-efficacy’s integration into traditional U&G
studies is important, because traditional U&G “may fail to fully account for Internet usage” as they “neglect variables that are important in social cognitive theory” (401). Eastin and LaRose (2000) found Internet self-efficacy to be a powerful predictor of Internet usage, and Ferguson and Perse (2000) found that expertise—measured by way of prior experience with computers and the Internet—predicted Web usage. It is this complimentary relationship between traditional U&G and self-efficacy that encourages their dual inclusion in the present study.

One of the most frequently reported motivations for older adults to learn skills, like technology use, is improving their quality of life (Silverstone & Haddon, 1996). This motivator can “mediate anxieties associated with computer use for older adults, including fearing they will break the computer or are too old to learn” (Chaffin & Harlow, 2005; McMillian & Macias, 2008). For the purposes of this exploratory research project, quality-of-life as a motivator was segmented into the three primary activities outlined above: disclosure, social support, and information-seeking. As we seek to understand whether hospice patients feel willing and able to use technology (self-efficacy), it is important to know how these patients might utilize the Internet (uses and gratification). That is, if patients are interested in and believe as though they could go online at their facilities, what activities are they interested in participating in? What needs or wants are they looking to fulfill via this mediated communication tool?

To date, a great deal of research has shown the benefits of offering patients Internet access, and yet little has addressed whether dying persons in end-of-life facilities are afforded adequate opportunity to access it. Before it can be asserted that Wi-Fi should be installed nursing homes across the country, we must gauge interest and evaluate self-efficacy among these patients. This exploratory study seeks to fill the gap in scholarship and to better understand whether the restructuring of the healthcare industry, according to technological advances and patient needs at end-of-life, is warranted. The following study will explore the technology self-efficacy of hospice patients currently residing in care facilities in San Diego County. It will also assess motivations for use among these patients in hopes of identifying opportunities for improved communication between patients and their families, as well as patients and their healthcare teams.
CHAPTER 3

METHODS

Case study methodology generally follows a qualitative, naturalistic approach, affording researchers the opportunity to describe, understand, and explain contemporary phenomena within their real world context (Yin 1984). Case studies often focus on understanding the particular dynamics within single settings (Huberman & Miles, 2002), though multiple sources of evidence can be used (Yin, 1984). As such, researchers can combine a number of data collection methods, including archives, interviews, questionnaires, unobtrusive measures, and direct observation. In terms of theory, case studies have been used to test theories, generate new theories, and provide context to existing bodies of scholarship (Anderson, 1983; Gersick, 1988, Harris & Sutton, 1986; Pinfield, 1986). This approach is often most useful when data is “nonstandardized” or when it would be “difficult or inappropriate to count” units of analysis or instances of the phenomena of interest (Gherardi & Turner, 1987; Miles, 1994). Though there are weaknesses in qualitative research, there are also substantial benefits in terms of exploratory research or discovery science. Qualitative case studies can “[persuade] through rich depiction and strategic comparison across cases,” which can “[overcome] the ‘abstraction inherent in quantitative studies’”(Firestone, 1987).

This study employed a two-step case study approach, first collecting survey data through a quantitative questionnaire, followed by in-depth interviews. Little is known about hospice patients’ interest in and access to the Internet, particularly at end-of-life facilities. Thus, this project was highly exploratory. The methodology selected was also appropriate due to the significant limitations of studying this particular population. Questionnaire and follow-up interview questions were created based on prior theorizing and research from the uses and gratifications perspective (motivations for mainstream media/new media use), as well as findings related to the concept of self-efficacy (belief about ability to enact behaviors confidently). Related theoretical propositions were developed prior to data collection in order to provide guidance to identify patterns of interest. This is sometimes referred to as “pattern
matching,” first described by Campbell (1975). Using this process, the researcher uses qualitative data from the same case to match (or not match) a theoretical proposition.

**ACKNOWLEDGEMENT OF BIAS**

Many researchers have acknowledged the benefits of qualitative case studies. Berg (1989) said “to raw experience, we may attach either words or numbers.” Campbell noted (1974) that “all research ultimately has a qualitative grounding.” Nevertheless, case studies, particularly those that follow a qualitative approach, have faced criticism in terms of their methodological rigor. Researchers using qualitative designs must recognize significant weaknesses in qualitative research and attempt to mitigate those weaknesses. This research project has taken a number of steps to combat potential biases and weaknesses in the qualitative approach.

To begin, researchers must acknowledge their own personal biases. Huberman and Miles (2002) noted that “we cannot step outside our own experience to obtain some observer-independent account of what we experience.” This is particularly true for case study research. One must acknowledge that different accounts of reality, whether by study subjects or other researchers, can all be equally valid perspectives. As proponents of the quantitative approach have frequently criticized qualitative research for this ambiguity in standards of validity, the following sections will address these issues (Huberman & Miles, 2002). Toward that end, the primary researcher in this project currently serves as a Vitas Hospice volunteer; she has worked with dying people in San Diego for two years. Of necessity, this experience has influenced the primary researcher’s interest in and beliefs about communication at the end of life.

**VALIDITY**

Researchers have struggled to define validity with regard to qualitative research. Unfortunately, validity has very specific and multiple meanings in quantitative research, including validity of measures (face validity, content validity, criterion validity, and construct validity), internal validity of designs to isolate cause-and-effect relationships, and the external validity of research designs to generalize findings from samples to populations (Babbie, 2007). These uses of validity in quantitative methods have no precise equivalencies in qualitative research.
Some propose abandoning the term altogether in qualitative research, replacing it with the concept of “authenticity” (Erickson, 1989; Eisenhart & Howe, 1992; Goetz & LeCompte 1984; Guba & Lincoln 1989; Kvale 1989; Phillips, 1987). Others value issues of meaning and interpretation (Cook & Campbell, 1979). Mishler (1990) argued that while validity is applicable to “inquiry-guided” research, “the attempt to extend the dominant experimental/quantitative model of validity to [qualitative study] is misguided” (as found in Campbell & Stanley, 1963).

When critics have asserted that qualitative research lacks substantial validity in its approach, some qualitative researchers have denied the “relevance of the quantitative…paradigm for what they do” (Guba & Lincoln, 1989). Others argued that the qualitative approach has “its own procedures for attaining validity” unique to its needs and purposes (Kirk & Miller, 1986). The primary researcher of the current exploratory study accepted both these tenets; specifically, statistical significance and hypothesis testing were considered inappropriate in this instance. Instead, the researcher used the definitions of validity discussed below. For purposes of this study, validity refers to steps taken to promote methodological rigor appropriate for a qualitative case study.

**Descriptive Validity**

Similar to acknowledging researcher bias, many qualitative researchers are concerned with the accuracy of their subjects’ accounts. That is, researchers must take care to ensure that they do not make up or change what they see or hear. For example, researchers must be certain they do not mis-hear, mis-transcribe, or mis-remember interview responses. Even verbatim transcripts of interviews leave room for descriptive validity errors. Non-verbal elements of speech, like stress and pitch, are very important contextually. Depending on the method of transcribing, such non-verbal cues may not be denoted in the transcription. Omission of these elements may threaten descriptive validity of the account itself. Arguably, the primary researcher in this study could not fully prevent such omissions or errors in this study. Therefore, the researcher acknowledges the possibilities for omissions and errors and takes this error into account when analyzing the data.

In this project, incorrect or inaccurate transcription was mitigated to the fullest extent possible. However, non-verbal attributes of speech noted above were not coded for such
cues. Instances where patients did not answer specific questions are noted in the following chapter. However, the researcher cannot speculate as to the participants’ motives when these silences occur or why other questions were answered with enthusiasm.

**Construct and Grounded Validity**

Construct validity is defined as the extent to which operationalized variables measure the larger concepts they are intended to measure (Cook & Campbell, 1979). This categorization closely matches the idea of theoretical validity, which includes both the concepts, themselves, but also the relationship that exists among them (Maxwell, 2002). In order to promote these types of validity, the primary researcher triangulated data via multiple methods and through multiple sources. The triangulation involves a quantitative questionnaire, in-depth interviews, interviews with social workers, and review of the patient database. This provides multiple lenses through which to observe the phenomena of interest and provides a grounded validity to the combined observations and also strengthens the reliability through cross-checking. Kirk and Miller (1986) described this element of validity as epitomizing “the blocks from which the research builds a model.”

This study can generalize a set of results to the broader theories of self-efficacy and uses and gratifications but cannot and will not attempt to generalize these results to a larger population, as is done in survey research using probability sampling techniques. Therefore, external validity is not identified as a project outcome for the present study. Qualitative case studies cannot test, in the statistical sense, whether one variable acts upon or causes change in another variable (causal relationships), nor can they control for all the myriad of influences at play when relationships are studied. Therefore, no attempt will be made to do so in this study. This study seeks to observe relationships that are “generalizable to theoretical propositions and not to populations or universes.” That is, this case study “does not represent a ‘sample,’” and it is the primary researcher’s goal “to expand and generalize theories,” not to identify statistical frequencies (Yin, 1988, p. 21). These categorizations of validity are valuable in qualitative research, because they afford opportunities for extreme or “ideal types” to present themselves (Yin, 54). Sets of participants may be interesting or important simply because they are special.
Interpretive Validity

Interpretive validity and descriptive validity are related concepts, since both are concerned with the issue of perspectives, intentions, and beliefs (Yin, 1984). However, threats to interpretive validity are very different than those involved in descriptive validity, because the construct deals with mental processes, rather than physical observations. Interpretive validity seeks to understand perspective from the participant’s position, rather than the researcher’s point of view. Whereas descriptive validity is a concern at the onset of a study, interpretive validity comes to the fore when analyzing data, as “a matter of inference from the words and actions of participants in the situations studied” (Yin, 1984, p. 50). The meaning gleaned from participant accounts are constructed by the researcher on the basis of the interview/account, as well as other pieces of evidence.

Reliability

The concept of reliability in qualitative research can be ambiguous. Some have suggested that reliability is an irrelevant term altogether (Stenbacka, 2001). Others have recommended substituting the terms “dependability” or “consistency” or “trustworthiness” (Clont, 1992; Lincoln & Guba, 1985; Seale, 1999). For the purposes of the present study, careful documentation of procedures is of the utmost importance. This helps ensure dependable, consistent, and trustworthy conclusions throughout the research process. Each step of this project has been documented as much as possible, in hopes that future researchers may replicate and/or extend its findings.

Design

This project employed a two-step, single-case design. The researcher’s interest lies in testing extant theories. This project also affords the opportunity to observe, analyze, and explore a phenomenon not previously accessed by social scientific investigators. This kind of exploratory opportunity and descriptive information alone can be significant (Yin, 1984) for qualitative studies. This project was conducted as a stand-alone research project; however, findings and the methods used may also serve as a precursor to further study (i.e., as the first of a multiple-case study).

This study also has an embedded case study design, which involves multiple subunits. Over the course of the research, questions can change, leading to a loss of focus in the overall
study. An embedded design focuses inquiry, presuming the study takes into account not only
the subunit level but also the larger unit of analysis. The present study not a multiple-case
study design, nor is it a holistic approach, because the dual elements of questionnaire and
interview are considered sub-elements of the greater project. Each patient’s case is
considered a sub-unit of the larger unit of analysis: end-of-life facilities.

In an effort to prevent researcher bias, initial questionnaires were distributed and
collected by VITAS treatment team members. Afterwards, consenting patients were
interviewed by the primary researcher, in hopes of providing greater context to initial
questionnaire data. To prevent bias and enhance reliability, multiple sources of information
were used for corroboration, particularly regarding the patients’ length of stay in facility and
the current level of Internet access within facilities. Interviews are considered “verbal
reports,” in order to differentiate from data such as demographic information gleaned from
the VITAS database. The present study recognizes that these “verbal reports” often include
inaccurate information due to participants’ limited recall or difficulty with articulation.
Interview probes were open-ended; the primary researcher maintained a conversational tone.
However, the researcher followed the interview protocol, using questions derived from the
initial theoretical analysis that served as the foundation of this study.

Mixed Methods

The present study does not take a traditional mixed methods approach, as neither
element was analyzed statistically in order to generalize to a larger population. Instead, the
two elements fulfilled much of what Green et al. (1989) described as benefits of mixed
methodology evaluation designs: the questionnaires and interviews were considered
complementary, as one could illustrate or clarify seemingly conflicting results from the other
method. Whereas survey methodology offers the benefits of standardized questions, as well
as simplified administration and data collection, depth interviews provide greater context and
descriptive data. Open-ended questions during the depth interviews allow for patient
narratives to come forth organically. By using both approaches to data collection, this study
could pose new research questions and explore emerging patterns in the Discussion chapter
(page 39) that were not previously identified as relevant areas of study.
Study Questions

Building upon current knowledge about new media uses and gratifications and the influence of self-efficacy on media use and life experience, the following research questions were posed as a guide to questionnaire construction, as well as patient depth interviews.

*RQ 1:* Are San Diego VITAS hospice patients interested in Internet access?

*RQ 2:* If San Diego VITAS hospice patients are interested in Internet access, what are they most interested in using it for? (motivations for use)

*RQ 3:* Do San Diego VITAS patients feel as though they have control over their own healthcare? (healthcare self-efficacy assessment)

*RQ 4:* Do San Diego VITAS patients feel as though they are cognitively able to use the Internet? (Internet self-efficacy assessment)

*RQ 5:* Do patients feel as though access to the Internet could enable them to exert more control over their own healthcare?

Recruitment

The research protocol, including the consent process and the questionnaires, were approved by the SDSU Institutional Review Board, as well as the medical director of VITAS, Dr. James Sinclair. Participants were recruited for this project from the VITAS patient database in January 2010. All participants met the following criteria:

- As of January 2010, participants were receiving hospice care from VITAS. According to insurance provisions, patients are only allowed VITAS hospice care if they are given a prognosis of six months or less to live.
- All participants were residing in a nursing home or assisted living facility. No patients were receiving hospice care in private residences.

Administration of the initial quantitative questionnaires was conducted by members of the patient’s treatment team. VITAS utilizes a treatment team model, which includes primary physicians, RNs, social workers and chaplains. Participating patients were members of one of the four VITAS treatment teams, identified as team numbers 956, 954, 953, and 952. VITAS assigns patients to treatment teams based on geographic location of residence. Therefore, participating patients were recruited throughout San Diego County.
Prior to questionnaire administration, treatment teams were trained to present the consent form and questionnaire to patients. A script was provided, which included the opportunity for patients to verbally complete the questionnaire or request an alternate administrator to their treatment team member. An alternative member and the primary researcher were offered as alternatives. This allowed those patients who were physically unable but cognitively capable to participate. It also prevented undue bias from treatment team members, so that patients did not feel as though their healthcare would be affected by answers. Patients were excluded from the study if treatment teams believed their cognitive impairment was too extensive to allow for total comprehension and informed consent. Patients could not participate, of course, if they died prior to completing the questionnaire and the depth interview.

Demographic information was gathered from the VITAS database, including patient age, gender, race, place of residence, and primary diagnosis. The primary researcher gave treatment teams approximately three weeks to administer the questionnaires to patients. The researcher asked treatment team members to indicate at the bottom of the instrument whether they or the patient had completed the questionnaire. If the questionnaire was incomplete, treatment teams were asked to indicate whether physical/mental impairment was the cause, or simply a patient’s lack of interest. Completed questionnaires then were given to the primary researcher. Identifying information was included in the returned questionnaires only if the patient agreed to participate in the follow-up depth interviews.

**MATERIALS**

The following section details the construction of both questionnaires and in-depth interviews.

**Questionnaires**

Questionnaires were constructed by expanding upon current self-efficacy research, as well as elements of uses and gratification study.

**USES AND GRATIFICATION**

Respondents completed 16 items in which they were asked to rate their agreement with statements that assessed their behavior and interest in the following: social support,
information-seeking in terms of their own health, and their emotional disclosure. A 5-point Likert-type scale was used, ranging from “strongly disagree” to “strongly agree.” Sample items for this measure include: “I feel support by my family,” “When I want information about my health, I can ask my medical team,” and “I can tell my medical team how I’m feeling.” The full questionnaire is included as an appendix to this thesis.

**SELF-EFFICACY**

Respondents completed 11 items which addressed their self-efficacy, both in terms of their own health and also in their use of technology (specifically the Internet). A 5-point Likert-type scale was used. Sample items for this measure include: “I am in control of my health decisions,” “I am confident in my ability to learn new things,” and “I would like to use the Internet.”

A total of 113 questionnaires initially were distributed to treatment teams. Of those, 19 surveys were returned indicating that the patient had died. An additional 21 surveys were returned, indicating that the patient lacked the cognitive capabilities to consent and/or participate in the survey. Three surveys were returned, indicating that the patient was discharged from VITAS survey due to an improvement of health or for financial reasons. Seventy additional surveys were not returned to the primary researcher for unknown reasons. Causes may include those listed above. Perhaps some social workers were unable to garner a completed questionnaire within the collection time allotted. Thus, the valid sample included only four patients, a 3.5% completion rate. The mean age of respondents was 82. The diagnoses for the four patients who completed surveys are defined below:

*COPD.* Chronic obstructive pulmonary disease is one of the most common lung diseases. Patients suffering from COPD have partially blocked airways in their lungs, so they experience great difficulty breathing. The diagnosis can include one or both the respiratory ailments, chronic bronchitis or emphysema.

*Cardiac Arrhythmias.* These conditions are a form of heart disease and make the heart pump less effectively, so that not enough blood reaches the brain and other vital organs. Patients can faint or suffer severe chest pain from the lack of blood flow. Cardiac arrhythmias can also cause sudden death.
End Stage COPD. End stage COPD means the case is severe. Patients are often unable to use 80% or more of their lung capacity. They suffer from severe reduction in airflow and what is referred to as “chronic respiratory failure.”

Parkinson’s disease. This is a degenerative disorder of the central nervous system. Parkinson’s disease often impairs patients’ motor skills and speech. This disease can also cause “neuropsychiatric” difficulties, including cognition, mood and behavior problems.

In-Depth Interviews

The primary researcher completed all interviews at the individual facilities of each participating patient. One of the four patients who had completed a survey, and who agreed to complete a depth interview, ultimately decided against participation. One of the remaining three participants lived in a skilled nursing facility in El Cajon; one participant lived in an assisted living facility in Vista; and the final participant lived in an assisted living facility in Carlsbad, California.

Each interview lasted from 20 minutes to one hour. Interviews were recorded and transcribed. Interviews were semi-structured and guided by the same research questions. The interview guide is provided as an Appendix.
CHAPTER 4

RESULTS

This section reports the results from the patient questionnaire and in-depth interviews with the patients. As well, the chapter includes information garnered from the VITAS database and facility administrators, regarding basic patient demographics and Internet access within facilities. With the limited number of research participants, these results could not be meaningfully analyzed quantitatively. Therefore, the patient interviews and social worker feedback are used to provide context and points of comparison so as to give greater perspective to the state of patients’ communication needs.

Patients were asked to agree or disagree with 27 statements regarding their feelings about their communication needs and opportunities with family and medical teams. These included items measuring emotional disclosure, information seeking and social support. Survey questions also included statements assessing each patient’s assessment of their own health, their healthcare self-efficacy, as well as Internet and technology use. Each patient’s answers are summarized below, along with example statements.

PATIENT A

Emily “Kim” Kirkpatrick is a 90-year-old female, suffering from Parkinson’s disease. She resides in an assisted living facility in North County, San Diego, California. At the time of survey distribution, Ms. Kirkpatrick had been living in the facility for more than 6 months.

Ms. Kirkpatrick reported that she was unaware of whether or not Internet access was available at her facility. However, an administrator reported that there are computers available but there is currently no wi-fi access inside of the facility. At the time of survey distribution, Ms. Kirkpatrick had not used the Internet at her facility.

Ms. Kirkpatrick was interviewed for approximately 20 minutes. She was seated in a front living area of the facility, surrounded by other residents, who were socializing with one another. Ms. Kirkpatrick’s responses to interview questions were quiet and brief, though it is
not known whether this indicates she was concerned about other residents hearing her speak or if her personality was simply one of a more introverted nature.

Based on her responses to the questionnaire, Ms. Kirkpatrick feels as though she can easily disclose how she is feeling with both her family and her medical team. She agreed with statements such as, “I tell my family how I’m feeling,” and “I feel like I can express my feelings freely.” Ms. Kirkpatrick reported being satisfied with the amount of social support she receives. She agreed strongly with statements indicating that her family visits her at the facility and that her family and medical team support her. Ms. Kirkpatrick disagreed with the statement, “I would like more support from my family.” Ms. Kirkpatrick indicated that she is most socially supported by her son. However, she also indicated that he doesn’t visit often, as he has “five girls, so that keeps him very busy.”

Ms. Kirkpatrick indicated that she is also satisfied with the amount of health information she currently has, as well as her opportunities to seek out more information from her family and medical team. She agreed with statements including, “When I want information about my health, I can ask my medical team” and “I feel like I have enough information on my health.” However, she also strongly agreed with the statement, “I would like more information on my health.” She did not say more on the matter of information-seeking in her in-depth interview.

In terms of self-efficacy in health management, Ms. Kirkpatrick reported feeling as though she is not in control and cannot have a positive effect on her own health. This is not surprising, as she understands she is being provided palliative, and not preventative, care. However, Ms. Kirkpatrick did indicate that she believes she has control over her healthcare decisions.

During her interview, Ms. Kirkpatrick, who suffers from Parkinson’s disease, expressed frustration over her worsening symptoms in regards to utilizing the Internet. She indicated that she does not currently know how to use the Internet and is not sure that, even with instruction, she could be taught to use it. However, she did report confidence in learning new things, in a more general sense, and says she has used a computer for playing games like “Solitaire,” but not for exploring the Web. In this case, Ms. Kirkpatrick exhibited both low interest in and low self-efficacy with regard to new media use. For example, when asked whether she would be interested in using the Internet for emailing purposes, Ms. Kirkpatrick
responded: “I don’t know much about that” but she reported that her adult son, does use the Internet. Clearly, Ms Kirkpatrick’s experience with new technology is highly limited, because when asked about her experience with other types of technologies, she described using an adding machine to “do calculations” in the past. That said, despite expressing anxiety over learning to use the Internet, Ms. Kirkpatrick explicitly expressed interest in it in order to overcome difficulties or “lost control” she experiences from her illness. When asked whether she would like to use the Internet to communicate with her son, she said:

Maybe, but the main reason I wanted one, I have Parkinson’ disease and I cannot write letters anymore. I can’t write period. I have terrible handwriting, it doesn’t even look like my handwriting. And it is such an effort to write a letter that I’d given up. So that was mainly why I wanted one. So I could type them.

Ms. Kirkpatrick’s direct interest in the Internet seems fueled by her loss of autonomy and the loss of a communication channel she once used (writing letters to loved ones). So, although she did not indicate any need for additional social support in her questionnaire, her interview responses indicated a desire to maintain that support through Internet use. And though she was not familiar with new media communication such as “email,” her reference to sending e-letters indicates it is that sort of communication activity which interests her most.

The fact that Ms. Kirkpatrick has prior experience with computers and has explicitly expressed interest in using the Internet indicates that she could potentially benefit from the integration of online opportunities in her facility. Although facility administrators indicate that Internet is available, the primary researcher does not know why Ms. Kirkpatrick has not been able to access it. This may simply be because (for whatever reason) she is unaware of its availability or because she would need additional instruction and assistance in actually using the hardware.

**PATIENT B**

Burke Belknap, Jr. is an 86-year-old male, suffering from chronic obstructive pulmonary disease and cardiac arrhythmias. He resides in an assisted living facility in North County, San Diego, California. At the time of survey distribution, Mr. Belknap had been staying at the facility for approximately 3-4 months. Mr. Belknap reported that wi-fi Internet access is available to residents, and this information was confirmed by the Director of the facility. At the time of survey distribution, Mr. Belknap had not used Internet in his facility.
Mr. Belknap was interviewed for approximately one hour, in his private room at the facility. He was alert and in good spirits, sitting up in his bed and interjecting jokes and stories throughout the interview. Mr. Belknap’s bed is directly across from a television, and pictures of his family hang on the wall. Mr. Belknap indicated to the primary researcher that he was pleased to have a visitor and would like to have more in the future.

According to Mr. Belknap’s questionnaire and his interview, he is very satisfied with his current opportunities to emotionally disclose. He agreed with the statement, “I can tell my medical team how I’m feeling” and strongly agreed with the statement, “I can tell my family how I’m feeling.” He also agreed that he could express his feelings via the Internet. During his interview, Mr. Belknap described his family and the amount of communication he has with his wife and daughters at length. He noted that his wife lives nearby and that she visits almost every day. When he does not see her in person, they speak on the cell phone she gave him when he entered the facility:

“Oh yeah, I talk to her three to four times a day. The girls, [a daughter named Val] , I talk to her and her sister, every three, four, five days. They call. We’re good.”

Mr. Belknap reported very high levels of social support. He strongly agreed with the statements, “I feel supported by my family” and “My family has come to visit during my stay here.” And he agreed with statements indicating he felt support from his medical team. Mr. Belknap strongly disagreed with the statement, “I would like more support from my family.”

However, since the interview with the primary researcher, Mr. Belknap’s social worker indicated that Mr. Belknap has requested additional social support. The social worker said Mr. Belknap has requested regular visitation from a VITAS volunteer for “friendly conversation.” She said their goal is to “get a volunteer in there” as soon as possible, preferably “a gentleman with similar life experiences” to talk with him. This seems to show that although Mr. Belknap, himself, said he was satisfied with his current social support, he is, in fact, interested in more. And his interest in a visitor of similar background is reflected in Mr. Belknap’s description of his primary care physician with whom he feels has experiences in common. Mr. Belknap indicated that these shared experiences increased trust and satisfaction between them. He also valued the doctor's availability:

“Actually, the doctor I see really is the proprietor of this establishment, Dr. La combs. And I see him, oh, three to four times a week.”
“The guy here, Dr. La Combs, the proprietor, is very accessible here.”

According to his questionnaire, Mr. Belknap is satisfied with the health information he has currently. He agreed that he could ask his medical team if he wanted more information and disagreed with the statement “I would like to use the Internet to find information about my health.” It could be possible though that his satisfaction in support and disclosure from his medical team is specific to his primary care physician only. This because Mr. Belknap voiced mixed feelings about the rest of his medical team.

“Oh sure. Yeah, they’re very good. Most of ‘em. There’s pretty good turn over. He’s got a couple that aren’t any good. But for the most part they’re pretty good. Some better than others.”

But Mr. Belknap’s social worker indicated that his “communication [opportunities] are pretty good.” She said Mr. Belknap could speak Spanish, which helped him communicate better with the predominantly Spanish-speaking medical team at his facility.

In terms of his health-related self-efficacy, Mr. Belknap reported feeling as though his health was not within his control. This, again, is not surprising considering his hospice status. He was “neutral” on the statement, “I am confident that I can have a positive effect on my own health.” However, he indicated that he does feel as though he can make decisions regarding his health and has the “control” to do so. Mr. Belknap disagreed with the statement, “I feel like the Internet could help me be in control of my health.”

Despite indicating that he feels as though his health decisions are within his control, Mr. Belknap told the primary researcher that he has relinquished a great deal of that autonomy to his wife. He also described his illness and care as a burden on his family financially.

Yea, actually I am largely let my wife handle [healthcare decisions]. She handles the checkbook. That’s probably the biggest problem. And I feel sad for her, because it’s not cheap here. And, well, we’re not in the poor house. But we could get there. And obviously, she doesn’t wanna see me turn up my toes. But on the other hand, she doesn’t want to go on paying this bill forever. So, she has a problem there.

In an effort to corroborate information with Mr. Belknap’s medical team, the primary researcher spoke with his primary care physician at the facility. The researcher was told that upon Mr. Belknap’s arrival at the facility, the primary care physician and Mr. Belknap’s wife attempted to integrate a computer into his room. His primary physician reported, however,
that Mr. Belknap’s wife was very concerned that if a computer was put into his room, Mr. Belknap would make online purchases that the family could not afford. This information was not discussed during Mr. Belknap’s interview. Instead, Mr Belknap attributes his lack of Internet access to his own mobility.

Well, I’ve always been technically inclined. I’m a chemical engineer by degree. And I’ve worked in technical fields. And my wife wanted to get me a little computer for here, but mechanically it just doesn’t fit. I hate not having it, but on the other hand, I’d be frustrated if I did.

This not only indicates a level of trust between the patient and his wife and supports the comments above, describing the frequency with which Mr. Belknap and his wife communicate, but also insinuates a sense of guilt and responsibility Mr. Belknap may feel as a result of his declining health. This frustration is echoed later in his responses to questions regarding use of a computer at his current facility.

He indicated that he had used the Internet to seek out information in the past and would like to continue to do so, though it was not indicated whether this information was at all health-related.

“Oh yea, looked up information. Did a fair amount of purchasing of various items.”

“It’d be for communication and searching. See something in the paper about a new gadget or product or something, ‘hey, I want to learn more about that.’”

In contrast to his physical capabilities, Mr. Belknap indicated much stronger self-efficacy for technology use. He strongly agreed with statements regarding his ability to learn new things and his ability to use the Internet. He agreed with the statement “I am interested in using the Internet,” and also said he believes he could express feelings and get support from others online.

In his interview, Mr. Belknap reported that he had used the Internet in the past, starting in 1982, and that he could use it again easily. When asked whether he knew of many others using computers at the same time, he indicated he said he was “pretty much on [his] own.” It was just days after his first computer purchase, however, that he was introduced to “George.”

I was very fortunate, a couple days after I bought it. I was at the shop and the guy said did you know there’s a computer club, a users group or whatever. Are you interested? I said yes. He gave me the guy’s name and I called him up and he said ‘come on board.’ And I joined that group and I’ve been a member of four or five different user groups since then.
When asked what activities he previously participated in online, he responded,

“Oh boy, email all over. Actually my favorite program is probably Desktop Publishing.”

Mr. Belknap and his wife belong to the Oceanelle’s country club in North County, San Diego. For many years, Ms. Belknap used his computer and the Desktop Publishing program to assist with events at the club.

There are various clubs that I belong to. Some of them was ballroom dance. And I did the tickets every month for ballroom dance…I would have one for each month, then I’d just pull up the one, make a few changes as to dates and times and whatever. And take ‘em over to Staples and get ‘em printed up.

“Over at Oceanelle’s country club there are three newsletters. There’s the newsletter, the village voice…Well, I was president…I wrote articles for it, editorials, stuff like that.”

“We have a computer club at Oceanelle’s country club also, I was one of the original ones in that. And I was listed as a source for help and information and what have ya. And they have a monthly newsletter that comes out.

Mr. Belknap indicated that becoming a technology “expert” for others was a significant source of pride in his life. He described how “George” had played the role of “IT guy” for him for many years. Mr. Belknap expressed a great deal of pleasure in the fact that many years later, he was able to act as someone else’s “IT guy.”

“George, we’re still in communication. Ever since ’82. And I would run into a problem, I’d call him and “George, what the hell do I do now?” and he’d say ‘tried this?’ ‘Yea.’ ‘Tried that?’ ‘Yea.’ ‘Try this?’ ‘Oh yea, there she goes.’

“And one of the best days of my life was the day somebody called me up and said “Burke, I got a problem.” I said “have you tried this?” became the expert and solved their problem.

Mr. Belknap also described how he enjoyed staying current on emerging technology trends. Just as he was “one of the originals” in his computer club, Mr. Belknap can be easily described as an “early adopter” and an “evangelist” of his other interests in his life.

“I got involved in Dianetics and Scientology. I don’t know if you know what that is. I got in right at the very beginning. Hubbard’s first class for auditors in 1951. And then I helped them develop the writing. So I’m a granddaddy of Scientology.
When asked if he believed he was good at learning new things, he responded quickly, that “kind of thing comes easy” to him. He went on to describe ways in which he stays current with new technology.

I don’t know if you’re familiar, Mondays in the paper. This guy has a column on computers. Pick up a Monday [North County] Times sometime. He has a column every Monday, people write him ‘how do I do this?’, ‘how can I do that?’, ‘how can I get rid of this?’

Mr. Belknap does not believe the Internet can provide or enable him to have additional control over his own health, because he does not feel as though his health is at all within his control. His health self-efficacy, in this sense, is very low. And his health management has been transferred to his wife. These factors play an important role in Mr. Belknap’s mixed overall interest in using the Internet at his facility. He continued to express concerns over the logistics of incorporating a computer into his facility room, due to his limited mobility. He repeatedly expressed his frustration with his limited physical capabilities.

“I live without [a computer].”

“I’m not really mobile now. Get around in a wheelchair I guess. That’s a bummer, let’s say.”

“Get more in facilities for people to use. Because I’m sure there are people out there who are not as limited as I am, that would be just in heaven if they had one.”

“Oh I’m sure I would [use it]. But I’m not sure whether I’d be more or less frustrated than I am without it.”

When prompted to explain, Mr. Belknap said:

“The mechanics. Where do I put it? Well, there was a…little pdf’s. One of them that I’ve seen that’s, in effect, a computer. But I wouldn’t have a printer, I wouldn’t have the scanner. Both of which I use a great deal.”

“As I say, I’m very much torn, because there are things that I would love to be able to do. On the other hand, if I had one I’d also be frustrated because I wouldn’t be able to print or scan or that kind of thing.”

When interviewing Mr. Belknap’s social worker, who visits him once each month, she indicated that his interest had waned since the patient interview. The social worker noted that she had told Mr. Belknap of another VITAS patient, who was able to use a computer in
his nursing home. She said Mr. Belknap, however, “really didn’t have interest” in setting up something similar in his room.

When asked whether he believes the activities he enjoys could be done without a computer, Mr. Belknap’s response was without hesitation:

“No. There’s no way to compare what you can do. It’s a whole other world (on the computer).”

His inner-evangelist, however, is readily apparent, and he continues to promote technology for others. He affirmed, as studies have shown (Nussbaum & Coupland, 2004; Fox & Madden, 2005; Voelker, 2005), that interest exists among older individuals.

Actually, there are far more people my age that are interested than a lot of people would believe. Our computer club over at Oceanelle’s country club, I think we have something like 220 members…If you’re a senior community, to have that kind of computer club, that’s not something people would take for granted for sure.

“But we had everything from people who were thinking of maybe someday getting a computer on up to people who had made a living with computers for 20 years. The whole gamut in between.”

**Patient C**

Donna Kennedy is a 70-year-old female, suffering from Sepsis and COPD. At the time of survey distribution, she had been living at an East County, San Diego, California nursing home/assisted living facility for approximately 4 months. Ms. Kennedy was not aware of whether or not her facility offered Internet access. The facility, itself, however, reported that the building was equipped with wi-fi for visitors. The facility also reported the availability of one computer on each of its four floors, which both nurses and patients are allowed to use. At the time of survey distribution, Ms. Kennedy had not used the Internet at the facility.

Ms. Kennedy was interviewed for approximately 20 minutes. She stays in a large room she shares with two other women. A floor-length curtain separates each patient's space, which includes a bed and bedside table. At the time of the interview, neither of Ms. Kennedy’s roommates was present. Ms. Kennedy sat upright on the side of her bed, with a table of food over her lap. Many of the researcher’s interview questions were not answered or were responded to with one-word answers. It is not known whether Ms. Kennedy
purposefully chose not to answer the questions, if she did not completely understand them, or if she was distracted by a lunch she was eating at the time of the interview.

Ms. Kennedy reported very consistent satisfaction with her opportunities to emotionally disclose with both family and her medical team. She agreed with the statement, “I tell my family how I’m feeling” and strongly agreed with the statement, “I feel like I can express my feeling freely.” Ms. Kennedy also reported satisfaction with her current health information and her opportunity to request more. She agreed with the statement, “I feel like I have enough information on my health,” and statements indicating that she could ask her family and medical team for additional information if she was interested in doing so. Ms. Kennedy was “neutral” concerning using the Internet to seek out additional health information. Ms. Kennedy reported that she currently has adequate social support. She strongly agreed that her family provides support and agreed that they have come to visit her during her stay at the facility. She disagreed with the statements, “I would like more support from my family” and “I would like more support from the people around me.”

She did not go into further detail regarding either her desire to emotionally disclose or seek out information during her in-depth interview. In regards to social support, Ms. Kennedy said that she was visited by her sister but “not often.” She also indicated that two women from her church had visited in her in the past. Ms. Kennedy reported that she speaks with her family and friends via phone, but it is not known if she currently owns a cell phone.

Ms. Kennedy indicated that she speaks to her medical team on the phone, unless she is in the hospital, in which case they visit her bedside. The primary researcher was unsure as to whether this response was an indication that Ms. Kennedy is not fully aware of her current medical residence. When asked if she could easily communicate with her medical team she said yes and that they were, “very good about that.” However, when asked if she felt “in control” of her own healthcare, in terms of asking her medical team for things she wants, Ms. Kennedy did not reply.

Ms. Kennedy has a positive sense of self-efficacy in terms of her health and healthcare. She agreed to statements indicating that she is in control of her health and in control of her own health decisions. She was “neutral,” however, to the statement, “I can make decisions about my health.” She also disagreed with a statement indicating that the
Internet could help her exert more control over her own health. She had nothing to add regarding her feelings of health-related self-efficacy in her interview.

Ms. Kennedy has displayed positive views about technology use and learning new things. She said she knows how to use the Internet but is “neutral” in her interest to use it again. She also agreed with the statement, “I feel like I could get support from others by using the Internet.”

In her interview, Ms. Kennedy responded affirmatively that she had used the Internet in the past, though she said she had never used email functions. She did not answer a question as to whether she had ever sought out information online. She said that she did own a computer, as did her children and grandchildren. And she said she does have a cell phone, but does not use it very often. This information could not be confirmed by her social worker. When Ms. Kennedy was asked if she would like a computer in her current facility, she said yes. When asked if she would like to communicate with friends on the computer, she said yes.

However, it is not clear whether many of the answers from Ms. Kennedy’s interview can be used to draw any significant conclusions about patterns of Internet interest and use. Despite Ms. Kennedy not having any documented cognitive impairments, it would be irresponsible to describe her interview responses as true indications of her thoughts and feelings. The possibility exists that Ms. Kennedy was simply responding in the affirmative to questions she did not completely comprehend. When corroborating information with Ms. Kennedy’s social worker, the primary researcher was told that cognitive impairments have not been noted for Ms. Kennedy.
CHAPTER 5

DISCUSSION

The multi-faceted concept of self-efficacy made for an interesting case study analysis of these three patients. Whereas the primary researcher set out to assess both health and healthcare self-efficacy among participants, it became evident that the reference to health self-efficacy was in and of itself problematic. That is, hospice patients are inherently lacking in control or autonomy over their medical conditions; by allowing or by receiving hospice care, they are therein saying that they are not willing or interested in pursuing outside means to better or maintain their physical health. Therefore, the health self-efficacy variable was transitioned or redefined into a self-assessment made by patients regarding their own physical health. The assessment’s inclusion in this study is important as it relates to healthcare self-efficacy. Although these hospice patients may universally feel a loss of autonomy in regards to their physical health decline, their healthcare self-efficacy can differ greatly, as can their Internet interest. This study has found that these variables, in fact, are dependent upon two measurements: patients’ attitude toward their declining health, as well as their prior experience with new media. These findings will be discussed further, but first, it is relevant to detail the most recent trend research in regard to aged populations’ Internet use.

In October of 2009, the Pew Internet Research Project attempted to define and differentiate between types of Internet users. According to their survey, “e-patients” were characterized as broadband and wireless users, who search for health information online. E-patients are more likely than other Internet users to engage in social media use, including creating and reading others’ blogs or status updates on sites like Facebook or Twitter. If one assumes that engagement in social networking sites is an example of seeking social support, it can be said that e-patients are more interested and active in all three technology uses, or are at least motivated by one or more of the activities previously noted: information-seeking, disclosure and seeking social support. The report described 10 types of networked individuals, differentiated by characteristics in Internet use, interest and influence over
others. The most relevant of these groupings—in relation to the current study’s participants—are the Digital Collaborators, or DGs, and the Tech Indifferent, or TIs.

In February and March of 2010, the Pew Research Center updated their differentiations of technology users in its reports on “Millenials” and “Baby Boomers” (see page 46). Their studies compared values, attitudes, and behavioral differences among and between generations. The 2009 e-patient categories will be developed further enhanced by insights gleaned from the 2010 reports, as Pew seeks the best way to categorize e-patient types, such as the participants in the current study. This chapter will also describe the most relevant motivations for use and types of self-efficacy (including new media and healthcare) exhibited by the study participants.

**TI’S, DG’S AND THE SILENT GENERATION**

In the February 2010 Pew study, researchers examined technology activity in terms of participation in social networks, general Internet, and cell phone use. The Pew study found great variance in time and effort spent online by certain populations. Millenials, or participants between the age of 18 and 29, posted higher levels of utilization when compared to older Americans, regarding nearly all types of Internet and cell phone use. They are described as “technology enthusiasts,” who lead the charge in terms of innovation and practice. Millenials also hold very different beliefs as to the benefits of Internet use. For Millenials, technology makes life easier. Only half of those categorized as the Silent Generation, or participants aged 65 and above, share that belief. In fact, equal numbers of Silent Generation users indicate that technology (1) helps people use their time more efficiently and (2) encourages users to waste too much time. This group is also divided in its belief regarding virtual communities: 44% say it makes people more isolated and 44% say it brings people together.

The study found significant age differences in terms of Internet use. According to the survey, nine out of 10 Millenials use the Internet, whereas only 40% of Silent Generation users do so, even only on occasion. Far more Millenials than those in older generations used wireless connections to use the Internet. Only 11% of Silent Generation users access the Internet via wireless when they are away from home or work. A contributing factor to this percentage may be the shorter length of time older people spend away from the home, when
compared to Millenials. Cell phones, which can be categorized as a gateway technology for more advanced online activities, are used by 62% of the Silent Generation.

Although participants did not unanimously indicate experience using the Internet for health-related purposes, each participant can be described in terms of the e-patient typologies, as explicated in the 2009 and 2010 Pew Research studies.

**Linking Ms. Kirkpatrick to the Pew E-Patient Typology**

According to her responses, Ms. Kirkpatrick may be called Tech Indifferent. Members of this group are not heavy Internet users, and although most have cell phones, they may not like their intrusiveness. Tech Indifferent users could easily do without modern gadgets and services. They may believe modern technology is too much trouble with too little payoff. This group is often included in what the February 2010 study describes as the Silent Generation. Ms. Kirkpatrick is certainly old enough to be included within this population, but she also displays other characteristics of the Tech Indifferent, as identified in the Pew studies. This includes her lack of Internet use. Though she did not articulate it specifically, she may be included in the 44% of the Silent Generation, who believe technology can make users closer. When she expressed interest in using technology, she described wanting to reach out to those whom she can no longer write letters to. Ms. Kirkpatrick also may be included in the half of the Silent Generation who believe technology can make life easier; she explicitly expressed interest in Internet use to combat the difficulties she experiences in hand-writing her correspondences by hand.

**Linking Ms. Kennedy to the Pew E-Patient Typology**

Ms. Kennedy may also be categorized in terms of the 2009 study as Tech Indifferent; perhaps more so than Ms. Kirkpatrick. Although her feedback was limited on both the questionnaire and in her in-depth interview, she displayed many characteristics of this group. She lives without use of the Internet. While she may own a cell phone, she certainly does not consider it a primary means of communication. Very few of the Silent Generation are e-patients, which is true for both Ms. Kirkpatrick and Ms. Kennedy. Neither expressed interest or prior experience using the Internet for the purposes of seeking out information about or participating in, their healthcare decisions. Ms. Kennedy is also in the age category of the
Silent Generation. The trend among the Silent Generation to show little interest or participation with the Internet matches the findings of this study for Ms. Kennedy.

**Linking Mr. Belknap to the Pew E-Patient Typology**

Mr. Belknap, however, fits into a very different category—both in the 2009 e-patient analysis and in the 2010 comparison of population technology use. Mr. Belknap could be described as a Digital Collaborator. He often uses technology to create and share with others. Mr. Belknap described his Internet use and interest in terms of using Desktop Publisher to participate in social functions at his country club. He also discussed collaborating with other Internet users with his computer clubs. Digital Collaborators are enthusiastic about using the Internet, as Mr. Belknap continues to read about new technologies in the *North County Times*. They are confident in their ability to manage devices and information. Digital Collaborators also described as “early adopters” and “potent influentials.” They share their enthusiasm for technology with others and are anxious to provide feedback in terms of their own use. He reported that he was the only person he knew to begin using the Internet when he first purchased a computer. He also described the computer clubs he established. Mr. Belknap became a computer “expert” during his lifetime and remains on the cutting edge at the end of life. Mr. Belknap expressed great pride in this “expert” title and satisfaction with his ability to utilize and help others use technology. He was also very enthusiastic in his in-depth interview and seemed anxious to give feedback to the primary researcher regarding all aspects of the Internet.

Mr. Belknap certainly did not display the characteristics of the Silent Generation. His enthusiasm for technology fits more closely with Millennials. His skills with Desktop Publishing allowed him to use his time more efficiently. Mr. Belknap cannot be categorized regarding his beliefs about technology making life easier. In his current physical state, he told the primary researcher that he was unsure as to whether using the hardware that the Internet requires would make him more or less frustrated. Although he said there was “no way to compare” what users can do online to what is possible offline, Mr. Belknap’s declining health seems to position him in the Silent Generation for some categories. This is an interesting and perhaps under-researched element in regards to older persons’ Internet self-efficacy. That is, the limited Internet interest and use exhibited by the Silent Generation may
be attributed to factors such as decline in physical and mental health. Their attitudes regarding technology—as a cause for isolation and/or as a waste of time—may be secondary to their medical condition. This idea is explored below.

**Patterns**

Along with the useful categorizations provided by the Pew Research studies, the in-depth interviews added significant context to the initial questionnaire results. With more participants, the results could have provided more complete answers to the research questions. Nevertheless, in-depth interviews and quantitative questionnaire results enabled the primary researcher to observe some very clear themes, that provided partial support for extant theory from the uses and gratifications perspective, as well as the concept of self-efficacy. More importantly, there were instances of reversed relationships and anomalous findings that do not support theoretical propositions deduced from prior research. These patterns are discussed below.

**Motivations for Use: Social Support**

The uses and gratifications perspective of an active audience seems to fit the information-seeking demands of Internet usage, especially for e-patients. Researchers using this perspective seek to understand how people use media to fulfill their psychological needs and wants—whether conscious or subconscious. For the purposes of this study, uses and gratifications referred to three primary motivations for Internet use: (1) emotional disclosure, (2) information-seeking, and (3) social support. Neither Ms. Kirkpatrick nor Mr. Belknap indicated that the acts of information-seeking or emotional disclosure were particularly important to them and so, because these motivations for technology use were not discussed at length or significantly associated with other variables of interest, they will not be discussed further.

However, the primary researcher discerned a pattern throughout the interviews that involved social support as an important motivation. Although both Ms. Kirkpatrick and Mr. Belknap indicated on their questionnaires that they were satisfied with their current opportunities for social support, both expressed interest in additional social support during the in-depth interviews. Ms. Kirkpatrick expressed interest in using the Internet to write letters to loved ones. Mr. Belknap asked his social worker for a weekly volunteer for friendly
visits with shared interests. This support resource would provide much of the same benefits of online communities—anonymity, sameness and consistency.

**Self-Efficacy: The Influence of Physical Health Decline**

In this study, perceived self-efficacy is context specific. It pertains to “a specific behavior in a particular context” and cannot necessarily be generalized to other settings (Hellstrom, Lindmark, Wahlberg & Fugl-Meyer, 2003). Patients’ perceived self-efficacy, of course, can be generalized to a greater theoretical concept. For the purposes of this study, self-efficacy is applied in multiple contexts: (1) health self-efficacy, which can be redefined as a patient’s *assessment* of their own physical capabilities, (2) healthcare self-efficacy, which refers to patients’ beliefs about their influence over their own healthcare decisions, and (3) Internet self-efficacy, which refers to their perceived ability to use new media/technology. On the patient questionnaires, Internet self-efficacy was explored only in terms of the cognitive requirements associated with technology use. Physical Internet self-efficacy, and patients’ beliefs in their ability or inability to physically use the hardware (ie. look at a screen, move a mouse, type on a keyboard), was not addressed in the questionnaires. This issue, however, was broached by patients in their in-depth interviews and will be discussed further below.

As previously referenced, the differentiation between the established academic understanding of self-efficacy and patients’ perceptions of their physical capabilities is important. The first pertains specifically to *cognitive* functioning only. Although researchers have studied self-efficacy in terms of physical health (Hellstrom et al, 2003; McAuley & Blissmer, 2000; Mendes de Leon et al, 1996), the concept of self-efficacy does not pertain to the physical body or the physical body’s capabilities. Self-efficacy is a “cognitive mechanism mediating behavioral change” (McAuley & Gill, 1983). If associated with physical behaviors, self-efficacy acts as a predictor (i.e., “I have the motivation to act, because I believe I can”). When the present study describes low health self-efficacy, this is Ms. Kirkpatrick’s own assessment of her physical decline. When discussing her healthcare self-efficacy, the phrase pertains to her belief that she has control over or could improve upon decisions that deal with her actual care. And when discussing her technology or Internet self-efficacy, it pertains to her belief in her ability to cognitively use or learn to use it. It does not, necessarily, pertain to
her belief in her own physical capabilities to use the hardware associated with the Internet (ie. a keyboard, mouse, etc.).

This “physical factor,” however, is a way of life for most hospice patients and can significantly affect a patient’s healthcare self-efficacy. Declining physical capabilities can lead patients to believe as though they have fewer care options or that their opportunities to navigate their own healthcare “pathway” has narrowed due to worsening symptoms or an advanced prognosis. Conversely, limited understanding of the relationship between declining physical health and the physical requirements necessary for using the Internet can encourage patients to retain interest in using the Web (see below). Patient’s own assessment of their declining physical capabilities plays an understandably important role in this project’s findings.

The nature of the hospice population introduces a confounding factor when theorizing about e-patients and social support: physical capabilities often decline while mental facilities remain intact. Although Mr. Belknap had high technology self-efficacy in that he believed he had the mental capabilities required to use the Internet, he had low health and healthcare self-efficacy due to his declining physical health. Mr. Belknap did not believe he had control over his declining physical health or the decisions related to his care. He had, essentially, given that to his wife. Mr. Belknap also had very low physical Internet self-efficacy. He believed that his declining physical health would prevent him from using a computer, a keyboard, and a mouse.

A mitigating factor for Mr. Belknap and Ms. Kirkpatrick may have been prior use of the Internet, supported by previous scholars as an influential factor in Web usage (Ferguson & Perse, 2000). Ms. Kirkpatrick had not used the Internet in the past, so when her physical health declined, she may not have understood how lack of mobility could prevent her from using the hardware required of the Web. Despite low health self-efficacy, Ms. Kirkpatrick displayed high physical Internet self-efficacy. Mr. Belknap, however, was a seasoned technology-user. He may understand the implications of his declining physical health—he may better understand how his lack of mobility becomes a significant barrier to use of the Internet for him, specifically.

Internet self-efficacy has been linked to an increase in confidence for patients attempting to maintain their independence. Mr. Belknap did not indicate that maintaining
independence is important to him at this point in his life. Conversely, Ms. Kirkpatrick had relatively low technology self-efficacy; she said she was unsure whether or not—even if she was taught—she could learn to use the Internet. However, despite this doubt and her own declining physical health, Ms. Kirkpatrick believed she did have control over her own healthcare. It may also be relevant to note that Mr. Belknap is currently bed-ridden, whereas Ms. Kirkpatrick is able to spend time in her facility’s common areas with the help of an aide. Perhaps this higher level of healthcare self-efficacy influences her interest in using the Internet. Despite her disabilities, she retained high healthcare self-efficacy. The differentiation most important, then, may be that a decline in physical health does not necessarily mean that patients no longer wish to improve their condition and/or decide to relinquish healthcare decisions to others. In this sense, physical decline becomes an important moderating variable, albeit a contextual one.

Mr. Belknap may have also encountered a psychological barrier to Internet use: his own identity. Mr. Belknap once took great pride in his ability to use and to help others use technology. Now, he is disinterested in attempting a task that he once mastered at a much lower physical level. This may be due in part to the fact that he his previous online activities—such as using Desktop Publisher to create tickets for his country club—are no longer relevant to his lifestyle.

Finally, these patterns can be analyzed from another perspective. We can, instead, begin with the environmental variable of declining physical health. Perhaps Mr. Belknap’s physical disabilities led to a decrease in his healthcare self-efficacy. As his motor skills deteriorated and he became unable to complete tasks he once accomplished with ease, Mr. Belknap may have given up the idea that he had any sort of control over his healthcare or over the improvement of his own health. Mr. Belknap is a rather complicated aspect of this case study. Independent of his physical condition, did his low healthcare self-efficacy lead to a decreased interest in the Internet? Or did his physical decline lead to low healthcare self-efficacy, which in turn led to a decreased interest in the Internet?

*The Pessimist and The Optimist:* If the process of physical health decline, as antecedent to declining healthcare self-efficacy is accurate in Mr. Belknap’s case, this constitutes only a single instance. That is, Mr. Belknap’s declining physical condition may have taken this once-competent computer “jock” (with low physical and high cognitive Internet self-
efficacy) and left him feeling disinterested in the Internet and the potential social support it could provide, because he saw the computer as potentially frustrating and control over his own health as a fleeting and declining condition. He was, in effect, pessimistic that the benefits of mediated communication could outweigh the perceived barriers of technology use.

A different self-efficacy type is evident in the case of Ms. Kirkpatrick. She was not deterred in terms of her healthcare self-efficacy or her interest in the Internet. In fact, a decline in Ms. Kirkpatrick’s physical health may have led to a sense of optimism and increased interest in the Internet. This could be because the disability did not seem to change her healthcare self-efficacy and it certainly did not affect her previous activity online because she had none. This lack of prior Internet use allows Ms. Kirkpatrick to retain high cognitive Internet self-efficacy, as she is unaware that her physical health decline can act as a barrier to physical Internet use. She reported that she feels in control over her own health decisions, despite having little control over her failing health. Perhaps this sense of autonomy and high cognitive self-efficacy encourages Ms. Kirkpatrick to actively pursue (or at least, maintain interest in) activities and resources that would improve the quality of her life. For this patient, use of new media and technology is a way of compensating for the loss of her physical health.

**CONCLUSION AND IMPLICATIONS**

Self-efficacy as a concept is very much dependent upon context; this exploratory research does not allow for any sweeping or conclusive findings regarding its influence on the lives of hospice patients or the aging population, at large. This social-cognitive perspective can be a significant and beneficial part of traditional uses and gratifications research. Self-efficacy, as well as the motivation to seek social support, can also greatly influence patients’ interest in using the Internet. Two patients (Ms. Kirkpatrick and Mr. Belknap) showed incredible similarities in their health-related frustrations and psychosocial needs. Yet, the influence of prior technology experience and polar feelings of control, in terms of their own healthcare, puts them at opposite sides of the Internet-interest spectrum. Thanks to the qualitative nature of this study, the cases of Ms. Kim Kirkpatrick and Mr.
Burke Belknap presented what Yin described as “extreme types.” Both are “interesting [and] important, simply because they are special” (54).

In addition to Millennials and the Silent Generation, the March 2010 Pew Research study also described the “Boomer” generation of adults ages 46 to 64. Over the last ten years, Boomers use of the Internet has nearly doubled. Today, this group makes up more than one-third of the Internet population. Sixty percent of Boomers believe technology can make life easier; and 54% believe technology helps people use their time more efficiently. Boomers use the Internet at nearly double the rate of the Silent Generation. Boomers are five times as likely to create a profile on a social networking site. In fact, use of these sites has grown substantially among Boomers, from 5% in 2005 and 2006 to 30% in 2010. More than 10% of Boomers indicate that they visit a social networking site multiple times a day.

These findings indicate the exponential growth of Internet interest and use as populations continue to age and technology continues to advance. Although the Silent Generation users, like Ms. Kirkpatrick and Ms. Kennedy, show minimal interest, the next generation of Boomers already exhibits significantly higher levels. Boomers seek online communities for information-seeking, emotional disclosure, and motivations for use. Boomers believe the Internet can make their lives easier. These findings indicate that, in terms of the 2009 Pew study, the population of e-patients will also grow. As these Boomers age and begin to face more physical and cognitive health impairments, they will approach and pursue technology use with much higher levels of both physical and cognitive Internet self-efficacy, due to many years of prior Internet use.

As Radin (2005) described the shift of the healthcare industry, at large, it will be necessary for scholars to conduct further exploratory research. With increasing numbers of patients dying in facilities rather than at home, such facilities will need to adapt and adjust in ways that fulfills patients’ developing communication and technology needs. Although this study was unable to determine whether hospice patients are generally interested in using the Internet, insights from these three participants allow us to develop a deeper understanding of the older generation of technology users. That is, although some current hospice patients may be unable or uninterested in Internet use, the coming years will bring an ever-growing group of e-patients; and these persons will already possess the Internet- and healthcare self-efficacy necessary to fulfill their communication needs online.
REFERENCES


APPENDIX

INTERVIEW GUIDES AND QUESTIONNAIRE
Appendix 1: In-Depth Interview Guide

INTRODUCTION:
As the researcher who requested their assistance on the questionnaire they’ve already completed. I will further explain my research goals and ask the following questions in reference to the responses I’ve already received from each patient.

1. How long have you lived in this facility?
2. How do you communicate with your medical team? (eg. call buttons, bedside visits)
3. Do you feel like you can tell your medical team when you need or want something? Can you tell them how you’re feeling?
4. Tell me about your friends and family. Do you feel like you have people around you who are supportive? Tell be about the people who are emotionally supportive of you? Family? friends? Your medical team?
5. How do you communicate with your family or close friends? Do you write letters to them? Do they write back? Do you call them on the phone? Do they call you? Do they come to visit you here?
6. Do you feel like you can tell your family or close friends when you need or want something? Can you tell them how you’re feeling?
7. Do you feel in control of your health? Why or why not? Please tell me more…
8. Do you ever have questions about your health where you wish you had more information about what’s going on with you and your health? Can you think of a recent time or situation when you felt like you didn’t have all the information that you would like to have about your health or condition? Please tell me about that… [PROBE FOR SOURCES OF INFORMATION SOUGHT.]
9. How do you feel about learning new things or new skills? Do you consider yourself a quick learner? Do you enjoy learning new skills?
10. Tell me about your experience with the Internet. Have you ever used it before? If so, what have you used it for? [IF PARTICIPANT IS UNSURE, ASK: Have you ever used the Internet for email? What was that like? How does that compare to sending a letter? Talking on the phone? PROBE FOR FACEBOOK, DISCUSSION BOARDS, BLOGGING, ANYTHING TO DO WITH COMMUNICATING WITH OTHERS]
11. Do you know if you have Internet access here? [IF NO, ASK: If you had access here, do you think you would ever use it?]
12. Do you have any interest in using the Internet while you’re here? Why or why not?
   If you could reach your family or friends using the Internet, would you be interested in using it?
   If you could find more information about your health, your diagnosis or your symptoms, would you be interested in using it?
   If you could talk with other people who have COPD/cancer/etc. using the Internet, would you be interested in doing so?
13. Age:
14. Sex:

Social Worker Interview Guide
1. Does this patient presently suffer from any kind of dementia?
2. Does this patient have access to the Internet at her/his facility?
3. To your knowledge, did this patient have prior experience with the Internet?
4. Does this patient have family or friends who offer support? Do they have visitors?
5. Has this patient expressed interest in additional communication or information resources? How so?

Patient Questionnaire
Sex (circle one)    M        F
Age (in years)? _____
In what type of facility do you currently live? (circle one)
Nursing home     Assisted living facility     Hospital     Other: ___________
I have been living here for how long? (circle one)
Less than a month    1-3 months    3-6 months    More than 6 months

Please circle one:
1. If someone taught me, I could learn to use the Internet.
2. I feel in control of my health.

3. I am interested in using the Internet

4. I feel supported by my family.

5. I would like more information on my health.

6. My family or friends have come to visit during my stay here.

7. I feel supported by my medical team.

8. I am confident that I can make decisions about my own health.

9. I would like more support from my family.

10. When I want information about my health, I can ask my family.

11. I would like more support from my people around me.
12. I feel like I could express my feelings by using the Internet.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

13. I tell my family how I’m feeling.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

14. I feel like I have enough information on my health.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

15. I feel like the Internet could help me be in control of my health.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

16. When I want information about my health, I can ask my medical team.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

17. I feel like I can express my feelings freely.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

18. I can tell my family how I’m feeling.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

19. I would like to use the Internet.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

20. I would like to use the Internet to find information about my health.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1  

21. I can tell my medical team how I’m feeling.  
Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree  
5 | 4 | 3 | 2 | 1
22. I am confident that I can have a positive effect on my own health.

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23. I feel in control of my own health decisions.

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24. I am confident that I could use the Internet.

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25. I know how to use the Internet.

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26. I am confident in my ability to learn new things.

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27. I feel like I could get support from others by using the Internet.

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I would be willing to answer more questions about my interest in using the Internet: (circle one) Yes No

Was the survey fully completed? (circle one) Yes No
If completed, please indicate by whom: (circle one) Patient Team Treatment Member
If not completed, please indicate reason:

___ Patient chose not to participate
___ Patient is mentally or physically unable to participate
___ Other

Patient Primary Diagnosis: ___________________________