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Family Caregiver Internet Experiences

by

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wonderful. This is really *our* degree.

Abstract

Family Caregiver Internet Experiences

Danita Lee Ewing

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Christine A. Tanner, PhD, RN

Family caregiver numbers in the United States are increasing as the population ages, rates of chronic illnesses increase, health care services are cut and more people are dependent on health care technology to live. Some caregivers are using the Internet to help support their caregiving. A two-phase, mixed-method study was conducted to describe characteristics and experiences of family caregivers who use the Internet. Data were collected first using an online survey questionnaire and then with followup telephone interviews of a subsample of 15 survey respondents.

The of 72 survey respondents sample was overwhelmingly white (88%), female (91%), middle aged (range 24-79, mean 49.54, sd 11.42) and well educated. Caregivers were fairly experienced and confident in their Internet use. All but one of the caregivers could access the Internet from home for their caregiving. On average caregivers accessed the Internet from at least two places. Information and support were the two main reasons to use the Internet. Caregivers initially went online seeking information. The most frequently sought information was practical information to help them care for their ill family member. Information credibility was critically evaluated by all caregivers interviewed. Social and emotional support needs were also met by going online, although how much online emotional and social support was desired varied greatly among caregivers. Emotional and social support enabled caregivers to feel decreased

senses of isolation, engage in cognitive restructuring about their caregiving situation, and access people they would not ordinarily have met. Accessibility of information, social and emotional support, health care providers, products and services were all beneficial to caregivers. The round the clock availability of the Internet, the variety of people and information and the ability to overcome barriers of geography were benefits of their Internet use. Caregivers described few limitations or negative effects of using the Internet as part of their caregiving.

The study's small sample size and homogeneity are limitations. Caregivers were able to describe in detail Internet based features and content that proved helpful to them and ways their Internet impacted their caregiving. This information can be useful for those designing web pages to support caregivers.

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CHAPTER 1

Introduction to the Problem

Statement of the Problem

The number of family caregivers in the United States (U.S.) is increasing, with 23% of U.S. households having at least one family caregiver (National Alliance for Caregiving & the American Association of Retired Persons, 1997). Factors contributing to the increase in family caregiving to care recipients with more complex care needs (Canning, Dew, & Davidson, 1996) include an aging population (Dennis, Blue, Stahl, Benge, & Shaw, 1996), increasing rates of chronic illnesses (Hoffman, Rice, & Sung, 1996), advances in treatments and life-saving technology (Barg et al., 1998), and decreasing length of hospital stay (Gillis & Belza, 1992). At the same time, the number of persons with Internet access in the U.S. is growing rapidly among all age, gender, and racial groups (National Telecommunications and Information Administration [NTIA], 1999). The existence of Internet sites such as the Family Caregiver Alliance (Family Caregiver Alliance, 2000) and Web of Care (Web of Care, 2000) indicates that family caregivers are going online. Family caregivers' experiences when they use the Internet, and how those experiences affect them and their caregiving, have not yet been studied. The aims of this two-phase research study were: (a) to describe characteristics of family caregivers who use family caregiving Internet sites, (b) to identify purposes for which family caregivers use the Internet, (c) to identify perceived benefits and limitations of Internet use by family caregivers, and (d) to describe family caregivers' perceptions of the effects of Internet use on their caregiving.

Family Caregiving in the United States

Family caregiver responsibilities in the U.S. are growing (Canning et al., 1996) and the type of care delivered at home is increasingly complex (Smith, 1999). In 1996, the National Alliance for Caregiving (NACG) and the American Association of Retired Persons (NACG & AARP, 1997) conducted a telephone survey to develop a profile of caregivers and identify the impact of caregiving on U.S. society. The survey was conducted with a random sample of U.S. caregivers 18 years of age or older. The study purposefully over-sampled minority groups, although it did not include caregivers without a telephone or those who did not speak English. The survey found that the U.S. has in excess of 22 million households in which at least one caregiver is caring for an ill family member. The average length of caregiving is 4.5 years, usually for a family member who has a chronic illness (71%) or a combination of long- and short-term illnesses (11%) (NACG & AARP). Caregivers were mostly women (73%), and women who are caregivers spend more time caregiving (18.8 hours per week) than men (15.5 hours per week). Almost three quarters of caregivers (73%) say that they receive help from someone else, usually another family member, in caring for the ill family member. Only 49% of caregivers feel that other relatives are doing a "fair share" of the caregiving (NACG & AARP). The study noted caregiver needs for a variety of services, including information, respite, help with housekeeping, help with care activities, and support. Caregivers' information needs included a central source of information (9%), information about paying for services (7.6%) and information about the care recipient's health condition (2.7%). A desire for more information was greater among those of higher socioeconomic status and those with at least some college education. Having someone to talk with, counseling, or support group services was listed by 6% of the sample. The need for social support increased as the level of care required by the care recipient increased.

A review of caregiving literature (Hunt, 2003) described negative concepts commonly found in caregiving literature, including caregiver burden and hassles, strain, and stress, as well as positive aspects of caregiving such as caregiver esteem, the uplift aspects of caregiving, and meaning associated with caregiving. According to the literature, caregivers can experience significant physical, financial, emotional, and health strains (Barg et al., 1998) and may feel unprepared, overwhelmed, and alone (Boland & Sims, 1996). Wicks, Milstead, Hathaway and Cetingok's (1997) study of 96 caregivers of family members with end stage renal disease found that caregivers' quality of life decreased as caregiver burden increased. Barg et al. found that 39% of caregivers of cancer patients reported that their health had suffered, 20% were very stressed by their caregiving role, and 35% felt overwhelmed. Hinds'(1992) study of 83 family *caregivers* of cancer patients found that family caregiver suffering was based on uncertainty, fear of loneliness, lack of support, and other factors.

Wright, Clipp, and George (1993) reviewed research on the health effects of caregiving and found that the caregivers at greatest risk for health problems were women, especially wives, daughters and daughters-in-law, and those caregivers from lower income groups. Informal support can be a mitigating factor, while formal support is not except when caregiver health declines. Caregivers (NACG & AARP, 1997) report negative impacts on their family and leisure time, physical and mental health, and emotional well being. Caregivers who were providing more demanding or complex kinds of care (e.g., dealing with high level physical or medical demands) reported higher negative impacts in these three areas. Caregivers coped mainly through using their own resources of informal social support networks, such as talking with friends and relatives.

However, not all aspects of caregiving have a negative impact on the caregiver and family. Family roles may change in both positive and negative ways through caring for an ill family member (Barg et al., 1998; Hilgenberg, Liddy, Standerfer, & Schraeder, 1992). Many caregivers have indicated that, despite the strain caregiving may cause, there are rewards associated with caregiving. Barg, et al. found that 67% of caregivers enjoy caregiving and 97% believe their caregiving is important. Stetz, McDonald and Compton's (1996) study of family members caring for bone marrow transplant recipients found that caregivers experienced personal growth and an increased sense of family togetherness as a result of their caregiving experiences. Rewards of caregiving reported in a national caregiving study (NACG & AARP, 1997) included caregivers' knowledge that their family member is being well cared for, expressions of appreciation or happiness from the care recipient, and a sense that what they are doing is good. Other rewards identified were watching the care recipient get better, time spent with the care recipient, and fulfilling the loyalty and sense of obligation they felt toward the ill family member.

Adequate information and support have been found to help family caregivers cope with the stresses of caregiving. Being prepared for caregiving and having a reciprocal relationship with the care recipient can alleviate some aspects of caregiver role strain (Archbold, Steward, Greenlick, & Harvath, 1990). When caregivers lack information, they report feeling inadequate; conversely, when they have information, they report feeling a greater sense of control of the situation (Brown & Stetz, 1999).

Research suggests that, in general, caregivers' information needs are not being met. Caregivers want more information that is individualized (Wiles, Pain, Buckland, & McLellan, 1998) and that will help them with practical, everyday aspects of caregiving (Magnusson et al., 1998; Turton, 1998). For these reasons, it is important for family caregivers to have access to information that is comprehensible, timely, and relevant to their situation, as well as delivered in accordance with the way they learn.

Background and Significance

Family caregiving can negatively affect the caregiver in a number of ways. Research has shown negative health outcomes for some family caregivers, including increased depression rates, compromised immune function (Wright, Clipp, & George, 1993), and increased mortality rates, when compared with the non-family caregiving population (Schulz & Beach, 1999). Researchers are exploring interventions to support family caregivers and reduce negative outcomes in response to the identification of family caregivers as a growing at-risk population (Gilliss & Knafl, 1999). Identifying family caregiver needs and ways to meet them can help nurse researchers design effective interventions to reduce or ameliorate negative health outcomes and consequences of caregiving.

Family caregivers have reported unmet needs for information and support (Boland & Sims, 1996; Davis & Grant, 1994; Hinds, 1992; NACG & AARP, 1997). One possible source of both health information and support for family caregivers is the Internet (Ferguson, 1996). Internet use is growing rapidly, with estimates of more than 57 million users in the U.S. and 17,000 new users daily ("57 Million U.S. Web users reported," 1998). A NTIA study (1999) found that Internet access in U.S. households increased from 18.6% in 1997 to 26.6% in 1998 and the increase crossed all age, gender, race, and income groups. A 2000 NTIA study found that Internet access had increased by 58% since the 1999 study, to 41.5% of U.S. households, with 116.5 million Americans online in August 2000. A 2002 study by the United States Department of Commerce indicated that Internet use was growing by approximately 2 million new users a month (Evans, 2002). The report further indicated that growth in Internet use was occurring in all age, income, education, racial, and gender groups.

Estimates of health-related Internet use are between 25% (Ferguson, 1997) and 49% (Glascow et al., 1999), although these estimates vary widely because of the way use is measured and the fluid nature of Internet membership (Thibodeau, 1998). One higher estimate reported in a study by the Pew Internet and American Life project (Fox et al., 2000) found that 52 million American adults (55% of Internet users in the U.S.) had used the Internet to get health or medical information. A majority of these searchers were found to go online at least monthly for health information. The study found that 36% of those who looked for information regarding someone else's health during their last online search said that what they found online affected their decisions about that person. Searchers also reported going online for support as well as health or medical information (as much as 9% of users). Conversely, the U.S. Department of Commerce (Evans, 2002) found that only 35% of U.S. Internet users are going online for health information.

Internet sites such as WebMD are growing rapidly with more than 400,000 members in more than 40 online communities as of January 2000 (Healtheon WebMD, January 2000). As of June 2003, the web site had more than 3 million hits a month. A 2002 Internet search using the metasearch engine Hotbot with "caregiver" as the primary search term and "family" as the secondary search term, and limiting the search to English language and North America, yielded more than 40,000 family caregiving-related sites. A search using the metasearch engine Google.com yielded more than 60,000 hits. Sites such as the Family Caregiver Alliance (2000) offer current information for a variety of chronic illnesses such as Parkinson's and Alzheimer's diseases as well as support for family caregivers. Web of Care (2000) offers caregivers opportunities to network and to make online purchases of products needed in caregiving. Such sites do not provide information about which contextual factors in the caregiving situation prompt family caregivers to use the Internet to support their caregiving activities.

A number of potential limitations of health-related Internet use have been raised, including the wide range in the quality health-related information and the lack of a consistent standard to evaluate that quality (Jadad & Gagliardi, 1998; Meric et al., 2002). Lay persons using the Internet may lack the ability to adequately evaluate the health information presented (Huang et al., 1998). In spite of these concerns about the quality of Internet information, potential benefits exist, including the ability to access current, relevant information and support 24 hours a day from a worldwide community (Sharf, 1997).

Use of the Internet may have several additional advantages for family caregivers. First, there is no need to travel to the source of information (e.g., library, doctor's office) or support (e.g., support group meeting), so transportation, respite, and geographic barriers are overcome by using the Internet. Second, there is a great deal of information available online. Third, it is possible to find others with similar situations from around the world, whereas it might not be possible to find someone else with a similar situation in geographic proximity. Fourth, it may decrease the sense of isolation that caregivers experience.

Current Internet-based research on family caregivers is lacking in several areas that were addressed by this study. First, most Internet-based caregiving research is content analysis of postings on one or more web sites. While such research provides important information about what the posters are talking about, it does not provide such data as contextual information about what was happening with the care recipient or caregiver that the caregiver was trying to address or what caregiving decisions were made based upon the caregiver's use of the Internet. Second, most studies do not differentiate among caregivers, patients, friends, clinicians, and researchers; therefore, most existing Internet research findings can be transferred to caregivers only with great caution. Third, the research speculates on but does not ask caregivers how they are benefiting from going online or what they perceive as limitations. Fourth, because most studies are of postings, the individuals who "lurk" rather than post or who post infrequently are entirely absent from any analysis. Finally, other possible caregiver activities online, such as use of e-mail or search engines, are not addressed in the current research literature.

Summary

The study described in the following chapters is the result of asking a national sample of family caregivers about their Internet experiences. Demographic and other selected data were collected to describe family caregivers using the Internet. Intensive Interviewing was used to collect additional data about the caregivers Internet experiences. The research added knowledge for nursing about (a) the kinds of caregiving problems caregivers go online to solve, (b) caregiver needs that can or cannot be met by going online, (c) how going online affects caregiving (i.e., decisions, caregiving practices), and (d) the kinds of Internet-based tools (e.g., chat rooms, e-mail, search features) caregivers are using and the purposes for which they are using them. In addition to generating a description of caregiver online use, the study serves as a jumping off point for future research and the development of web-based services for family caregivers.

CHAPTER 2

Review of Literature

This chapter includes an overview of caregiving in the U.S. and of selected literature on the information and support needs of family caregivers. This is followed by a review of existing research on computer-aided instruction, particularly in the area of patient education, and its ability to meet caregivers' information and support needs as research on the Internet's ability to meet such needs is minimal. Finally, an overview of the Internet and related research on the use of the Internet to obtain health information is included.

Literature Review: Caregiver Information & Support Needs

The following sections summarize the literature regarding family caregiver information needs at different points in the illness trajectory. Other topics to be addressed include what caregivers view as appropriate sources for specific types of information, the relationship between information and support for family caregivers, and research into ways information needs may be met using computer-based technology.

Caregiving in Chronic Illness

Many factors may contribute to caregiver information and support needs. One significant factor is the course of the care recipient's illness trajectory. A chronic illness is more than a biological process, as shown by Corbin and Strauss's seminal work on the Chronic Illness Trajectory. Corbin and Strauss have found that chronic illnesses affect the person and those close to him or her, such as family members. A chronic illness affects of the person who has it in many ways, including family and other relationships, their view of themselves, and their ability to participate in the activities of daily living. The trajectory affects, and is affected by, biological and social processes and the treatment strategies chosen to manage the illness course (Corbin & Strauss, 1992).

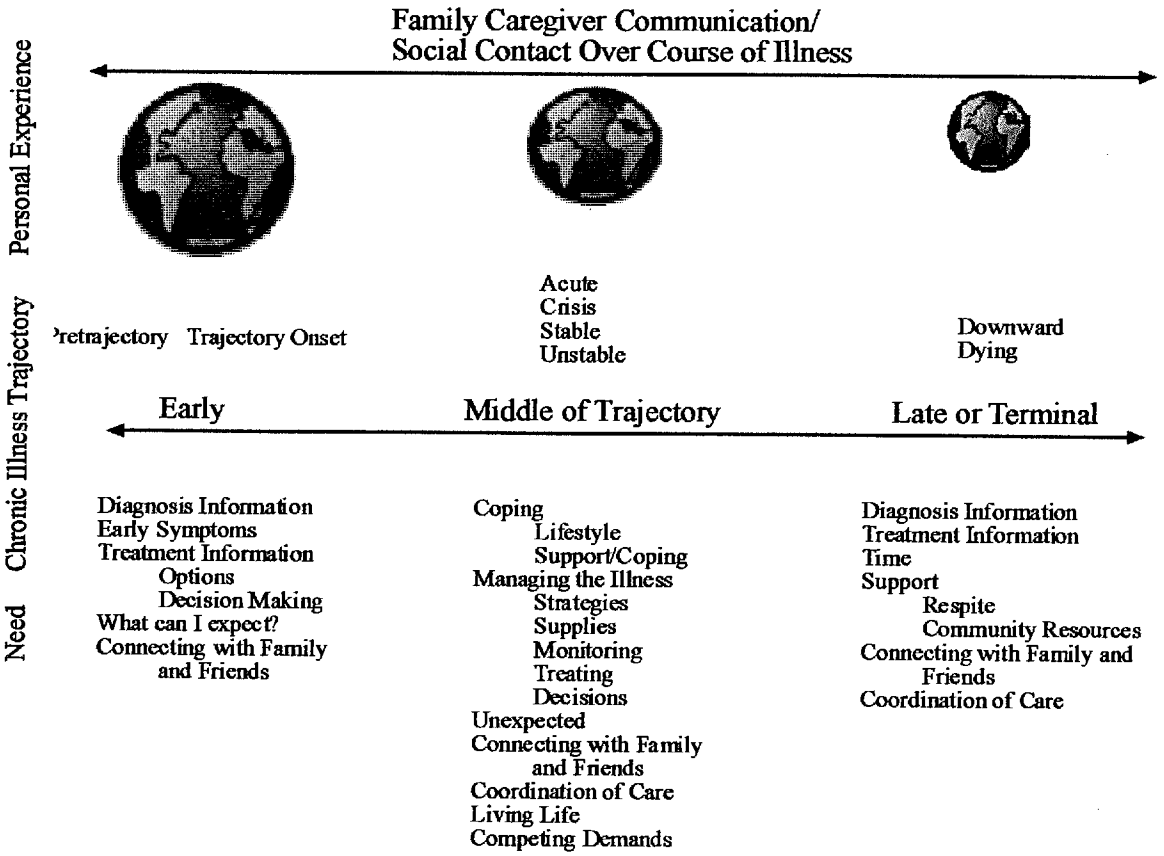
The central component of the model is the concept of trajectory in chronic illness. Trajectories are the course of a given individual's illness. Trajectories may or may not follow an expected course; the chronic illness or treatments and the efforts to manage aspects of the chronic illness have consequences and may complicate the trajectory (Strauss, Fagerhaugh, Suczek, & Wiener, 1981). For example, if a patient has cancer and is treated with medications that cause severe fatigue, the patient may be unable to fulfill roles in the family or at work. The patient and family must then come up with ways to manage the side effects of the treatment in their daily lives. Even in the course of illness that follows expected trajectories, family caregivers need information and support. Unexpected changes in the illness trajectory can increase the amount of information and support to fulfill caregiving responsibilities. As more people experience chronic illness and a growing subpopulation experience multiple chronic illnesses, demands on caregivers will only increase.

A national study by Hoffman, Rice and Sung (1996) noted that more than 90 million persons in the United States have at least one chronic health condition, with 39 million having more than one. Chronic illnesses have variable trajectories. For example, multiple sclerosis and AIDS are diseases with unpredictable remissions and exacerbations, while a disease such as Alzheimer's has a gradual onset and deterioration trajectory without recovery of lost capacities. A third trajectory is found in massive stroke, a sudden event with the possibility of some returning function, followed by likely residual and permanent functional loss.

Family caregivers deal with a variety of illness trajectories, depending on the number and type of chronic illnesses the care recipient has. Caregivers' information and support needs may vary with changes in patient condition. For example, a care recipient who has long-standing emphysema and then has a heart attack may change or increase the caregiver's role. In this case, the caregiver may have acute needs for information about cardiovascular disease treatment and for emotional support in the hospital. Several weeks after discharge, the caregiver may need information about how to help the oxygen-dependent emphysemic care recipient safely carry out the prescribed cardiac exercise program. Support from others may be needed to help the caregiver deal with fears that the care recipient's life may be shorter than anticipated. Later still, the caregiver may need information to help determine when the care recipient's shortness of breath is emphysema related and when it may be a sign of a recurrent heart attack. Support from others who also care for a family member with a life-threatening illness may be valuable to the caregiver at this point in the illness trajectory.

Because most family caregivers are caring for a family member with a chronic illness (NACG & AARP, 1997), the type and content of the information needed changes during the course of the illness (Stetz, et al., 1996). Even well prepared caregivers face ongoing information needs. Current literature on family caregivers' information needs and changes over the trajectory of a chronic illness tends to focus on acute care or care needed immediately after an acute episode. However, as shown in Figure 1 below, family needs for information and support may change over the course of a care recipient's chronic illness. The family caregiver's world gradually shrinks as the caregiver becomes more isolated. This process occurs at a time when the caregiver may most need support from their social network.

Figure 1 *Chronic Illness Trajectory Model for Family Caregivers Based upon Strauss and Corbin's 8 Chronic Illness Phases*



Family caregivers experience uncertainty as part of caregiving. Brown & Powell-Cope (1991, p.340) define uncertainty as "… the caregiver's inability to predict future events and outcomes and the lack of confidence in making day-to-day decisions about the ill person's health." Family caregivers report that having information is seen as a way to decrease uncertainty regarding the changes in care recipient's health during the illness trajectory. Family caregivers reported issues such as "watching the patient become more ill and not knowing what to do" as among the most difficult aspects of caregiving (Barg et al., 1998). Having information is also a way for caregivers to gain a sense of control and make meaning of the caregiving situation (Brown & Stetz, 1999). Information also helped caregivers judge care recipient progress and recovery and decreased their uncertainty (Dickerson, 1998).

Caregivers are required to make frequent decisions based on the care recipient's changing health status (Davis & Grant, 1994) and they need information to make those decisions (Lewis, Corcoran-Perry, & Narayan, 1997). However, family caregivers may receive little information from the health-care system (Brown & Stetz, 1999). Boland and Sims (1996) found that family caregiver stress could come from many sources, including financial issues, diminished support from outside the family, competing family demands, and the uncertainty associated with caregiving. Family caregivers reported that lack of information coupled with the responsibility for their family member's health created significant stress (Dickerson, 1998). Boland and Sims (p. 56) stated that "...caregivers are usually novices in providing complex physical care and are not prepared for the long-term consequences of caring for a family member. These novices are faced with emergency situations requiring rapid decisions that can affect the life of another."

Caregivers often perceived that the amount and type of information they received from health-care providers were inadequate (Brown & Stetz, 1999); (Stetz et al., 1996). Information was deemed inadequate when there was an insufficient amount or it was not what was needed (Wiles et al., 1998). Examples include inadequate information about treatment and future care needs, about how health-care providers made health decisions, and about why some treatment options were offered for their care recipient but others were not (Wiles et al.). Information that was vague or not from the desired source also was perceived as inadequate (Thompson, Ersser, & Webster, 1995). Caregivers feel a strong sense of responsibility toward their care recipient (Dickerson, 1998; Piercy, 1998) and want to provide quality care (Brown & Stetz); however, inadequate information to meet their responsibilities as caregivers caused them anxiety (Dickerson).

Caregivers also desired information individualized to their care recipient (Wiles et al., 1998) that could be used to deal with specific problems they faced. When that information was not forthcoming, there were negative consequences. For example, when their expectations of having specific information about the patient's course of illness were not met, caregivers felt frustrated (Brown & Powell-Cope, 1991) and anxious (Conley & Burman, 1997) even though the health-care providers may not have had the individualized, definitive answers to give them (Brown & Powell-Cope; Wiles et al.). Without specific information about what to expect for their care recipient over the course of the illness, caregivers expected their lives would soon return to normal or near normal after the illness event (Wiles et al.). When this did not occur, caregivers were confused and disappointed. Caregivers also made decisions that placed unnecessary limitations on care recipients because they lacked knowledge about what activities the care recipient could safely perform.

Caregivers saw obtaining and evaluating information as part of their role as caregivers (Brown & Stetz, 1999; Bull & Jervis, 1997; Stetz et al., 1996). They needed the information to manage and evaluate the patient's condition and care needs (Davis & Grant, 1994). Caregivers also made evaluative choices about the quality of the information and how it might affect the care recipient (Stetz et al.). If information was not forthcoming, caregivers sought to manage the care through trial and error or seeking information from other sources (Bull & Jervis; Davis & Grant).

Family caregivers were seeking several specific types of information, both clinical and practical (Wiles et al., 1998). Clinical information was information related to disease processes, treatments, medications, medical terminology and symptoms (McLennan, Anderson, & Pain, 1996). Prevention of recurrence, prognosis, recovery, and the effects of the illness on the care recipient were also desired types of clinical information (Wiles et al.). Practical information needs included community resources, reasons for symptoms, therapy, psychological needs, hospice care, and what to expect during the dying process (Steele & Fitch, 1996). These types of information were desired during hospitalization (McLennan et al., 1996), but were also needed by caregivers later in the illness trajectory (Steele & Fitch; Wiles et al.).

Caregivers wanted practical information to help them provide day-to-day care. Examples include information about how to perform daily living activities (e.g., bathing, transferring care recipient from bed to chair) (McLennan et al., 1996), as well as information about in-home and out-of-home activities, medication, and follow-up (Wiles et al., 1998). Finally, caregivers wanted information to be provided in a timely fashion, before it was needed (Stetz et al., 1996). Seven of twenty caregivers in a study conducted by Steele & Fitch (1996) requested a 24-hour hotline for caregivers. This could indicate that caregivers felt information was needed around the clock and that they considered the telephone to be an acceptable way to obtain information. Although detailed information was valued by caregivers, they could not take in a great deal of information all at once (Thompson et al., 1995), so pacing of information was also important.

In summary, most of the caregiving literature focuses on information needs for acute care or immediately after an acute episode during the illness trajectory. However, family caregivers consistently describe the need for ongoing information to care for their family member and actively seek such information. Clearly family caregivers have ongoing information needs during non-acute periods that are not being met adequately. Using the Internet to find information at different times in the illness trajectory may be beneficial to family caregivers, and will be discussed further in later sections of this paper. The literature consistently demonstrates that family caregivers believe having adequate information is important as a way to increase their sense of control. Information decreases uncertainty as information helps caregivers know what to expect.

Caregivers believe that seeking and evaluating information is part of their role as caregivers. The adequacy of the information they receive, however, is lacking in timeliness, comprehensibility and applicability. Caregivers also want information from specific sources for specific purposes. The next section describes sources of information for caregivers and how they obtain information.

Information Need and Source of Information

Research indicates that family caregivers actively seek information (Conley & Burman, 1997) from multiple sources and for multiple purposes. Studies that focus on how family caregivers seek information, and from whom they seek information, will be reviewed in this section.

Dickerson (1998) found that family, clergy, health-care staff, and friends were all seen as sources of information and support for spousal caregivers. Caregivers sought people with specific attributes for assistance. The attributes of someone who was helpful included being available, knowledgeable about relevant aspects of the situation, and concerned for the spouse. These attributes were seen as characteristic of a supportive source of information. Guidance was sought from formal information sources such as hospice team members and through informal sources such as the caregiver's social network (Brown & Stetz, 1999). Practical advice from others who had similar experiences was also seen as helpful (Dickerson, 1998). Caregivers also expressed feeling a need for someone to help guide them through the health-care system (Brown & Stetz, 1999). Fear of seeming incompetent, isolation caused by care recipient needs, time constraints, and the inability to access resources all prevented some spouses from obtaining adequate help (Dickerson).

Caregivers accessed multiple information resources, including printed material, nurses, and physicians when seeking information; however, stress and the use of unfamiliar medical language made the information from health-care providers difficult for caregivers to understand (Dickerson, 1998). Brown & Stetz (1999) found that usual sources of information for family caregivers in the study were books, other health-care providers, community agencies, and the family caregivers' social network. Thompson, et al. (1995) found that physicians were the preferred source of information and support, but did not adequately meet the information needs of participants. Thompson et al. did not report specific areas in which participants felt information given by physicians was inadequate.

Caregivers actively sought information (Bull & Jervis, 1997; Stetz et al., 1996) from health-care providers and used strategies such as asking for explanations and writing down questions for providers before meeting with them (Stetz et al.). However, providers did not consistently or accurately assess the information needs of patients or family members. Turton (1998) compared the self-perceived information needs of patients and their spouses with what nurses perceived the needs of patients and spouses to be and found that the information needs differed. Nurses focused on the biomedical needs of the patient, such as wound care and medication. Spouses rated information most important when it related to practical issues. Emotional aspects of care were considered less important. Symptom management and lifestyle were considered the most important information by patients and by caregivers. It is interesting to note that often the spouses wanted more information than the patients in the study.

The needs of caregivers and care recipients are different, yet some research treats caregiver and care recipient information needs as though their needs are the same. This is a weakness in the research and limits the use of the findings. The literature indicates that family caregivers are fairly consistent in wanting information on such topics as prognosis, symptoms, and treatment options from health-care providers (formal sources) and practical, "how to" information from those who have had similar experiences or from their social network (informal sources). Family caregivers employ a variety of strategies to find the information they need and gather information from multiple sources. Family caregivers also seek information as a form of support. This will be discussed in the next section.

Information Need and Social Support

In a literature review of social support and caregiver burden, Vrabec (1997, p. 385) notes three common elements of social support "...(a) structural aspects of the support network, (b) functional types of assistance available or actually received, and

(c) the nature of the support." Structural aspects are the number and type of interpersonal ties the caregiver has while functional types are defined as "… emotional, appraisal, informational and instrumental support." The nature of support is a function of the caregiver's satisfaction with support, the reciprocal relationships caregivers have with the members of their support network, and the characteristics (conflicting or helpful) of the relationship.

Support and information often are linked for family caregivers. As noted previously, having adequate information can decrease feelings of uncertainty and confusion in caregivers as well as enable them to perform caregiving roles. The psychosocial effects of caregiving can lead to a need for social support. Having information is also seen by caregivers as being supported emotionally (Dickerson, 1998). Dickerson found that the spousal caregivers studied needed support, which was perceived as being able to vent feelings and have them validated. Getting information about what would happen to their family member was also seen as supportive and helped reduce the uncertainty the caregivers felt. The information helped the spouses know what to expect. Hileman and Lackey (1990) studied 15 caregivers and 15 care recipients with cancer. Both caregivers and care recipients in the study ranked psychological needs highest. Psychological needs included support to maintain their emotional health and relationships with others. Canning et al. (1996) studied psychological distress in 83 family caregivers of heart transplant recipients. Psychological distress was measured three times over a 1-year period post transplant. Distress was significantly higher 2 months after the transplant but had decreased by 7 months. This study indicates that, like needs for information, family caregiver psychosocial needs may vary over time. High quality social relationships were found to have a positive effect on caregivers in the study.

A sense of aloneness and isolation are recurring themes in the caregiver literature. Barg et al. (1998) found that family caregivers had fewer outside activities (reported by 54% of sample) than before caregiving. Boland and Sims' (1996) grounded theory study of 17 family caregivers of adult and child care recipients found that caregiving was a "solitary journey," and that caregivers felt isolated and alone. Family caregivers often felt unable to leave the care recipient alone or to have outside activities that might conflict with caregiving responsibilities. Caregiver commitment was very strong and caregivers often felt that others could not know the care recipient or his or her needs well enough to provide the same quality of care. Lack of outside support was a source of family stress, but other support sources were limited by the caregiver's willingness to use them as a result of concerns about the perceived quality of outside caregiving. Conley and Burman (1997) found that caregivers reported family members who were not direct caregivers as an additional source of stress when family members were willing to give advice but were not as willing to provide physical assistance or respite that the caregivers needed.

These findings were consistent with Davis and Grant's (1994) study, which found that caregivers sought support from their social network of family, friends, and neighbors, but that the support had limits. Caregivers felt that others who offered support or assistance could only do a certain amount and that they were unable to do what the caregiver really needed. Davis and Grant (1994) also found that caregivers would turn to specific individuals for specific kinds of support or information.

In their study of cancer and AIDS family caregivers, Brown and Stetz (1999) found that caregivers usually chose to disclose diagnoses and what they were going through to others because the caregiver's sense of isolation had become unbearable. Disclosure occurred at varying times in the illness trajectory. Where lack of information had exacerbated family caregivers' feelings of uncertainty, positive feedback from others helped caregivers "appreciate their own growth from the experience." Caregiving was a profound growth experience for caregivers—greater inner strength, pride, compassion, and personal changes were among the benefits caregivers described. Some caregivers found giving information to others gave the caregiver validation and provided emotional and social support. Some participants became active on behalf of others in similar situations because of their experiences as caregivers.

In a study of 83 family caregivers of adults with cancer, Hinds (1992) found that lack of support, uncertainty, and loneliness led to family caregiver suffering. In addition, while caregiving was seen as a growth experience, lack of knowledge about what would happen and lack of support also led to caregiver suffering.

While information is a form of support, support also encompasses (a) validation of caregivers emotions and feelings, (b) emotional health, (c) reduction of the caregiver's sense of isolation, and (d) having others with whom to share the experience. Family caregivers need support and use the exchange of information and their social networks to receive it. Most of the studies were with small groups of subjects and some studies reported findings from caregivers and care recipients together. Most of the caregiving studies were largely or exclusively of women. Male caregivers may have different experiences and different needs for information and support than women. Additional research is needed to determine the types and sources of information and support that are most helpful to caregivers and patients. In addition, because these two groups have differing needs, caregivers and patients should be studied separately.

Information Needs, Computer-Aided Instruction, and Learning Style

Telecommunications technology such as the Internet may be a way to address caregiver needs for information and support. The following sections address current research on computer-aided instruction in patient care management, information needs, and the value of computers to address varied learning styles.

Research on the use of Internet technology to provide caregiver or patient information is minimal. However, research on computer-assisted instruction (CAI) has shown CAI to be an effective way to meet patients' information needs. Although the studies have generally focused on patients rather than caregivers, information regarding learning style and the effects of CAI can probably be generalized to caregivers to a considerable degree. Findings of selected computer-assisted instruction findings are shown in Table 1.

CAI and Internet interventions may have similar benefits for caregivers because many features of computer-based learning are shared with the Internet. Specifically, because CAI and the Internet are not dependent on the presence of a health-care provider to provide information, the educational intervention may be used by multiple family caregivers, each with their own pace and style. Although there has been little study of patient learning-style preferences in health-care settings (Foltz & Sullivan, 1996), studies with other populations have found that people learn differently, and some learners learn best when information is presented in a visual format while others learn best when the information format is auditory (Duffy, 1997). The Internet offers features such as sound, video, animation, and interactivity that may enhance the learning process for family caregivers. Family caregivers indicated that information may need to be repeated for them to comprehend it (Steele & Fitch, 1996). The ability of caregivers to return to an Internet site at their convenience and review content repeatedly may also be valuable.

Table 1 *Selected computer-assisted instruction findings*

Sample	Findings	Discussion
Ramirez, 2002 Computer-based education for patients with cancer at Latino Border Hospital	• The software was helpful to Latino users independently of age, ethnicity, and education • Patients and family members used the software at equal rates	Computer based education can be used to provide culturally sensitive cancer education for Latinos in a range of educational and age groups. Family members are an important part of care for Latino patients.
Jones, Atkinson, Coia, Paterson, Ross, McKenna, Neil, Morrison, & Gilmour 2001 Randomised trial of personalized computer based information for patients with schizophrenia	• Computer sessions were of shorter duration than sessions with a psychiatric nurse • Twice the number of patients preferred meetings with the nurse to computer sessions • Psychological outcomes were the same for the educational sessions with the psychiatric nurse and educational sessions on computer.	Since patients had to be transported to the computer sessions, there was no cost difference in the interventions. The personal aspects of having a nurse do the education may be preferable for some patients. Sample was 67% male
Huss, Salerno, & Huss, 1991 Randomized comparison trial of adult asthmatics implementation of and adherence to an environmental control regimen	• The CAI group had significantly higher post-test adherence scores. • Greater increase between pre- and post-test scores in the intervention group. • Intervention group more likely to report changes in behaviors.	Behavior change was measured by self-report. Measurable increase and greater increase in knowledge in CAI group scores.
Consoli et al., 1995 Comparison of benefits of CAI in hypertensive patients versus hypertensive patients with conventional controls	• All patients' knowledge scores improved. • Greater improvement with CAI. • Women improved more than men, but their scores were also lower before the intervention.	There may be a gender difference in men and women CAI users. The authors reported this but did not speculate or elaborate further on this finding. Improved knowledge scores.
Krishna, Balas, Spencer, Griffin, & Boren, 1997 A review article of 20	• The time required to use interactive CAI varied widely among programs. • For the diabetic populations in	Authors noted that patients "...seemed more willing to confide in computers than in human interviewers, possibly

Table 1 *Selected computer-assisted instruction findings*

Sample	Findings	Discussion
randomized controlled clinical trials of CAI education	the review, there was a 10 to 20% reduction in blood glucose. • Although no significant difference between controls and experimental subjects on knowledge scores was noted, 40% of those using CAI reported more involvement in their disease management. • Another study found that the diabetic CAI users spent 39% more time with their physicians. • Diabetes and nutrition knowledge levels also increased and scores also increased with the use of instructional computer feedback instead of right or wrong feedback. • CAI users reported higher levels of satisfaction with care and a more positive attitude toward their blood glucose monitoring. • Significant knowledge gains were found with asthmatic, rheumatoid arthritis and hypertensive patients who were CAI users when compared with controls. • Patients showed ability to perform skills such as clean catch urine specimen collections with fewer errors when instructions were given with CAI. • Medication instruction with CAI had 20% less total nonadherence than with the control group.	because the computers were perceived as nonjudgmental or evoked less embarrassment on sensitive subjects." (p.32). Across the studies, age did not affect acceptability of CAI and positive results were shown in ages from children to elders. The authors point out that the use and benefits of CAI for those with lower literacy and education levels have not been established. This is also a concern for potential family caregiver Internet users. The review indicated that CAI users had significant gains in knowledge, treatment adherence, psychomotor skills, and satisfaction with treatment.

Table 1 *Selected computer-assisted instruction findings*

Sample	Findings	Discussion
Mercer & Sweeney, 1995 Study of CAI intervention in women's' health clinic Family and patient education intervention development using an interactive multimedia CAI program	• Many of the features that enhance learning were incorporated in the system, such as the ability of the learner to pace themselves and repeat content, learner choices, and audio as well as visual learning. • These features provided benefits for different learning styles and took advantage of learning principals such as repeating content to increase information retention. A key feature was that patients and families were asked about their information needs and the authors incorporated their feedback into the system design.	CAI intervention was originally designed for women's maternal-infant health needs in a clinic with a large Hispanic patient population. However, the providers noted that other family members began using it, so the intervention was redesigned to include them as well. Study reported on design and implementation of CAI. Patient and family responses were grouped together. Authors believed key factor in success of the CAI was user feedback.
Day, Rayman, Hall, & Davies 1997 Multimedia CAI for patients, their caregivers, and health-care professionals	Report of CAI, not research study	Ability to interact with material was beneficial. This is not usually an aspect of nurse-to-caregiver teaching. Only article with caregivers as specific target of CAI.

Table 1 *Selected computer-assisted instruction findings*

Sample	Findings	Discussion
Castalsini, Saltmarch, Luck, & Sucher, 1998 Pilot test of multimedia CD-ROM for education of diabetics	• Program reported easy and fun to use by participants. • Perceived increase in knowledge scores. • Animated cartoons and audio were particularly helpful to participants. • Individualized information, interactivity, and information presented in an interesting way were noted as advantages of the CAI. • Quiz sections that could test user knowledge and provide immediate feedback for correct answers and positive reinforcement to increase self-confidence and self-esteem were included in the intervention.	Knowledge scores not measured, although quizzes were part of the intervention. Few methodological details were provided in the article.

The literature on CAI indicates that laypersons are willing and able to use computer-based technology to learn medical information. The CAI-delivered educational interventions result in desirable outcomes, such as (a) increased adherence to treatment regimen, (b) ability to perform psychomotor skills, (c) greater patient satisfaction and (d) higher levels of knowledge. CAI shares many features with the Internet, including interactivity, audio, and video. These features address a wider range of learning styles and information needs than more traditional patient education pathways.

Use of the Internet for Information and Support Needs

Internet user profile

The Internet is a telecommunications technology first proposed in 1966 as ARPANET. The Internet emerged from ARPANET in 1990 (Zakon, 1993-2001).

However, use of the Internet did not begin to spread widely until 1993 with the advent of Mosaic, an early Internet browser (Gray, 1998). The following summarizes growth in Internet use in the U.S. According to a 1999 NTIA study, one-third of the U.S. population had Internet access (NTIA, 1999). The NTIA study (1999) found that 34.3% of the men in the U.S. population had access to the Internet as compared with 31.4% of U.S. women. Since 1994, sequential surveys have been conducted quarterly by the Graphic Visualization and Usability Center (GVU) to determine the demographic characteristics of Internet users. Until the 10th survey (GVU, 1998), women were closing the Internet gender gap, with more new users being women then men. The GVU data from October 1998 and the 1999 data from NTIA would seem to indicate that women's access rates are falling, but a more recent NTIA study (2000) has nearly equal use rates by men (44.6% of users in August 2000) and women (44.2% of users in August 2000). Web users' education levels tend to be considerably higher than the general population. The fastest growing educational group is those with some college experience, increasing from 30.2% in December 1998 to 49% by August 2000 (NTIA, 2000). A continuing trend from earlier GVU surveys is that, increasingly, most users (78.7%) access the web each day from home rather than work (GVU). The age of the average Internet user has remained stable at 37.6 years. The largest growth in age groups is in the 50 and older category, with a 35% increase by August 2000 (NTIA, 2000). The majority of users are white (87.2%), although there is greater ethnic diversity among younger users. User surveys by GVU show an increase in income from the last two surveys, with the average annual income of respondents at $57,300. While all groups show increases in Internet access, racial disparities still exist, with Internet access among Blacks (23.5%) and Hispanics (23.6%)

lower than among Whites or Asian/Pacific Islander (56.8%) groups (NTIA, 2000). Further, the gap between Black and Hispanic access rates is increasing rather than decreasing when compared to the national average number of households with Internet access.

A study by Lenhard et al. (2003) indicates that during the last 18 months, Internet rate use has leveled off with rates of 57-61%. The study findings indicate that 42% of the U.S. population has never used the Internet. However, only 24% are "truly disconnected". Some people (20%) find work arounds so that although they are not online, family members or friends perform Internet related activities such as e-mail for them. Another 17% are former Internet users who, like ¼ to ½ the sample, ceased Internet use at least for a period of time.

The GVU data were consistent with a cross-sectional interview study conducted by Mandl, Katz, and Kohane (1998) in the emergency department of a pediatric hospital. A majority of the 132 subjects were female. Subjects were patients aged 16 years or older or parents of patients below the age of 16. Connectivity to the Internet correlated directly with income. White respondents were more likely to be connected to e-mail and the World Wide Web. The study reported that 29.5% of respondents had used the Internet to access medical information.

Level of Internet expertise also varies among Internet users (GVU, 1998). The GVU survey used a list of Internet activities (e.g., have you ever made an online purchase for more than $100, created a web page, customized a web page for yourself, or changed your "cookie" preferences) that respondents had performed to categorize the level of Internet expertise as novice, intermediate, experienced, or expert. The study found gender and age differences in the activities of Internet users. Older respondents were more likely to have purchased books about the Internet than other ages but less likely to have customized their browsers. Women (29.6%) were more likely than men (24.4%) to have attended a seminar about the Internet but men were more likely to have performed all the other activities than women. The study also assessed the relationship between expertise level and length of time using the Internet. The largest category of number of years using the Internet was 4 to 6 years (37.1%). The study findings indicate an expected shift to more experienced Internet users as the Internet has been in existence longer and because the rate of new users going online is beginning to decrease. While the number of years using the Internet tends to increase the expertise level of users, some novices are longtime users and some experts have been online only a short time.

A study (Messecar & Miller, 2002) of older and younger caregivers' willingness to use the Internet for information about home modifications and assistive technology used focus groups to interview 43 caregivers. The study found that older caregivers were more likely to perceive barriers to Internet use and report more problems while younger caregivers focused on limitations of the Internet such as being time consuming, having slow load times, and experiencing searching difficulties. Another study (Nahm & Resnick, 2001) of five homebound older adults' experiences with the Internet and e-mail found that, with practice and support, the adults were able to overcome barriers to Internet use. Caregivers with a range of ages were sought for this study.

Age, gender, and level of expertise may affect what activities family caregivers perform online and how caregiving is affected. Of note is that the longer someone has had Internet access, the more likely it is that that individual has gotten medical information, with 59% of those who have been online 3 years accessing health or medical information compared with 47% who have been online for 6 months (GVU, 1998).

Health Access and the Internet

Family caregiver needs for information and support may be met by going online. (Miller & Reents, 1998) reported that 17 million U.S. adults have looked for health and medical information online and projected that in 2000 the number would be 30 million. A more recent study (Fox et al., 2000) found that 52 million seekers of health information were online in the U.S., so use of the Internet for health-related concerns by the American public may be growing at faster than expected rates. Approximately 5.5 million Americans per day are seeking online health information for themselves (43%) or someone else (54%). Online support groups for persons with the same health problems had been used by 9% of the sample; however, a prior study by Pew (Fox et al.) found that 36% of users had gone to a support group, so estimates of online support group use may be difficult to verify. Miller and Reents noted that the Internet may be more capable of delivering the kind of personalized information health-care consumers are seeking than any other media because searchers are able to find information specific to their particular needs around the clock. Fox et al. noted that there were no racial, ethnic, or income group differences in online health information seeking; however, gender differences exist in relation to obtaining health-care information online. Women were more likely to look for health and medical information online than men (Miller & Reents, 1998). The Pew study (Fox et al., 2000) found that 63% of women sought health or medical information online as compared to only 46% of men. The Pew Internet and American Life project conducted a follow-up study two years later and found an even larger number of women going online for health information (Fox & Rainie, 2002). The follow-up study found that 62% of Internet users (72% female, 51% male) had gone online looking for health information at a rate of approximately 6 million per day. The 2002 Pew study (Fox & Rainie et al.) found that women and men were equally likely to be searching for health information for a parent or other relative. However, men and women tend to look for different information online. Men are more likely to look for material about their own health conditions, prognosis, what happens to someone during an illness, and specific treatments or drugs. Men are also more likely to have their medical decisions influenced by information they find online. Women are more likely to have searched for information about illnesses and illness symptoms.

Users appreciate the convenience and anonymity as well as the large amount of information available online. As consumers experience greater roles as health decision-makers, they are looking on-line for more information that they can access and comprehend easily (Sunquist, 1997). The 2000 Pew study (Fox et al.) found that seekers of health information may be bypassing providers and friends and going directly to the Internet instead, although a large portion (86%) are concerned about the credibility of the information they are finding online. Women are more likely to worry about the credibility of online information than men.

Internet Research

Studies have examined Internet use with several groups and indicate that health-related support and information are being found on the Internet. (Huang et al., 1998) reported on four cases of young, well-educated men who used the Internet to seek information about diagnosis and treatment options for their mental health conditions. The authors analyzed the cases for themes and reported that the patients were more active in their health care and had increased knowledge of treatment options that influenced their decisions about what treatment they agreed to. The authors also pointed out the Internet may be used for both self-treatment and for treatment of others, especially through support group activities and people sharing information, support, and personal experiences.

Helwig, Lovell, Guse, and Gottlieb (1999) found high levels of acceptance of health-related Internet use in their study of 50 family practice patients who were given access to the Internet during clinic visits and also given instruction in Internet use if necessary. Helwig et al. found that 94% of patients found the Internet information helpful, 77% would change a health behavior because of the information they found, and 90% were more satisfied with their visit than usual. Their satisfaction was related to feeling that they learned more, and their perception that the Internet session added more attention or depth to their visit. In addition, they believed the Internet information was better than what they received from the physician.

A study of Internet support for diabetics (McKay, Feil, Glasgow, & Brown, 1998) found that information (36% of activity) and social support (60% of activity) were the most popular pages on the Web site. The site was visited more than 21,000 times by 111 persons over a 10-week period. Persons using the site had had diabetes a mean of 9.2 years, were primarily male (66%), well educated, and from all over the world, although most were from the U.S. (83%). Analysis of use patterns indicates that users take advantage of the around-the-clock, 7-day-a week availability of the Internet. McKay et al. (1998) found that the Internet is a feasible way to deliver information and support to help people manage chronic health conditions.

Studies specifically focused on caregivers and the Internet are rare or mix caregivers with other groups. A study is currently being undertaken in Texas (Sweeney, 2002) to provide ways for caregivers to interact with clinicians. The goal is to ease burdens for family caregivers. The study found that the overwhelming majority of users who completed satisfaction surveys would use the system on a regular basis (75%). Another study (White & Dorman, 2000) examined support for caregivers of persons with Alzheimer's disease. The content analysis of 532 posted messages on a mailgroup found that the mailgroup was used to locate and exchange information, provide encouragement to other caregivers, and share experiences as caregivers.

Klemm, Reppert and Visich (1998) studied Internet messages from an online cancer support group for patients with colorectal cancer and their family members. The researchers' content analysis of postings indicated that more than 25% related to information seeking/giving. Supportive messages were the second most frequent content at the site. These findings are similar to two other studies on Internet use with cancer sites, which are discussed below.

Klemm, Hurst, Dearholt, and Trone (1999) compared content by gender for sites related to breast, prostate, and colorectal cancer. Messages from men on the breast cancer site and women on the prostate cancer site were rare and not included in the analysis. The researchers did find different cyber communication patterns based on gender. While the findings of information giving/seeking remained number one and support content messages remained number two as in the previous study, men were three times more likely to give information and were more likely to discuss political activism. Women were twice as likely to offer supportive messages and were more likely to share personal experiences. In the caregiving literature, there is some evidence that men have different information need priorities (Vanetzian & Corrigan, 1995) and different experiences as caregivers (Neufeld & Harrison, 1998) than women.

Sharf (1997) used discourse analysis and participant observation over a 9-month period to study the postings on a breast cancer bulletin board. Analysis revealed that information requests and responses were the most common communication on the site. Support was the second most common and Sharf noted that having access to those who had "been there" with breast cancer was considered especially valuable. This is consistent with caregiver literature, although members on the site were a mixture of those with breast cancer, family and friends of the person with cancer, and researchers and health professionals. Sharf also found that empowerment to make more informed decisions and to act more for themselves or for others was a recurring theme on the site.

White and Dorman (2000) studied 20 days of postings on an Alzheimer's disease mailgroup web site. The researchers used (Klemm et al., 1999) 8 categories for content analysis of postings by the clinicians, caregivers, and researchers on the site. Findings of the analysis were similar, with information giving/receiving being the most frequent content posted on the site and supportive/encouraging messages ranking third. Sharing personal experiences as caregivers ranked second. The authors noted possible advantages for online support group users, including round-the-clock availability, lack of need for a respite caregiver to attend support group meetings, and overcoming transportation and geographic barriers.

Magnusson et al. (1998) conducted a study using focus groups consisting of 471 family caregivers and providers as Phase 1 of a European study to establish an online support program for family caregivers. The study found that caregivers desired more information, especially for practical aspects of caregiving as well as about the complex procedures they performed. Even very experienced caregivers wanted more information. Caregivers also expressed their need for support. The caregivers believed that having someone to talk to would help them cope. The authors reported that caregivers had a positive attitude toward using online technology. A follow-up survey, conducted for the ACTION intervention (Tilley & Chambers, 1997), found that caregivers want more information about a variety of issues, including finances, respite care, and what to do in an emergency. Study participants also wanted communication between caregivers and professionals, between caregivers and other caregivers, and among professionals. Caregivers noted that psychosocial support was very important. They also had varying degrees of receptivity to the technology, but none wanted information technology to replace personal contact with health-care professionals.

Tetzlaff (1997) studied parents of children with cancer to create an online intervention for parents and got their feedback on the intervention when it was complete. Although parents as caregivers may have different issues than adult caregivers of adult patients, findings were similar to the studies mentioned earlier. The parents overwhelmingly wanted more information (97%), especially practical information and information to help them solve the problems they faced as caregivers. Emotional support was also important. Tetzlaff reported that 70% of the sample felt comfortable using computers and parental response to the online system was positive. Parents studied felt it would be especially helpful early in the diagnosis; this was the only reference in the literature as to what phase in the caregiving experience an online intervention would be helpful.

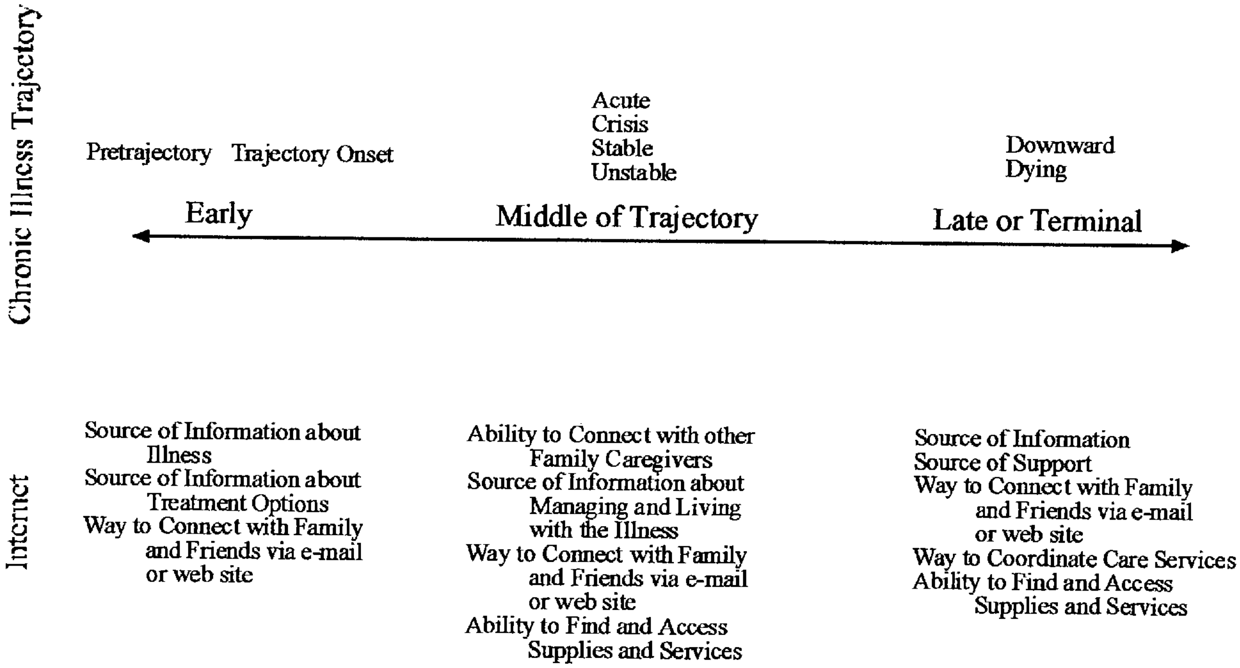
Brennan, Moore, and Smyth (1991) designed an intervention called ComputerLink, a freenet-based communication, electronic encyclopedia and decision-making support system that has been extensively studied with family caregivers of Alzheimer's disease patients. Studies consistently found that the communication systems (i.e., e-mail and public forums) were the most often used (Brennan et al., 1991, (1992). Using ComputerLink (Brennan, et al., 1995) enhanced caregivers' decision-making confidence. Although these studies are not specifically of users who self-initiate Internet activity, they do support the findings that users access information online primarily to meet information and support needs. Bass, McClendon, Brennan, and McCarthy (1998) found that ComputerLink provided a buffering effect on role strain for some caregivers in their randomized trial with 102 family caregivers. They also found that more frequent use of communication systems led to a significant decrease in strain for the more stressed caregivers and for nonspousal caregivers.

Examination of caregiving and Internet literature indicates four areas in which the Internet may be particularly suited to meet family caregiver needs: (1) practical information on caregiving, (2) communication with health-care providers and other family caregivers in similar care situations, (3) access to information specific to their care recipient's needs, and (4) a cost-effective way to access and provide selected health services. Although communication with providers is a possible use of the Internet by family caregivers, a recent study (Fox et al., 2000) indicates that most people using the

Internet for health reasons are not using it to communicate with health professionals. The most common use is to find information and make health decisions about an immediate health problem based, at least in part, on that information. Figure 2 shows a number of benefits that may exist for family caregivers that access the Internet at various points in the care recipient's illness trajectory.

Figure 2

Possible Internet Benefits at Different Stages in the Chronic Illness Trajectory



Summary

Research indicates that the Internet may be a powerful tool in connecting family caregivers with information resources and support networks. The Internet may also provide users with several advantages over more traditional information and support sources. These include:

- The caregiver's ability to access information and support 24 hours a day, 7 days a week.

- The caregiver's ability to access information and support without the need to transport or leave the care recipient. This may be especially important: (a) in the early days of home care, (b) during later stages of the dying process when the caregiver is reluctant to leave the care recipient alone, (c) when there is an unanticipated change in care recipient's condition, or (d) when the care recipient has complex care needs.
- The caregiver's ability to access information in a variety of ways to address different learning styles, as well as the ability to access information repeatedly, and to individualize information according to the caregiver's needs and the care recipient's illness trajectory.
- Because the Internet is an interactive medium, Internet-based interventions can capitalize on the enhanced learning that has been shown to occur when adults can interact with learning material and other learners.
- Chat groups and online support groups may provide a way for caregivers to connect with an expanded network of others who have had similar experiences and share what they have learned about caregiving, as well as about navigating the health care system. These are both caregiver needs that have been identified in the literature. These groups may also reduce caregivers' sense of isolation, and provide them with an opportunity to share their experience and what they have learned, thus validating their experience.

- The "anonymity" of the Internet may allow caregivers to increase their knowledge in a less threatening or non-threatening environment, reducing the feelings of appearing incompetent that some caregivers cited.
- Caregivers may be to access products or services online without leaving home.
- Family caregiver experiences with Internet use may be empowering for caregivers.

In addition to the possible advantages of Internet use in supporting caregivers, several constraints have been identified. These include access to the Internet, especially for low-income, minority, and less educated populations, and concern about the varying quality of information available on the Internet.

The research reviewed for this paper indicates that family caregivers have ongoing information and support needs that are not being met through traditional health-care channels. Additional research on CAI indicates that patients who have access to CAI have improved understanding of their disease and adherence to treatment regimens than those who do not. Research also indicates that patients and caregivers have used the Internet for information and support. However, other than the two intervention studies for family caregivers, there are few data available about Internet use by family caregivers. While the two studies are excellent examples of the potential of the Internet to deliver care to family caregivers, studies of why caregivers access the Internet on their own are lacking in the literature.

Family caregivers need accurate, individualized information that can help them with the everyday activities and decision making inherent in caregiving, give them an increased sense of confidence in their ability to care for their ill family member, and improve their ability to give care. Social support that can reduce feelings of isolation, uncertainty, and stress is also an important need. While information and support are distinct needs for family caregivers, they do overlap. Early research has shown that Internet users can and do find health information and support on the Internet.

Understanding what family caregivers may and may not be gaining from the Internet has implications for health-care providers who can make recommendations for patients and their caregivers about Internet use. The proposed study findings will also serve as a springboard to future studies of Internet-based interventions for family caregivers. Additional research is needed to identify how and why caregivers are turning to the Internet for information and support, and how health-care providers can help patients and caregivers tap into this rapidly growing resource.

CHAPTER 3

Methods

Introduction

This chapter describes the methods used in the completed exploratory, descriptive study. The study was divided into two phases: The first phase was a survey which involved linking a research web page to family caregiver Internet sites in order to collect data about the demographic characteristics of caregivers as well as their caregiving and Internet experience. Phase two involved in-depth telephone interviews with a subsample of the phase one participants. Study methods used in phase one and phase two are discussed in this chapter, followed by sampling for phases one and two, and instrumentation and study procedures.

Sample

A multistep process was used to sample family caregivers who used the Internet. The sampling goal was to obtain 200 participants who met the following criteria.

- At least 18 years of age,
- A self-identified family caregiver for a family member with a chronic illness,
- Currently using the Internet and a family caregiver web site as part of caregiving,
- An English-speaking U.S. Resident, and
- Willing to complete a research questionnaire and potentially to participate in the second phase, or interview portion, of the study.

For the purposes of this study, family caregivers were defined as follows:

- Having a blood relationship (e.g., parent, niece) to the care recipient,

- Having a legal relationship (e.g., adoption, marriage) to the care recipient, or
- Having a long-term association through which they consider themselves family (e.g., domestic partner).

A caregiver was further also defined as someone who either provides some form of instrumental or functional support to a chronically ill family member or engages in caregiving activities for the chronically ill family member. Caregiving activities include, but were not limited to:

- Assistance with daily living activities (e.g., bathing, dressing),
- Direct care,
- Transportation to provider appointments or other health-related transportation, or
- Housekeeping or household maintenance activities.

Internet use in the study was defined as:

- Any use of caregiver web sites by family caregivers for online activities such as searching for information, participating in chat rooms or on-line support groups as part of caregiving activities, e-mailing, or using file transfer protocols.

A five step process was used to obtain the phase one and two samples. First, a search was conducted for family caregiver web sites, eliminating duplicate, non-English, non- U.S., and pedicatric sites. The initial search yielded over 100,000 sites. The search process is described in more detail later in the chapter. After elimination of duplicates and other sites that met the criteria, a total of 2,016 potential web sites remained for recruitment of subjects.

The second step in the sampling process was to generate a randomized list of sites by domain strata and to review sites as potential places to post a recruiting message for caregivers. The highest percentage by domain of sites that met the study criteria were .edu sites, followed closely by .org sites. Sites were most often excluded if they were not family care focused. It was fairly common to find sites that had a link to a caregiver site on a links page but no other content related to family caregivers. Such links were almost always to the National Family Caregiver Alliance or, less often, the National Family Caregiver Association. The .net sites generated a high percentage of mailer daemon or undeliverable messages to the author or web master, which means that potentially eligible .net sites were more likely to be excluded from the study more often than other domain types, especially .com sites. However, when contact was possible, .net sites were the most likely domain type to agree to post the study message and were almost twice as likely to post as the next highest site strata. See table 2.

Table 2 *Search results by strata type, eligibility*

Strata Type	.com	.edu	.net	.org
Total number in each strata	840	243	180	973
Total number reviewed	840	243	180	846
Number eligible n (total % of sites reviewed)	200 (24%)	93 (38.3%)	36 (20%)	293 (35%)

Table 2 shows the total number of sites in each domain strata that met initial inclusion criteria (i.e., English speaking, nonduplicative, nonpediatric focus). Of these, all of the sites in three of the four strata were reviewed. Not all the .org sites were reviewed as data saturation was reached before the fourth strata was exhausted. Of the sites reviewed, the number of sites visited by the researcher and determined to meet study criteria for posting of a study link varied between 20 and 38.3%. The actual number of sites that then agreed to post a link to the study site ranged from 8.6% to 19.4%. The third step in the site selection process was to ask permission of the site owner or web master to post the message about the study on their site. See table 3.

Table 3 *Search results by agreement and nonagreement for participation*

Strata Type	.com	.edu	.net	.org
Number of actual posts n (% of eligible sites)	22 (11%)	8 (8.6%)	7 (19.4%)	28 (9.6%)
Rationale for not posting provided n (% of eligible sites)	14 (0.7%)	9 (9%)	5 (14%)	42 (14.3%)
Undeliverable n (% of eligible sites)	11 (0.6%)	9 (9%)	4 (11%)	19 (6.5%)

Sites that refused to post the study link usually gave reasons as to why they would not be able to post. The .com domain strata had the lowest response to contact by the researcher, along with the lowest rate of undeliverable or Mailer Daemon error messages. Among those .com sites that did reply, the most common reason for not posting a study link was a site policy against such posts. Other reasons included feeling that their site was not a good fit with the study or that the site was in the process of a web reorganization or had limited web support.

The fourth step in the sampling process was to recruit phase one subjects through postings on family caregiver web sites. The fifth and final step was to obtain a convenience sample of caregivers who completed phase one and were willing to be interviewed in phase two. Through this process a total of 72 participants completed phase one and 15 completed phase two.

The phase one instrument contained an item asking if the participant was willing to be contacted for a telephone interview. The item included a brief description of the topics to be covered in the telephone interview and an approximate length of time (30 to 45 minutes) for the interview. The researcher reviewed the data from phase one submitted by the participants who indicated willingness to be contacted for a telephone interview. The participant was contacted by e-mail to set up a telephone interview at a mutually convenient time. The e-mail included the text of the study consent and asked the participant to review it prior to agreeing to participate. The participant was asked if he or she was willing to be contacted for a second interview if needed to clarify the researcher's understanding of the data or if the interview were interrupted for some reason. The web site indicated that only some of those who volunteer to participate would be contacted for a possible interview.

When the researcher reached the point where data emerging from interviews fit into existing categories in the analysis and where additional interviews no longer yielded new understandings, data collection stopped.

Instruments

Survey Instrument

A data collection instrument was used to collect the information for theoretic sampling purposes (study aims two, three and four) and to describe the sample (study aim one). Data were also collected on aspects of the caregiving situation to assess whether caregivers' Internet experiences are affected by the intensity of the caregiving situation. (See the attached instrument.) An item at the end of the questionnaire asked if the participant was willing to participate in phase two.

The instrument was designed to take caregivers approximately 15 minutes to complete and incorporated demographic items and two constructs, Internet Self Efficacy and Caregiving Context. Items were selected for descriptive and theoretic sampling reasons. The items were also selected to be as parsimonious a way to collect the desired data as possible to minimize the burden placed on participants.

Demographic items. The phase one instrument had four demographic questions. Since research indicates that men and women experience caregiving and use the Internet differently, both men and women were sought for the study. Age, racial background, and education level items were included to describe the sample and assess the sample diversity. Although socioeconomic status was considered an important variable, it was not included because it may have led to decreased response rates by participants. Education level was instead used as a proxy for socioeconomic status.

Internet Self Efficacy and Internet Use. The next items focused on length of time using the Internet and computers because duration of Internet use may have affected caregiver Internet experiences. The items were also included because a variety of levels of experience with Internet use were desired for theoretic sampling during phase two. Eight items were included in the instrument relating to Internet self efficacy. Self efficacy, rather than a list of tasks caregivers perform, was chosen because self efficacy may be a key way to separate novice from expert Internet users (Eastin & LaRose, 2000). Self-efficacy may be particularly important in this study because users who are not comfortable or confident using the Internet may perceive more barriers to Internet use, use fewer functions of the Internet, and may be more reluctant to use the Internet. Internet self-efficacy was found to be an important determinate of Internet use in studies of an instrument developed by Dinev and Koufteros (2003). The instrument, was tested largely with college students and had 22 more items than the Eastin and LaRose scale. Eastin and LaRose (2000) define Internet self efficacy as "... what a person believes he or she can accomplish online now or in the future" and that it "… assesses a person's judgment of his or her ability to apply Internet skills in a more encompassing mode…". The eight items measuring Internet self-efficacy were from Eastin and LaRose's Internet Self-Efficacy Instrument; however, as they note in their study, only one of the items measures information need and only one of the items measures support. Information need and support were two key concepts in the proposed study. The lack of more items in those two areas may make it insufficiently robust to measure information need and support in relation to Internet self efficacy.

Standardized item alpha for the Eastin and LaRose scale in this sample was .9025. This is slightly lower than the reported .93 alpha from the initial report of the scale (Eastin & LaRose, 2000). The Eastin and LaRose scale score was computed by summing the items.

There was also an item requesting data about places the caregiver accessed the Internet. Caregiver experiences may be affected by where the Internet is accessed. For example, a caregiver may be reluctant to ask sensitive information if they are accessing the Internet at work and a coworker might walk into their work area. This concern did not prove to be an issue during interviews, but may still be relevant to others in the sample.

Caregiving Context. Because research findings indicate differences in caregiver experiences based on the relationship of the caregiver to the care recipient, an item about the relationship to the care recipient was included. This item also showed that the person was caring for a family member as defined by the study. An item about length of time caregiving was included as it was speculated that longtime caregivers may have different needs that are being met by the Internet than novice caregivers. A checklist item was included in the caregiving section to assess types of caregiving activities performed by Internet-using caregivers. Archbold and Stewart's (1986) list of 80 caregiver activities were used to generate the 7 caregiver activities. Because caregivers who feel more stressed by their caregiving may have different needs being met by Internet use than caregivers who are not as stressed, a single item was included to ask caregivers to rate their stress level as caregivers. An item asking how long the family member they are caring for had been ill was included to gain an approximate measure of whether the care recipient is in early, middle, or late stages of a chronic illness trajectory. For ethical reasons, caregivers were not asked to provide more detailed medical history information about the care recipients. Care recipients did not consent to having their medical information released to the researcher. The final item on the instrument was a yes/no question pertaining to the participant's willingness to be interviewed by phone for phase two. If yes, there was a place for the participant to enter their e-mail address for later e-mail contact by the researcher.

Interview Guide

The interview used a semi-structured interview guide. The interview guide questions and rationales for each question are listed next. Sample probes are also listed. The researcher also used direct probes to get more detailed, specific information. New probes were created in response to emerging themes in the data. Probing yielded more depth and detail so that the researcher could obtain a greater understanding of the participants' experiences and the meanings they ascribed to their experiences. The researcher also used probes to clarify meanings and to get the participant to explore new aspects of the experience or to reflect on the experience. (See Appendices H and I.) If the interviewee was unclear about the question or probe, it was restated or reframed until the interviewee was clear on what was being asked.

Pilot testing of the semi-structured interview guide occurred before the phase two sampling and served three purposes. First, the ability of the initial interview guide to solicit information from participants about their Internet experiences was assessed. The pilot study participants were asked specifically to comment on whether there were any questions that were unclear or confusing. Second, the pilot study was a step to help the researcher be more sensitized to the caregivers' experiences. The interviews were taped and transcribed. Initial coding was done to help with sensitization, but the data were included in the study analysis. Third, the pilot study aided the researcher in sorting through several practical problems. For example, the researcher gained an idea of the approximate length of time required for the interview so that later study participants could be given a realistic estimate of the time required to complete the interview.

Two pilot interviews were conducted. Both pilot interviews were conducted with women who were experienced caregivers, white, and middle aged. The pilot interviews were conducted with women similar to those who participated in phase two. Based on the pilot interviews, the first question on the interview guide was a merger of two items on the previous guide. More probes were also developed and included in the final interview guide.

Procedures

When the potential study participant linked to the study home page, the following content was on the home page: (a) a welcome to the page, (b) a more detailed description of the study, including information about factors such as time commitment involved in participation, (c) a list of inclusion criteria (see previously listed inclusion criteria), (d) a link to the researcher, sponsor and OHSU IRB, (e) a link to a brief researcher biosketch and (f) directions to click on a link to the consent form if they were interested in participating in the study. The consent information was on another web page. If participants agreed to participate in the study, they clicked on a link to the final study web page that contained the data collection instrument. Once the instrument was completed, it was electronically submitted to a secure database when they clicked on a submit button. (See Appendices C, D, E, and F.)

The first step in the sampling was to perform the web searches. Eight separate searches were done—one for each stratum in each of the two search engines. As a first step, web sites were stratified by domain. A domain is a classification used on the Internet to indicate the type of site content. Sites with Uniform Resource Locators (URLs) ending in .com are commercial, .net sites are usually owned by individuals, .edu sites are for educational institutions and .org sites belong to associations or organizations. During the course of the study, it was found that some URLs had both .org and .com mirror sites, consequently, domain strata were not as clear-cut as was originally thought.

Government (.gov) and military (.mil) web sites were excluded from the sample because they were either unlikely to allow posting of a link to the research study homepage or unlikely to have much caregiving content. A limitation of this exclusion is that any caregivers using only.gov sites for their caregiver Internet activities will have been missed.

A search was done in each stratum using the search term "Family caregiving." The initial search included the terms "family caregiver," "family carer," and "caregiving." However, because the initial search resulted in more than 100,000 hits, or page results, a second search was conducted using only the term family caregiver and limiting the search to the last 6 months. In addition, if allowed by the search engine features, the searches were restricted to the United States or North America and English as well as domain type. More than 40,000 hits resulted from the second search.

Four comprehensive lists of family caregiver web sites from .com, .net, .edu and .org sites were generated. Sites were then stratified by domain type into four strata. It was hypothesized that family caregivers go to different types of sites for different purposes. Including caregivers from different types of family caregiver web sites increased the ability to adequately sample the population.

Two search engines, Hotbot and Google, were used to conduct searches with each of the four domain types (.com, .org, .net and .edu). Using more than one search engine was expected to result in greater site retrieval numbers. These two search engines use different search strategies:

- Hotbot uses a web index generated from a web crawl of more than 1.6 billion URLs to create a database. Indexing is both human and automated. Some material (e.g., that with adult content and spam) is automatically removed from the database. Documents are relevance ordered (Search/Web, 2001), and the relevance of the document for retrieval is determined by document characteristics, including text content, source, and associated links.
- Google ranks pages by the number of links pointing to the page in question. Each link counts toward the importance ranking for that page. Votes are weighted so that links from other important pages count more heavily. Further, Google

indexes text terms on each web page and linking pages (Google Search Technology, 2001).

Because two search engines were used, the results were compared to eliminate duplicates. Duplication could occur in two ways: (1) listed in the results for both Hotbot and Google and (2) multiple web pages listed for a single URL/web site. The result of this process was a list of unique web sites divided into the four domain strata.

These search results were then examined to eliminate sites that (a) did not meet the criteria (i.e,. language other than English, not actually related to family caregiving), (b) were duplicate sites, 3) were multiple hits for the same homepage, or 4) were .gov or .mil sites. After these sites were deleted, a comprehensive list of the remaining family caregiver-related web sites was created in each of the four domain name strata.

Web sites on the list were visited by the researcher to determine if they met additional criteria for inclusion in the study sample. The lists were visited in the order of relevance listed by the search engines. Inclusion criteria included authorship, ability to contact the web site owner, site purpose (information, support, products, entertainment, community resources, other), domain type, and currency (when was the site last updated). Sites that had no designated author and no way to contact the web master were excluded, as were sites that had not been updated in the last year. Site strata were noted to test the hypothesis that caregivers might visit different types of sites for different purposes; because a variety of site types were desired for the theoretic sampling used in phase two; and to increase sample representativeness and sample as diverse a caregiver group as possible. Web sites owned by individuals, associations or organizations (e.g., the American Cancer Society, Family Caregiver Alliance), health care facilities (e.g., hospitals, hospices, home care agencies), or web sites offering free or for pay services or products to caregivers (e.g., Web of Care) were included in the sample.

Contacting potential web sites

Initially, only one web site per domain strata was randomly selected for posting of the study description and a link to the study web page. The small initial number was a way to pilot test the response rate for family caregivers visiting the study site and agreeing to participate in the study. (See Appendices A and B). Once the initial study was done, the number of future sites to be contacted and posted were based on the initial response rate. To arrange this and each subsequent posting, the researcher contacted the web site owner or web master, briefly described the purpose of the study, and requested permission to post a brief description of the study and a link to the researcher's OHSU home page.

The researcher's OHSU web site contained an overview of the study and an e-mail link to the researcher and advisor. The study web site included a summary of the study proposal, a list of inclusion criteria, a brief researcher biosketch, and the informed consent and questionnaire forms so participants could examine the forms and proposal before contacting the researcher.

Initial subject to the pilot posting (one web site per domain strata) was minimal. Consequently, after several weeks the number of web sites per strata was increased to 10 per week. Later in the study, the number of sites per strata was increased to 20 per week. The process of randomly selecting web sites, evaluating them, and contacting the author or web master for permission to place the description and link on their web page was repeated until an adequate phase two sample was generated.

Intensive interviewing was selected for phase two to elicit family caregiver experiences of their Internet use. There are three situations for which Intensive Interviewing is particularly suited, each of which was relevant to the study. In the first situation, the "research interests are relatively clear and well defined" (Taylor & Bogdan, 1998; p. 90). The research study was fairly narrow in scope and had a specific focus.

In the second situation, the researcher uses Intensive Interviewing to obtain data about aspects of a phenomenon that cannot be directly observed or are not feasible to directly observe. Such interviews are "...directed toward understanding informants' perspectives on their lives, experiences, or situations as expressed in their own words" (Taylor & Bogdan, 1998; p. 88). It was not possible in some cases or feasible in others to gain such understanding by spending time with the participants in their homes or work settings while they were active on the Internet. It was also not possible to know how their Internet experiences were affecting them as caregivers or their caregiving without asking. Intensive interviewing provided a way to access the participants' perceptions about their Internet experiences. The participants became the researcher's observers on the phenomenon.

In the third situation, a range of aspects of the phenomenon of interest are studied, including the context in which the phenomenon occurs or other people involved in the phenomenon. Interviewing the participants about their experiences was a way of learning about them and the processes in their experiences. For example, the participant was asked to provide examples of caregiving situations in which the Internet was used. If the participant was seeking information, ways the information was evaluated for possible use to solve a caregiving problem or to make a decision were explored in depth. Intensive

Interviewing also allowed the researcher to study a broad range of people and their experiences and perceptions, which was especially useful when the phenomenon being studied had not yet been well explored, as was the case with family caregivers' Internet experiences.

Data Management and Analysis

Survey Data

Data collected during phase one was entered into FileMaker Pro, a database software program. The database was hosted at digitalforest.net, a secure database system. Digitalforest provided multiple T1 connections, backup routing systems, and other features to ensure that the database was secure and that the site remained available for potential participants. However, during the first few months of data collection, there were several times when the site hosting the research study page had technical difficulty resulting in the site being inoperational. How many subjects were lost is unknown. During the last months of the study, such interruptions were much less frequent.

Frequencies were generated on the data to describe the sample using the Statistical Package for the Social Sciences (Solaris, 2001) and will be reported in Chapter 4. Data collected during phase one were used for theoretical sampling during phase two. Data were kept on a password-protected computer.

Interview Data

Data collection and analysis was an iterative and ongoing process. The researcher conducted an interview, then analyzed the interview and put the emerging impressions and findings in context with other interviews. Each subsequent interview was conducted in light of the understandings gained from prior interviews. The researcher returned to the interview transcriptions and theoretic memos again and again, always trying to make sure that concepts and emerging categories were supported by the data. The data analysis process was one of induction and moved back and forth between the data and conceptualization.

Taylor and Bogdan (1998) describe a number of different strategies for data analysis. The strategies used in the study will be described here. Coding of data was an initial step in data analysis. The codes were ways the researcher tagged parts of the narrative text for further analysis. The codes were refined during the course of the data analysis and sorted and resorted into categories that make conceptual sense in the context of each particular interview. Field notes were added to transcripts and analyzed as needed to help the researcher remember contextually important factors and impressions of the interviews. The use of analytic memos to track developing insights was an important part of data analysis. The researcher's analytic memos served two functions in intensive interviewing: (1) keeping track of how the analysis should proceed and (2) helping the researcher avoid losing valuable insights and impressions as the researcher was immersed in the data. The researcher returned again and again to the data, rereading, writing more memos and using other strategies such as constructing charts and diagrams to help organize the data and analyze it from different viewpoints.

All of the telephone interviews were audiotaped and transcribed by the researcher. Transcriptions were verified and then the tapes were erased at the conclusion of the study to protect participant confidentiality. All data were entered into QSR NUD*IST 5 (N5, 2000) to facilitate data analysis and to support an audit trail. Transcripts and field notes were all entered and treated as data (Taylor & Bogdan, 1998). The research journal used by the researcher contained researcher questions and insights about the data and the emerging analysis as well as information on the phase one data collection progress. Theoretic memos were written and included in the analysis.

Data were coded and analyzed for themes, patterns, and exemplars. Data were collected, analyzed, and subsequent interviews conducted in light of previous analyses. Interviews were analyzed individually and across cases to identify themes. A master list within case and cross case codes was kept and analyzed. The lists changed as analysis proceeded, more data were collected, and data were reexamined in light of new findings. Analytic memos written during data analysis were included in the research journal as well as linked to specific sections of text in NUD*IST. Memos were used to help summarize information and to move the analysis to a higher level of abstraction.

Demographic data and a summed expertise ranking from the Internet expertise questionnaire were tagged to the interviews after entry into NUD*IST. The data from the caregiving questionnaire were entered at the same time. Analysis proceeded across all cases but also included examination of transcript data for any differences in Family Caregiver Internet experience based on level of experience, caregiver activities, or age. Given the small size and the range of age, the lack of range of experience, and the similarity in caregiver activities, no differences were noted.

Protection of Human Subjects

Procedures for conducting scientific research must be developed with attention to ethical issues. The following section describes study procedures for protection of human subjects.

Survey

The Web page described earlier contained a description of the study and a copy of the informed consent form as well as the phase one questionnaire. The phase one questionnaire data were entered by the researcher into a password-protected server from the on-line database questionnaire form. The page also included a link to the researcher's OHSU e-mail address and to Dr. Tanner's e-mail address. Potential participants were invited to e-mail the researcher if they had any additional questions. No participants e-mailed the researcher with questions except about participating in phase two. Several participants e-mailed the researcher with additional comments about their experiences. Several others e-mailed the researcher with requests for additional research regarding their particular population (e.g., children) or asking for the focus of the study to be expanded (e.g., to include asking questions about available resources for the disabled). The e-mailed data were not included in the study findings because the individuals involved either did not go through the approved consent process or did not meet study criteria.

Consent during phase one was signified by completion of the demographic and other phase one data. To access the questionnaire, participants had to click a "yes, I agree to participate" button at the bottom of the consent page. Clicking on the button took them to the questionnaire.

The information included in the consent on the OHSU study web site included: (a) provisions for confidentiality of information, (b) the right to withdraw from the study at any time without consequence or penalty, (c) potential risks and benefits, (d) the purpose of the study, (e) expectations of them as participants in terms of time commitment and what would be asked of them, (f) an explanation of how data would be handled and confidentiality assured, (g) an acknowledgement or their right to ask questions about the study and their participation in it at any time, and (h) phone numbers for the Institutional Review Board (IRB), the grant sponsor, and the researcher. Participants were also informed of mandatory reporting legal requirements. Participants were able to download a copy of the consent form from the web site.

Interview

The researcher obtained telephone consent for phase two. (Please see script for telephone consent.) The researcher asked the participant if they agreed to participate in the study, read the consent form, and asked if they had any questions before beginning. Verbal permission to tape record the interview was also obtained.

The data obtained from individuals in the study was in the form of demographic data consisting of age, gender, race, educational and income levels, previous Internet and computer experience, and caregiving situation information. Data were collected by audiotaping 10- to 90-minute-long interviews and transcribing them before entry into a computer software package for qualitative data analysis. Transcripts, original audiotapes of phase two interviews, and hard copies of data printouts were kept in a locked box. All audiotapes were erased at the end of the research study. Phase one data could be anonymous. Phase two data were identified by an e-mail address rather than a participant's name. E-mail addresses were kept in a separate locked box so that actual data could not be connected to an individual participant. No records will be kept of the persons who visited the Web site or who contacted the researcher but did not chose to participate in the study. The computer software (Filemaker Pro 5, SPSS, and NUD*IST

5) used was on a password-protected system and no data were placed on public computer drives.

IRB approval was obtained before posting the Web page. A sample of the Web page was included in the IRB application. If the researcher believed, based on comments made by the family caregiver, that additional support or resources were needed, the family caregiver was asked directly about the need and referred to their provider. The researcher did not answer clinical questions about the caregiver or care recipient but referred them to their provider.

CHAPTER 4

Results

This chapter describes findings from the study. The findings will be presented in terms of the four specific aims noted in chapter one. The aims were to describe family caregiver characteristics, the purposes for which caregivers used the Internet, how caregivers did or did not benefit from Internet use, and how the Internet affected their caregiving. The first aim of the study was addressed using the phase one online questionnaire data and demographic and other characteristics data. The data for the remaining 3 aims was derived from the phase two telephone interviews.

Characteristics of Family Caregivers who use Family Caregiving Internet Sites

The sample for both phases was overwhelmingly white, female, and well educated. The mean age for the phase one sample was 49.54, range of 24 to 79, and a standard deviation of 11.42. The mean age for phase two was slightly younger, 45.3, with a range of 24 to 60. See Table 4 for additional demographic information about the phase one sample. The 15 participants who agreed to be interviewed in phase two are comparable to the total phase one sample on gender, race and education.

Table 4 *Participant demographic characteristics*

Demographic	n (%) Phase One	n (%) Phase Two
Gender		
Female	62 (91.2%)	14 (93.3%)
Male	6 (8.8%)	1 (6.7%)
Unknown/Missing	4	0
Race		
White	64 (88.9%)	14 (93.3%)
African American	5 (6.9%)	
Hispanic/Latino	1 (1.4%)	1 (6.7%)
Native American	1 (1.4%)	0
Asian	3 (4.2%)	
Unknown/Missing	0	
Education		
Less than High School	3 (4.5%)	
High School/GED	8 (12.1%)	2 (14.3%)
Some College	11 (27/3%)	3 (21.4%)
College Degree	31 (47.0%)	6 (42.8%)
Doctoral Degree	4 (6.1%)	1 (7.1%)
Post Doctoral	2 (3.0%)	2 (14.3%)
Unknown/Missing	6	1

Nearly three quarters of the sample (72.3%) had been using the Internet between 2 and 10 years. Caregivers had been using a computer for longer than they had used the Internet as shown in Table 5.

Table 5 *Length of time using the Internet and computer*

Length of Time	How long have you used the Internet? n (%)	How long have you used a computer? n (%)
Less than 6 months	4 (5.6%)	3 (4.2%)
6 months to 1 year	2 (2.8%)	1 (1.4%)
>1 year, < 2 years	4 (5.6%)	5 (6.9%)
>2 years, < 5 years	31 (43.1%)	20 (27.8%)
>5 years, < 10 years	21 (29.2%)	13 (18.1%)
>10 years	10 (13.9%)	30 (41.7%)

Caregivers accessed the Internet from a variety of locations. All but one participant (98.6%) accessed the Internet from home (see Table 6). The mean number of places phase one participants used to access the Internet was 1.9, with a range of 1 to 7 out of a possible 8. The standard deviation for number of places caregivers accessed the Internet was 1.9.

Table 6 *Number of Internet access locations used by participants*

Access from:	n (%) Phase One	n (%) Phase Two
Home	71 (98.6%)	15 (100%)
Work	30 (41.7%)	7 (50%)
School	9 (12.5%)	1 (7.1%)
Family Member	11 (15.3%)	2 (14.3%)
Public Kiosk	1 (1.4%)	0
Library	12 (16.7%)	0
Friend	6 (8.3%)	2 (14.3%)
Other	4 (5.6%)	0

Caregiver Internet self-efficacy is reported by item in Table 6. The items in Table 6 are listed in the same order as on the questionnaire and reported as percent of total. The range of possible scores was from 7 to 56. The mean of actual scores was 40.36, with a range of 19 to 56 and a standard deviation of 9.21. The sample was skewed toward people with higher levels of Internet self-efficacy.

Table 7 *Caregiver Internet Self-Efficacy*

I feel confident:	SD	D	SWD	N	SWA	A	SA
1. understanding terms/words relating to Internet hardware	0%	1.4%	11.1%	4.2%	25.0%	36.1%	22.2%
2. understanding terms/words relating to Internet software	0%	1.4%	14.1%	4.2%	21.1%	35.2%	23.9%
3. describing functions of Internet hardware	2.8%	15.5%	14.1%	8.5%	22.5%	23.9%	12.7%
4. troubleshooting Internet problems	12.5%	13.9%	11.1%	8.3%	23.6%	22.2%	8.3%
5. explaining why a task will not run on the Internet	8.7%	20.3%	8.7%	14.5%	24.6%	11.6%	11.6%
6. using the Internet to gather data	0%	1.5%	0%	4.4%	10.3%	29.4%	54.4%
7. learning advanced skills within a specific Internet program	2.8%	2.8%	1.4%	4.2%	26.8%	38.0%	23.9%
8. turning to an online discussion group when help is needed	0%	7.0%	2.8%	15.5%	18.3%	16.9%	39.4%

SD = Strongly disagree, D = Disagree, SWD = Somewhat disagree, N = Neutral, SWA = Somewhat agree, A = Agree, SA = Strongly agree.

Item 4 had nearly 40% disagreeing to some degree. Items 3 and 5 also had more "disagree" responses than other items. Technical skill may be an area where the study participants lack confidence in their ability or it may indicate that caregivers were experiencing technical difficulties. Participants were most confident in using the Internet to gather information, with 83.8% agreeing or strongly agreeing. Most of the other items rarely had a strongly disagree response, which may indicate a flooring effect when the scale was used with this sample. Item 8 focused on social support in the sample. Most of the sample indicated considerable confidence turning to an on-line discussion group when help is needed. The amount of Internet experience in the phase two group was almost entirely moderate to extensive. Only one participant in phase two indicated limited Internet experience.

Caregiving Context

Participants in phase one were caring for at least one ill family member, usually a spouse/partner or parent/step-parent, as shown in Table 8. Note that some caregivers were caring for more than one family member, so the sample number totals less than the number of relationships.

Table 8 *Caregiver/Recipient relationship types*

Relationship to Caregiver	n (%) Phase One	n (%) Phase Two
Spouse/Partner	22 (30.6%)	6 (40%)
Parent/StepParent	39 (54.2%)	8 (53.3%)
Aunt/Uncle	2 (2.8%)	1 (6.7%)
Grandchild	1 (1.4%)	0
Grandparent	7 (9.7%)	2 (13.3%)
Friend	1 (1.4%)	0
Other	9 (12.5%)	0

Most of the sample were fairly experienced caregivers. Caregivers in phase one had a range of caregiving duration, as shown in Table 9. Family members generally had been ill longer than the caregiver had been caregiving.

Table 9 *Length of time caregiving and length of time family member ill*

Length of Time	Phase One Caregiving Length of Time n (%)	Time Family Member Ill Length of Time n (%)	Phase Two Caregiving Length of Time n (%)	Phase Two Family Member Ill Length of Time n (%)
Less than 6 months	6 (8.3%)	4 (5.8%)	2 (14.3%)	1 (7.7%)
6 months to 1 year	13 (18.1%)	10 (14.5%)	2 (14.3%)	2 (15.4%)
>1 year, < 2 years	12 (16.7%)	4 (5.8%)	4 (28.6%)	0
>2 years, < 5 years	23 (31.9%)	29 (42.0%)	5 (35.7%)	7(53.8%)
>5 years, < 10 years	15 (20.8%)	16 (23.2%)	1 (7.1%)	2 (15.4%)
>10 years	3 (4.2%)	6 (8.7%)	0	1 (7.7%)

Caregivers performed a number of tasks for their ill family members, as shown in Table 10. The number of tasks caregivers performed ranged from one to nine. Specific tasks are shown in Table 10. Caregivers performed an average of 5.73 task categories for their family member, with a standard deviation of 1.97. The most common task category was Managing and Monitoring Family Member's Health while the least common task category was Managing Equipment. Caregivers reported stress due to caregiving, with 2.9% reporting that caregiving was not at all stressful, 15.3% reporting a little stress, 34.7% reporting moderate stress, 37.5% reporting being very stressed, and 9.7% reporting overwhelmingly stress.

Table 10 *Tasks reported by caregiver participants*

Caregiver Task	n	%
Shopping and Errands	62	86.1%
Assistance with Medications	59	81.9%
Assistance with Personal Care	48	66.7%
Assistance with Functional Activities	34	47.2%
Help with Mobility	39	54.2%
Decisionmaking	62	86.1%
Managing Equipment	15	20.8%
Managing and Monitoring Family Member's Health	65	90.3%
Other Tasks	26	36.1%

Participants were primarily female, white, well educated and experienced in both caregiving and Internet use. The most difficult Internet related activities for caregivers related to technical aspects of the Internet such as hardware and software problem solving. Access to the Internet occurred most often at home, followed by access at work. Caregivers in both phases were likely to be caring for a spouse/partner or parent/step-parent. Caregivers performed an array of tasks for their ill family members.

Purposes for which Family Caregivers use the Internet

Caregivers identified two primary issues that led them to the Internet: (1) the need for information and (2) the need for emotional and social support. In all but one case, caregivers initially went online to search for information. Caregivers wanted information in response to a specific practical caregiving situation (40%), a new diagnosis (40%), a crisis in the caregiving situation (13%), or to help the current primary caregiver (7%). Specific statements to describe why caregivers went online include: "He was really ill and every time I took him to the doctor's, nobody could do anything for him. Eventually I got him admitted into the hospital and I, actually because of the Internet, was able to diagnose his illness one day before the doctors did. And that's how he got diagnosed is because of the research that I did." "I feel like I kind of went out there and got everything I could and then started focusing in on the things that helped me, like the individual people and people who are actually dealing with (the disease)." Once caregivers were online, they found not only information but support groups, chats, and links to other sites which helped them with their caregiving. Information continued to be a priority for all caregivers, although the importance varied depending on the caregiver and the caregiving situation.

Caregivers acknowledged that providers don't have time to give them the depth and variety of information they need regarding each point of care. Participants saw this as just the way the system worked and sought information and support elsewhere, including the Internet. A typical comment was, "Let's face it, doctors don't have time, an hour each visit, to sit there and answer your questions." However, a few caregivers noted that they actually were able to use e-mail to increase their practitioner access. One participant used e-mail with her family member's nurse, physician, and nutritionist to get caregiving questions answered.

Participants perceived that health care providers don't always have the type and quantity of information caregivers needed. For example, one respondent said, "The doctors don't seem to be very, you know, good at giving you information. They just want to prescribe a pill and get you in and out in 15 minutes and for caregivers that doesn't quite do it." Practical, how to information from others who had "been there" was desired in addition to more purely medical information. "I needed advice from people that had more experience in caregiving than I do," commented one respondent. Most of those who mentioned inadequacies in the information provided by the health care system attributed it to lack of time on the provider's part during an office visit. Only two of the caregivers perceived a lack of skill on the part of the health care provider.

Most of the caregivers began searching online by entering terms into a search engine, but two said that a physician or nurse had given them a URL and that was where they started searching. "The nurse that was there. .... He knew that my (family member) had never been sick...when he saw us back (in the Emergency Department) he said, 'You know, I feel uncomfortable letting him go because I know that his issues have not been addressed.' Well, we had to take him back and have him admitted. When we did, he came running up to me and he said, 'You know what, I am so glad to see you. This is what I found out.' It turns out that the next day after we were there, he had gone to another doctor who gave him a few ideas. Well you know, this guy (nurse's name) got on the Internet and spent his time on the web, he spent his own personal time researching information and so I took what he had along with what I had and got on the Internet and that's how I was able to diagnose him before the doctors were was with somebody else's research that they had done on the web to get me started. So I mean, without it, we wouldn't be where we are."

There was usually a specific trigger of some sort that led the caregiver to the Internet to find help with their caregiving. Participants described new illness diagnoses, changes in a current illness pattern, insufficient information from the health-care system, or attempting to get a diagnosis as reasons for going online as caregivers. "She was having memory problems and we went to the neurologist and he said, 'Oh, you have (disease)' and that was IT." Caregivers expressed considerable motivation to find the information and other support and resources necessary to care for the ill family member; however, they didn't know where to find what they needed. The Internet was one of the places they sought help. One participant said, "I all of a sudden realized I was, I couldn't do it anymore. In my head, I was just so frustrated and I didn't know where to go and I didn't know who to talk to, where to get help."

Information seeking

Information helped caregivers feel a sense of control and was a way they coped. According to one, "My way of dealing with things was to immediately seek information. So that I felt that I was being in some way effective." This group had fairly minimal interest in emotional support or "stories" of other caregivers. They might occasionally look at such material on the web sites they visited but not often. "Now there are other people who clearly, whose emotional lives around the disease are handled on the web site. That is not true of me, " said one respondent.

Information type

The type of information that caregivers found beneficial was practical, disease, or treatment oriented. While most caregivers looked for information about the disease initially, later caregivers were more likely to look up information such as drug side effects or new research in treating the disease. Almost every caregiver commented on the need for practical information. The practical information need remained constant although specifics changed as the family member's needs changed. Caregivers needs for practical information fell into several categories. The largest category was problem solving and caregiving tips with 11 of the 15 caregivers mentioning that need. A related need for 6 of the caregivers was specific "how to" or skill information. Seven caregivers used information found online to determine whether a sign, symptom or change in condition was related to the disease or not and whether there was a need for intervention. Seven caregivers also sought information on services that were needed to help them care for the family member. Services could be home care, legal, financial, placement or insurance related. Typical of caregiver responses were, "Now every time I go in and he's on a new medication, I look it up because I want to make sure he's getting the proper care"; "So if they gave information about how to deal with things, those were the best ones for me"; "The really, the day to day, actually dealings with the (disease), not just the textbook stuff."

Information Credibility

Caregivers do not blindly accept anything they find online. Each caregiver was able to describe a process of establishing information credibility and deciding how to use and trust what they found online. The criteria were different from caregiver to caregiver, but themes did emerge from the data. Caregivers are aware that not everything on the Internet is credible. One caregiver said, "A lot of it is garbage… I can pretty well determine what's valid and what isn't. Some of the sources are consumer driven and when I need information I go to sites that I really trust like (named internationally known institution and a national not-for-profit organization)."

Sites with name recognition or perceived authority were most often mentioned as trustworthy sites. Well known organizations or hospitals that had web sites were used frequently. "I probably have a tendency to start first with something that may come from an actual medical school," was one response. Sites were seen as more credible if there was attribution of source material and the source was reputable, as one respondent explained, "...but if they have, well so and so wrote this and they are a nurse and blah, blah, blah, and they have done this, for more information click here." Caregivers particularly liked it when they were able to link to or find the original source material in its entirety because that indicated more credibility. "This was taken from this article in this magazine, published by these people, at this date. You know, that kind of thing, then I'm more likely to go okay, that's probably a more reliable source," commented a caregiver.

Once a caregiver had repeatedly determined the content on a site was trustworthy, they were more likely to trust information found there in future. As one stated, "I double check the sources and if it's an article on a web site and if it's a web site that I have found in the past to be correct then that's good. If I find an article outta nowhere, I'm like um, okay, well, let me see if I can find something to back it up." Double checking information was the most common way caregivers determined credibility. Comments about this included, "...if I'm still concerned, to check it. If I'm still not sure, then I take it to my doctor and then say, you know, I read this somewhere..."; "I guess if I go to one site that tells me one thing and I go to another site and find the same thing, then I'm pretty sure that its sound, reasonable to me." Caregivers found sites less credible if they were trying to sell them something, if the advice defied common sense, wasn't attributed, represented a single case, or was from a site that was new to them.

Emotional and Social Support

The second most common reason caregivers went online was to meet emotional and social support needs. Many caregivers said they initially went online for information, but remained active online primarily to meet their social and emotional need for support.

Caregivers who used the Internet reported that their sense of isolation decreased, they developed friendships, they felt less depressed, and they felt that they were helping others, as expressed by one caregiver who said, "I feel like I'm being a help, too, to others, you know, who are facing the same thing." Information seekers also provided feedback and assistance to others, but it tended to be more informational or advice-oriented rather than emotionally oriented. Caregivers were able to meet at least some of their social needs online, which could otherwise have been especially difficult if they were unable to leave the ill family member or were geographically isolated. One participant said, "You can't you know, always get out. You know there's really no place for me to go here when I do get out, other than the store and back home. The Internet provides companionship."

Specific emotional and social support needs met online included interaction with others in similar situations who would understand and would not be judgmental about caregivers' "It's (web site) a welcoming place. It's (web site) not a judgmental place." Part of the nonjudgmental support was the sense that the other online caregivers had all been through similar experiences. The support groups served as an information source for this group as well. One caregiver explained, "You know, kinda like 'how to' and that's what I find most in the support group."

Providing emotional support to others and activities such as reading message boards regularly may be beneficial. Several participants developed long-term friendships with other caregivers they met online. Contact was deepened by phone, e-mail, in-person visiting, and exchanges of photographs. One participant's initial web posting reflected the desires to connect and to share information, "Is there any other children out there, not necessarily children's age but children of (disease) patients that just want to talk to somebody else about what it feels like to possibly lose a parent and what that makes you life feel like, let me know and I got a whole bunch of personal e-mails. There's a couple of personal correspondences and even a personal phone relationship with one woman." Another respondent commented, "Actually, I did find one person with whom I shared a great deal and with whom I have maintained contact off the listserv." Two participants had met or planned to meet someone they had met online. Some caregivers have become more involved in their local or virtual communities as a result of their online activities. One said, "I've gotten involved in my town and we're building a caregivers' network here to screen caregivers in our community and I've built them a web site, which I'm in the process of building." This caregiver goes on to point out that by chatting with others online as a moderator, she feels less isolated and depressed. Two of the caregivers interviewed acted as moderators in an online chat room or message board.

While there may be benefits to online use, caregivers may also experience drawbacks. Other caregivers chose to limit their contact with others outside of caregiving or to take "breaks" to regroup emotionally. As one pointed out, "...but as much good news and clinical trial information as you get, you also, you know, you sign online and (screen name) lost her dad today and you've known her dad you know, just two months and you just can't handle it." The caregivers expressed appreciation for a culture and medium that allowed them to choose what they could handle and when. The term "lifeline" was used by several caregivers to describe the importance and intensity of their Internet experience. "That is my lifeline. Whether I write every day and I don't or whether I answer every person, I really try to read every single one." When asked by the interviewer if she posted every day, the respondent replied, “No, no, not at all. I don't because on the flip side of that, it can get very, very discouraging very quickly.” Even the most intense users occasionally needed breaks.

Internet Use Patterns

Use patterns varied widely among caregivers. Some used the Internet occasionally for a few things, others were online daily for many different needs. Caregivers were sometimes caring for more than one family member and used the Internet for different purposes for different family member illnesses and caregiving needs, which also varied the caregiver’s Internet usage pattern. As caregiving needs changed and as they became more familiar with what was available on the Internet, caregiver Internet use patterns changed. One caregiver said using the Internet for social support was important initially “…but I think as the disease progresses, you have different needs and right now that is not my need.” Some caregivers began to be very active immediately and others “lurked” for a time before taking further steps to access material and people on the Internet. “I probably started doing this around November of last year and it was around June that I finally got to the point and I threw out a couple posts on their message board and I got wonderful responses and wonderful help…,” said a caregiver.

Some participants were familiar with the Internet and turned to it right way when faced with a caregiving need. “I’ve used the Internet as a resource for other things and turned immediately to the Internet as a resource for (disease) caregivers as well,” said one. Previous success with the Internet and familiarity did encourage Internet use by participants, but less experienced users got more confident using the Internet with practice. “I think when you first start out, you don’t know exactly what you’re doing but the more experienced you are, the more comfortable you are," commented one newer user.

Caregivers tried various sites and ways of using the Internet in their caregiving as well as other resources. For some, the Internet was able to replace face-to-face contact like support. One caregiver noted "I felt like I really, really needed to find someplace that even if they didn't see me, even if they did not see how you know, I, how I looked ecause I felt horrible, I could at least say, tell me that there's hope today and there would be 20,000 e-mails going it's okay, we know what it's like." Caregivers talked about things that were available online which fit them and their needs, "I think it's a really wonderful source of knowledge to be talking to people who are in the situation and it's really the only source I've found that seems right."; "I had tried an (disease name, nonvirtual) support group and I just thought it was stupid. You know, well what's your problem, well you know, this too shall pass kind of thing. And so I just felt like I really connected with the message board." The data did not yield a description of what was acceptable or inadequate online support.

Participants from both rural and urban environments had difficulty locating and accessing acceptable resources and support. Caregivers also went online searching for products necessary to care for their family member. Often they were searching for products available to meet a specific need. Those seeking products online occasionally got recommendations about a specific item for a care need, but most often just went looking themselves. One caregiver mentioned that an onsite product video helped her to determine a better way to care for her ill family member. One caregiver reported a lack of specificity about the products she was looking for online, but noted that the same problem could have occurred if she went to the store. The caregivers were looking for details about the product, for example, how much weight a grab bar could handle. A third of the sample purchased products online and several mentioned that looking for caregiving products online was a way to comparison shop.

The study sample included 5 of the 15 caregivers who were caregiving long distance. These caregivers lived in a different state or city than the care recipient. Two made trips on a regular basis to provide hands on care to their direct family member but the other three did almost all their caregiving over the Internet or other communication technology such as the telephone. Long distance caregivers described being able to use the Internet to find services and products, look up drug and other treatment information, and find information to address health problems that the ill family member was experiencing.

An event in the caregiving situation often led to the caregiver going online, initially for information. Caregivers expressed a primary need for information. Types of information that were particularly needed were practical information to help them solve caregiving situations, and disease- and treatment-related information. Caregivers were deliberative in their evaluation of the credibility of information found online. Emotional and social support needs could also be met to varying degrees online.

Perceived Benefits and Limitations of Internet Use by Family Caregivers

Caregivers described a number of benefits and some limitations of their Internet use as caregivers. The caregivers also described what features were helpful on an Internet site. Benefits, limitations and desired features will be discussed in this section.

Benefits

Caregivers were identified a number of benefits of Internet use to support their caregiving. Accessibility was a key benefit.

Internet Accessibility. One of the most consistent benefits that emerged from the data was the accessibility of the Internet. Caregivers were able to access the Internet at any time. Although not all those interviewed lived with their ill family member, all interviewed caregivers could access the Internet from home around the clock, 7 days a week. Caregivers said they were able to find what they needed online most of the time, although not always: "… and it could be at 3 o'clock in the morning or it could be, you know, in the middle of the day and I had multiple options….it wasn't like I had time to make only one phone call and then I ended up talking to somebody who was really not what I needed." The caregiver went on to say that going elsewhere could be a "waste of time" when compared with using the Internet. Another caregiver described the accessibility of the Internet, "Again, your doctor doesn't always have an hour to sit with you and you don't always think of the questions you're gonna want to ask. And if you think of them in the middle of the night, you get up in the morning, you go down and you get online and you post that message." Having practical information so the caregiver could safely provide care was an advantage. "When I need help, I need help now. I don't have time to wait for months and then somebody says, okay we're ready for you. I've already figured it out on my own and I've found out that I've had to do a lot of stuff on my own," said one caregiver.

Access to others. Another form of accessibility had to do with access to other caregivers in similar situations. This was perceived as especially important when geography or a rare disease was involved. Caregivers were sometimes in another state and still able to use the Internet to access many resources, products and information for their family members. Said one caregiver, “I live in a very small town and so there's just not, there are no support groups in this town other than maybe AA. .... There, there's nothin. There's not anything for people who are ill. There's nothin for us of the sandwich generation.” Another said, “Since it is a rare disease and the community of caregivers has the best advice... so I have gone to that community of caregivers on several occasions because I can figure out how to deal with an arising problem.”

Caregivers spoke of having access to other caregivers in similar situations that they would not have had without the Internet, “It gives you access to a great number of people that you wouldn’t normally encounter. You can seek out groups of people that share a particular interest or a particular problem and you know, become part of a forum that you wouldn’t normally encounter.” Caregivers can share with those who understand what they are going through but are not personally invested in the situation to the same degree as the actual caregiver. “You go online and you find a network of people that are where you are that aren’t part of your family. You find people that like get it but can hear it from you, you know and can think about what it means to you that your (family member) would pass away, even though your family members are too overwhelmed to discuss that with you,” said one. This may be especially important when other family members are not in the same part of the experience as the caregiver. Several caregivers indicated that noncaregiving family members did not understand what was happening with the ill family member or what caregiving was like. For example, one said “I get criticized for what I do. They don’t really want to participate.” Online, caregivers can find people who do understand. Most caregivers expressed relief that they were not alone and indicated that their Internet use decreased their sense of isolation, "I just felt, oh my gosh, you know, I'm not crazy."

A number of caregivers indicated that an added benefit of contact with others in similar situations is the ability to compare their own caregiving situation to others. The caregivers invariably found that there were others in situations the caregivers defined as worse than their own caregiving situation, "I found I wasn't the only one going through this, that there were other people in worse situations, you know, than I." This feeling helped them believe it was possible to get through whatever was currently happening in the caregiving situation. One said "What I find fascinating is that when you read the plight of other people, you realize how easy you have it so to speak in the caregiving realm." Other comments included, "You know, just reassuring me that they'd all been there and it is, you know, is possible to, to get through it."; " I felt like I really, really needed to find someplace that even if they didn't see me, even if they did not see how you know, I, how I looked because I felt horrible, I could at least say, tell me that there's hope today and there would be 20,000 e-mails going 'it's okay, we know what it's like. I had this problem and this problem' and that was something else that gave me the strength to just go, okay, this person's got it a whole lot worse than I do." Even those who were primarily information seekers found this aspect of the Internet beneficial.

Access to providers and other caregivers. Health-care providers that the caregivers would not normally be able to access were also located online. One respondent said, "I found doctors online and I research the doctors now online. Their credentials, anything that I can possibly find on them. Any publications that they've ever put out, research that they've done. All of that I find on the Internet." Three caregivers mentioned that they use information from the Internet to educate other providers and paid caregivers about their family member's condition or care needs. Those caregivers were all dealing with rare illnesses. "I mean with a rare disease, that's what happens. When I go to meet a new caregiver, I print out the information about the disease and the four stages and you know," said one. A fourth caregiver, also dealing with a rare disease noted that, "That's the only place (Internet) I've been able to get information because, I mean, other people, we had doctors that have no clue. His disease is so rare that they know nothing about it. I know more about it than they do and that's because of the Internet." Caregivers sought providers and other family caregivers with specialized knowledge because the nondigital health-care system had little or no information on the family member's disease. Other caregivers with more common illnesses did report keeping information found online and organizing it, usually in a hard copy notebook, for future use with professionals and for themselves. "Yeah. I keep it in the notebook and also to give to my sister-in-law who does the medical stuff so we have a running notebook of any pertinent medicines, procedures, anything pertinent to us," said one.

An additional benefit was the ability to keep family and friends updated, as one respondent explained. "...so when we go to the doctor appointment, I will just jot them a letter off on e-mail to tell them how the appointment went and how things are going." Multiple family members were sometimes involved in caregiving using the Internet. One caregiver also pointed out that being able to send out one e-mail to all the concerned friends and family not only saved time, but also the emotional wear of having to go over the same information so many times with different people, "Especially in the beginning when he got sick. You know, you think about talking 40 times a day saying the same thing over and over. All you do is send out 40 e-mails and you're done."

Access to products and resources

A final access theme was access to products and resources. Caregivers looked for legal and financial advice, funding for care and equipment, products, social services and paid in home caregivers on line. One caregiver said, "I actually found a web site strictly for family caregivers and that's where I started finding information even though it's only general information. It's not something that is geared toward him specifically, but it did give me other resources. Then I was able to go to the insurance company and get him a lift chair. So, through them, I was able to find a company that said, hey you know, these are the kind of lift chairs that there are and this is what you can do and this is how you do it." She is one of several caregivers that reported "fighting the insurance company" to get products or equipment that they had researched online for their family members.

The caregivers were able to locate what they needed online without having to go shopping for it or make multiple calls. Caregivers were able to access types and amounts of information and support online that they couldn't get elsewhere. As one caregiver noted, "It's been an integral part of what I'm trying to do. And see, I'm working full time, so it's really hard for me to pull these things together." Five caregivers spoke of searching for something to meet a specific caregiving need or solve a problem. They did not necessarily know what exactly they needed when starting the search. Three caregivers mentioned comparison shopping and three caregivers reported making online purchases as for caregiving supplies.

The findings of this study indicate that the Internet can save time and resources for caregivers. While there were many important benefits and, overall, caregivers gave very positive reports of their experiences, they also noted some limitations.

Limitations

Caregivers identified limitations or barriers to their use of the Internet for caregiving support. These will be discussed in more detail in the following section.

Time and Skill

The limitations described were connected in different ways to the Internet, both as a piece of technology and in other areas. Time was a concern that caregivers mentioned frequently. While using the Internet could be a major time saver, it could also take up caregiver's time, and less skillful users sometimes expressed frustration about how much time was needed to learn to use the Internet. One said, "I think the biggest thing is just time.... It seems so confusing at first because there is just so much to see and you go from one spot to another and don't even remember where you started." Another stated, "I found that on the Internet, depending on what keywords you put in, is what information you get. But if you go in and you rearrange those words in the search, you can go in and get a whole new array of information. Which is a, you know some of that stuff, it would have saved me hours of research if I had known that ahead of time and I didn't." None of those interviewed quit looking at or for something on the Internet because of the amount of time it took or frustration they experienced, but it may be a factor for other caregivers not included in the study. A strong sense of motivation and, in a few cases, desperation, led caregivers to persevere until they were able to get what they wanted. Comments included, "I have found probably, trial and error basically is what I've done"; "It's just the experience that kind of teaches you, you know, how you get to different sites and how to get out of a site and where you start from."

Time spent online

Time spent online was also an issue. Three caregivers used the term "clearinghouse" to describe a perceived lack of a centralized location to find the information they wanted, "...there needs to be a clearinghouse"; "...let's say its for (topic) you can go to (site name) and it has everything from soup to nuts for people with (topic) health problems. If there could be something more like that for caregivers. I haven't found one that has everything. So I've relied on several to provide my needs. But it would be nice to see one very inclusive site. More like a portal to act like a centralized location for all the things that are out there." The resulting lack of a centralized information location was that they had to search for longer periods of time and sift through more information that was not relevant to their situation or repeated information they had already found. As one respondent commented, "Now you can find cancer information. That's easy. BUT, the type and what you're looking for is what takes detective work."

Volume of Information

Caregivers sometimes found the sheer volume of information and the time it took to sort through it overwhelming, "Just the volume of e-mails that can come in. You know, its hard to keep up with it"; " ... and in a pinch, you can't really say, hold on (family member) and I'm going to go online and figure it out cause you have to be there and support your loved ones." It was also difficult for caregivers when they found conflicting information on web sites. "There's a lot of different information out there," said one caregiver. "One, one place will say that it's progressive in a stepwise fashion. Another will say it progresses like Alzheimer's." After a certain point, caregivers coped by going to sites where they felt a good fit, where their needs had been met in the past, or limited their participation in certain groups or other strategies. "I just am kind of getting to the point where I just have to look at my (family member) and know what's happening and quit trying to absorb so much information," said one.

Timing of Information

Timing of information was also important. Caregivers wanted to know what to expect as time passed. The Internet could provide them with valuable information so that they could assess their ill family member's condition and disease progression. This enabled them to make plans, obtain necessary treatment, or find practical solutions to emerging caregiving needs. As one caregiver put it, "I try to project ahead for what I know is coming and try and project ahead for the next stage." There was a strong downside to the timing of information as well. The Internet was particularly beneficial as a way for caregivers to decide what they were ready to learn about, but it was not possible to entirely filter out information that could be distressing. While the Internet allowed them to tailor information to their needs and proceed at their own pace, the caregivers could find information online that was frightening or intimidating, "...and sometimes it's, you know, depressing to see what the future holds..." Caregivers coped with this by choosing not to view certain material or filtering the material in some way mentally and emotionally. One caregiver cautioned others "... to read carefully, that not everything that is said online is going to relate to them and their particular caregiving situation and not to be afraid of some of the stuff that they read. It's a little bit like being pregnant. You can hear what's going to happen ahead but until you get there, you don't really feel the impact."

Virtual versus Face to Face Interaction

The lack of actual physical or face-to-face contact was distressing for a few participants. They noted that the other caregivers online could not tell when you'd had a bad day by your appearance as a no virtual fellow caregiver could have. Some caregivers took time from the caregiving situation and had no virtual social interactions. Others found the caregiving situation too demanding or respite too lacking to have time for such interactions, "And so, you know, I kind of rely on them for actual physical companionship." However, for one participant, the lack of face-to-face contact was freeing. She felt more comfortable in a virtual support group than in a face-to-face one.

Synchronicity

Synchronicity was an issue for some caregivers. Synchronicity was the ability to interact with others in realtime online using features such as chat and instant messaging. For most of the participants who mentioned it, there was a preference for asynchronicity. They were able to perform necessary tasks at their convenience, such as "...being able to jot a couple notes and a letter type of thing and have them just pick it up in their own time frame." One caregiver pointed to synchronicity as a liability however. She saw it as a negative in that the site she particularly liked for chat was in another time zone. By the time she was able to sign on, others were signing off.

The time and intensity caregivers spent online could become a drawback. Comments included "it was a lot of research and it was a lot of hours but it came in handy"; "You spend too much time searching and playing and sending meaningless e-mails to people and you don't get out to your garden or breathe air or talk to your spouse or go make friends or go have a cup of coffee. I mean, the Internet is an unreal, or perhaps… I have a real strong belief that there's something hypnotic about the flashing screen." Caregivers made sure they had some balance between their lives and Internet use.

Design, features, content

Some of the concerns caregivers had about Internet limitations were related to site design or features. Caregivers were fairly consistent in their comments on design and features as well as content. Feeling comfortable and safe on the site was important to caregivers. Site design, site content, authority of the site and its content, the atmosphere or milieu of the site, and anonymity played a part in feelings of safety and comfort with the site. "I didn't have to sign up, give any information I didn't want to give. It's however much disclosure you'd like to offer is your choice. But the environment is such that you really can disclose a whole lot and feel safe." One caregiver did express concern that others might see information and wished she'd used a screen name other than her own for her online activities. "I just felt like once I found somebody who could identify with me, I was pouring out too much onto the Internet." Those who mentioned anonymity felt free to ask questions even if the questions seemed fundamental. As one respondent said, "...you don't ever, ever, ever feel silly about asking a question."

Navigation

Caregivers indicated that rapid easy navigation was important. Clearly labeled categories about topics such as stages of diseases, treatments, and how to navigate the site were beneficial to 5 of the 15 caregivers, "I'm thinking of like one page, I think it's called caregiving or something, anyway, I'd go to the homepage and their particular web page has pages for different stages of caregivers"; "I think one of the things that makes a good site is they have a good menu… you know, with good subtitles." Design features that allowed the caregivers to know what they were looking at on screen and select what they needed were valued.

Such features and design issues could help caregivers save time. Time was a frequent concern of caregivers and they did not want to waste it. Caregivers spent limited amounts of time on a given site. "If I'm on a project, I want to find out. I don't want to waste a lot of time getting shot off to the wrong sites," commented one. If what they needed wasn't readily apparent, they moved onto another site. As another stated, "I'll pursue that for a little bit and if it's nothing, you know, nothing that really applies to me, then I just move on to another one. I just don't spend a lot of time if I don't immediately find something that I feel relates to me."

User Friendly

The caregivers were not interested in a lot of what one caregiver called "flash" in the design of the Internet site. They wanted sites that were relevant, easy to navigate and didn't take a lot of time. Lots of "flash" got in the way of that. "For me, I probably like a more straightforward one. One that's set up with not a lot of fluff. You know what I mean? As far as like, pictures or, I don't mean, how can I put this? Almost in abstract form, you know like when you're reading an article from a journal or something, they have the abstract right there?" Sites that had information briefly summarized were also perceived as useful. Nine of the 15 caregivers mentioned online articles or publications, particularly summaries that could link them to other information as valued. User friendly was a term used by three caregivers. User friendly had to do with ease of navigation and clear language used on the site. Said one, "User friendly in the fact that you can get some of the basic information or be referred at a glance kind of thing. I'm not a person, I'm probably more impatient. I want to be able to kind of glance and click onto something that I'm interested in." Caregivers also liked information presented in such a way that they could go deeper into a topic. Links were a particular way of doing that.

Links

Caregivers want links that are current, relevant, lead to greater depth and variety of information, and are functional. One respondent commented, "Just, if you're going to talk about (name of disease) then I want to know about (name of the disease). What goes with it. Who to contact. What happens with it and every single piece of information about it. Even (site) has medical information listed under this disease but it's not about this disease." Caregivers used links to deepen their search and find other information they needed: "Better links. See, I like links on the disease that I want or medical information but you know what, if you need more information, here's a list of links and all I have to do is click on it and it'll automatically go." They were frustrated if the links weren't current or if the links they needed weren't there. Three of the caregivers mentioned updated and current content as important, including updated links. One caregiver described trying to search for in-home care for her ill family member online. The local site she went to had phone numbers but not links or e-mail contacts for the agencies. She was familiar enough with the local agencies that she knew some had links but the links were not included on what was supposed to be a local resource page. "They didn't put up any web sites and I know some of them do have web sites," she said. "You know they have the phone numbers, which is good, and I think the last time I went it wasn't current cause I think in the last 6 months a couple other businesses have come online and under this (name of site) hadn't updated that portion."

Information Comprehension

None of the caregivers said the information presented online was too difficult to understand, but several wanted information with more depth. "When you first start you don't really know what level you're going to need," said one. "So if you preface it perhaps, even staging information—You know obviously every cancer has stages. I'd like to see more details for each stage. What's common, what's a symptom. What to expect, what not to expect. And then, where to go from there under each stage...That's something you find out, kind of circumventing."

The caregivers struggled at times with the content, particularly medical terminology, but were able to comprehend the information, even on sites with complex material. Said one caregiver, "It was frustrating and it was tiring and it was just emotionally stressful because the majority of the information that I could find only scratched the surface, but when I started to get into the deeper information, the deeper information that I could get was only stuff from autopsies." Another respondent asked for "...easy to read terminology. If the terminology is something, you know, different or a new word, a meaning of it, like a dictionary where you could highlight the word with the meaning. Especially in terms of surgical procedures." Having a medical dictionary and pronunciation guide was considered helpful by four caregivers. They noted that a pronunciation guide helped them feel more confident when going to the doctor to talk about their family member. As caregivers became more familiar with the disease, it became easier to find and understand more complex information. As one caregiver said, "Now, I'm not a doctor. I don't play one on TV (laughs) but I am college educated. I have used computers before and I think I can read."

Chat or Message Boards

Message boards or chat rooms were useful to some caregivers, both as a place to ask practical questions and for emotional support and social connection. Eight of the 15 caregivers used message boards or chat and found it a very helpful aspect of the Internet. Only one caregiver specifically said she didn't like chat or message boards.

Caregivers varied on how much and how many personal stories they wanted. A caregiver with a middle point of view expressed it this way, "I take care of so and so and it's really hard and we had to do this and that's a really good thing and I'm glad that they are able to do that but for me, a paragraph about somebody's caregiving crisis is great. And that you know, because every once in a while, it gives me, wow, you know, they have it worse than me or oh, I can relate to that but I, I need the facts and I need the practical ways that I can be helped and the ways that I can look at it and go well this is what my (family member) needs and I didn't realize it before because I had never seen it." Only one caregiver specifically said that she wanted personal stories on a site as a feature but most of the others mentioned the value of such stories, even if the content was only viewed occasionally.

Having a professional to answer questions got mixed reviews. Only a few mentioned it at all. For the most part, caregivers were finding and evaluating the information and advice they found online themselves. As noted earlier, there was a strong perception that members of the formal health care system did not necessarily have the type of information desired or the time to provide the information.

There were two types of contact on the Internet, contact with the text or information on a web site and contact with other people. Both could be ways to provide information and emotional and social support. Caregivers benefited by gaining information about how other caregivers solved problems, by knowing that they were not alone, and by interacting with other caregivers. The intensity of caregiver activities varied by caregiver and the caregiving situation. Caregivers found that time could be saved by their online activities, but time was required to find what was needed and develop proficiency. Caregivers described a number of desired features in a caregiver web site including:

- Current updated links
- Categories and levels of well organized material
- Minimal distracting elements on a site such as animation or lots of pictures
- A site design that was easy to navigate

Family Caregivers' Perceptions of the Effects of Internet Use on their Caregiving

Caregivers described ways the Internet had affected them and their caregiving. The form of the impact varied. All caregivers described how they were able to use what they found online to care for their ill family member. Caregivers who sought products online were able to find products they needed such as incontinence supplies. They determined whether a new symptom was part of the illness or something else, and how to treat or manage the symptom. Social and emotional support were found online.

Health Care Interactions

Almost half the caregivers described other changes such as how they interacted with the health-care system and others. One example from a respondent was "I don't know how to explain it. Just that we knew that something was wrong and that (family member) ended up with virtually no short-term memory after that. So, it was affecting his rehabilitation because people thought he was being belligerent and not doing his exercises, staying in his room and the like. And you know, I kept saying, something's wrong, something's wrong, so that's why I started using the Internet, was to search about the (disease)." This caregiver, like several others, described being able to figure out what was wrong based on what she found online and advocate for changes in her family member's treatment. Not all providers, however, were happy to have caregivers bringing in information they found online. One respondent described the doctor's response as defensive and threatened, "You know, it was only bad when we lived in (name of town) and the doctors there didn't like that there was someone who knew more than them who didn't have a medical degree."

Caregivers were able to find information online that could be taken to providers and result in changes in care for their ill family member. "It's funny because he just got put on a new medication called (name of medication) and he's just now getting put on the medication, but I had the information for (name of medication) on (date)." She was able to find a medication to treat her family member's symptoms and talk with the provider about changing his treatment regimen using information from the Internet. She went on to point out that because the disease was rare the doctors "just had no clue."

As one caregiver put it, “I guess just, you're their best advocate and just jump in there. You have to. You don't have a choice. If you sit back and wait for the doctors to give you the information and you're not a savvy consumer, shame on you.” Caregivers felt empowered by what they found online and were more comfortable approaching health care providers with specific requests for their family member’s care. “Very much so. Very much so. Are you kidding? We go to the doctor now and we have our facts. We have our information and we know what it means. We don't call ourselves experts but we can at least understand what he's telling us,” said one. They also felt a greater sense of control over the situation and their ability to handle it. “I think that’s the reason I turned to any online solution. I don’t have the medical tools to make my (family member) better. I’m not a particularly religious person, so I wasn’t the type to sit down and pray, though I think these things make you start. I didn’t really have anyone to turn to. I couldn’t give him his job back, I couldn’t turn back time, but what I could do was try to find some kind of hope, some sort of action plan online.” The Internet provided them with more choices and more options when making decisions, a caregiving activity for 86.6% of the phase one sample. “You’re a better informed person, so, they, you have more choices too, cause you know what’s going on.”

Other Resources

Caregivers used other resources in addition to the Internet; however, no themes emerged from the data about what other resources were used. Resources used depended on what was needed by the ill family member, what was available to the caregiver, and what the caregiver chose to use. In addition to contacts with the formal health-care system, two caregivers chose to use face-to-face support groups rather than an online support group. The face-to-face contact was more important than what they could get online. Five of the caregivers described support from family members. Five caregivers spoke about friends as sources of support, but two other caregivers talked about friends not understanding their lives as caregivers or that friends "didn't know what to say" whereas their online caregiver contacts did know and understand what it was like to be a caregiver. Only one caregiver mentioned libraries as a resource. Three others, however, indicated that if they didn't have the Internet, they would go to a library, two specifically stating a medical library.

A number of caregivers described being empowered by what they found online. How much of that empowerment resulted from the caregiving experience and how much from online experiences was beyond the scope of the present study. Caregiver's use of the Internet in caregiving changed the treatment and care that the ill family members received by getting treatment sooner or changing treatments. Interactions with health-care providers and other aspects of the health-care, system such as insurers, also changed.

Conclusion

Online activities by family caregivers are focused primarily on meeting information and support needs in order to help them care for their ill family member. Caregivers in the study described a number of ways in which the Internet helps them to meet those needs. The Internet helped them find information related to disease, treatment and to solve practical issues in their caregiving. Caregivers described benefits and limitations of the Internet as well as features and content that were helpful to them. This information can be used to develop or refine Internet sites to support family caregivers.

CHAPTER 5

Discussion, Summary, and Conclusions

This study was conducted to add to knowledge about experiences of family caregivers and their experiences using the Internet to support their caregiving. The chapter begins with a discussion of the findings and their implications, followed by a discussion of the methodological implications. Strengths and limitations of the study are also described.

Discussion

Caregiver Characteristics

Study sample characteristics will be discussed and compared to a national study by the National Family Caregivers Association and the American Association of Retired Persons (1997). The study provided information on characteristics of caregivers who used the Internet. The study sample was not random and respondents did not represent the typical caregiver population demographically. Because these caregivers were more educated and possibly more affluent than the typical caregiver in the U.S.; in the researcher's clinical experience, it is possible that they had access to more resources and thus experienced less stress than the national sample. The data did provide useful information about these online caregivers.

Although the study sample differed from the national sample demographically, they did represent the population in other ways. Length of time caregiving was similar to the national sample of family caregivers (NACG & AARP, 1997). The caregivers in this study sample were more likely to be female (92%) than subjects in the national sample

(73%) and white (NACG & AARP). The national sample deliberately over- sampled minority caregivers. Since the national study was not ethnically representative of the U.S. caregiver population, it is unknown how closely this sample matched the U.S. population ethnically. The national study had a lower percentage of women (73%) than either phase one or phase two participants. The mean age in the national sample was 46, slightly older than the phase two sample and slightly younger than the phase one sample.

The study sample was better educated than the national sample of family caregivers and possibly more affluent. The caregivers in the national sample from higher socioeconomic status groups and those with at least some college education indicated a desire for more information. Information was important for this study's well educated sample. Whether information would be as important to other caregivers with less education is unknown. As a consequence, the study sample may be biased in terms of the importance of information to caregivers.

More than 80% of the caregivers identified in the national sample were caring for a relative, a finding consistent with this sample. However, only 5% of the national sample were caring for a spouse/partner, compared to 30.9% of the phase one sample. Because the national study purposively over-sampled minorities, it is not possible to compare the study sample on ethnicity. However, most of the study sample was white. The ability to transfer the study findings to other groups such as male, lower socioeconomic, minority, or less educated groups is not possible.

Caregivers in the study sample almost all used home Internet access. Some accessed the Internet at other locations as well. A study by Evans (2002) indicates that as of September 2001, 56.7% of U.S households access the Internet at home. The report notes a trend toward more Internet access outside the home. The study sample had higher rates of at home access than national trends in access location. The higher levels of education and, by proxy, economic status of the study sample may be a factor affecting the high percentage of caregivers who are accessing the Internet at home.

Purposes of Internet Use

Information seeking was a major focus of caregiver Internet activity. Caregivers in the study were searching for particular types of information related to diagnosis, treatment and practical needs. Caregivers felt that health care providers did not necessarily have the time or type of information they were seeking. This is consistent with findings from a study by Ferguson (1999). A study of 191 online self-helpers (Ferguson, 1999) found that patients preferred online support communities to specialists or primary care physicians in 10 of 12 areas studied. While the study was with patients, not caregivers, there were overlaps in what kind of material was preferred by the online groups. For example, the self-helpers believed that the best in-depth information about their condition could be found in the online community (76.92%), compared to either specialists (20.88%) or primary care physicians (2.20%). The online groups were seen as most convenient, most helpful with emotional issues, the best way to find medical resources, the best source of practical information, and the most compassionate and empathetic. These findings were consistent with the caregiver study. Other areas such as most helpful with death and dying were not specifically addressed in the caregiver study.

A study of genetic information and Internet use by families (Taylor, Alman, & Manchester, 2001) found that 47% of the respondents had visited the web on their own to find information about the genetic disease before the visit. Only 5% of the Taylor et al.

sample had been referred to a site by a physician. Only two of the 15 subjects interviewed had been referred to a web site by a physician or nurse. The study by Taylor, Alman & Manchester (2001) was the only one the author could find in the literature that examined health care provider referrals to the Internet. The Internet as a resource may be being under-utilized for patient and caregiver education.

Study participants described several types of information they sought online. Caregivers were looking for information to solve problems, learn specific skills, assess a symptom and determines whether intervention is needed, plan for future changes in progressive conditions, and find services. These practical areas are all areas in which nurses have information and skills that can help caregivers. Nurses could use information from this study to assist in organizing information for caregivers. First, information categories can be developed and presented online such as information grouped by disease stage. Second, information about what to expect can be similarly grouped. Third, factual information about the disease, disease progression and treatments can be presented online. The fourth area relates to practical information.

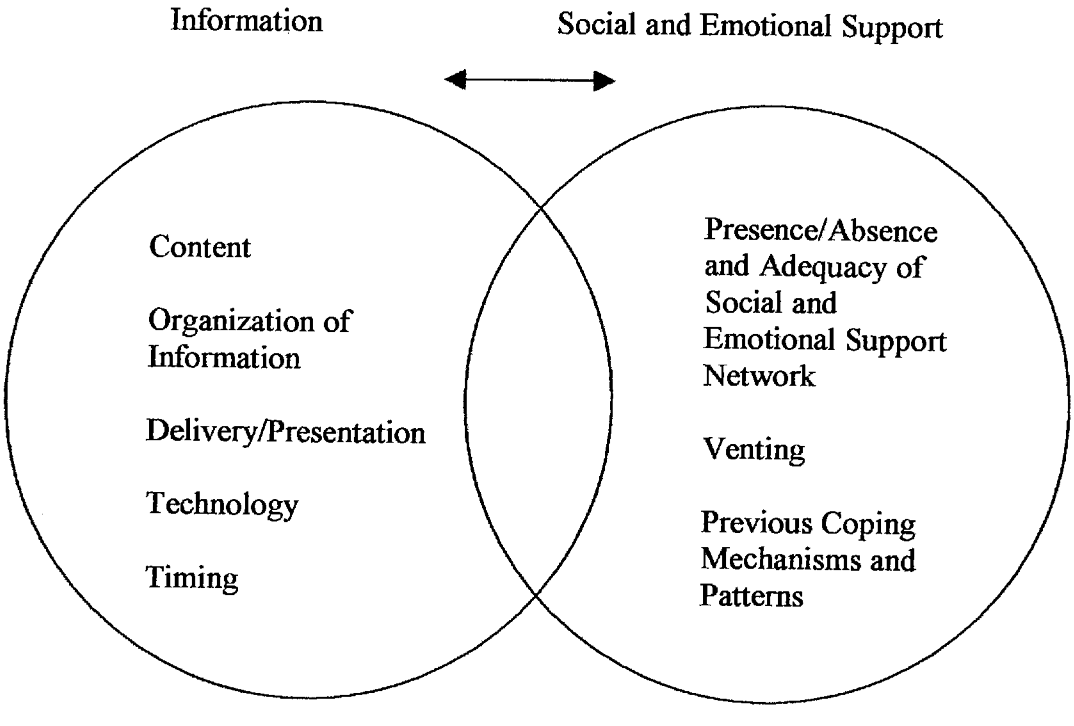
Even with a group of caregivers that self identified as skill Internet users, there were areas identified as problems that might be amenable to intervention. For example, putting information on a caregiver web site about how to deal with common Internet hardware and software problems might be helpful to some caregivers, particularly those who are more novice Internet users.

Emotional and Social Support

A second major purpose for caregiver's internet use was for emotional and social support. Social support, as described by caregivers in the study, is consistent with a review of nine articles describing online cancer support groups (Klemm et al., 2003). Most of the studies sited by Klemm were quantitative and had small samples. The qualitative studies were mainly content analysis of postings, several by the article's main author. Klemm et al. chose to group information seeking/giving and support. White & Dorman (2000) also chose to group information and support together.

However, in this researcher's opinion, the two are separate but overlapping concepts, and the ways in which information and support interrelate online need to be studied further. Information may not be viewed as supportive. However, information can be a form of social support. See Figure 3.

Figure 3 *Interrelationship of Information and Social/Emotional Support*



Contextual factors such as family member condition, personal preferences for both information and support and the timing and amount of either may vary within the individual caregiver and over time. Aspects of support such as having someone to listen while the caregiver vents are not related to information. At the same time, aspects of information such as information delivery systems or delivery skill of the presenter are unrelated to social and emotional support.

This study sample was small and covered a wide array of diseases of caregivers' ill family members. How social support is enacted online for other groups with chronic illnesses is an area that should be further explored. Both qualitative and quantitative methods could yield important information about the types of social support available online, how that support affects caregivers and their caregiving, and the types of support desired by different groups of caregivers (e.g. male caregivers, minority groups).

Loneliness and a sense of isolation are noted frequently in the caregiving literature as negative consequences of caregiving. Interviews with caregivers in this study indicate that the Internet can, to a degree, help ameliorate that loneliness for caregivers. The ability to overcome barriers of geography and time to help connect with others in similar situations around the world was valued by caregivers. Studies for caregivers of those with rare diseases or who are homebound or in a rural area should be conducted. How caregivers use the Internet in long distance caregiving is a priority area for research given the large numbers of persons caregiving at a distance in the U.S. and the Internet's apparent ability to overcome limits of geography.

Nurses could assess the adequacy of caregivers' social and emotional support. Standardized tools to assess caregiver stress and burden could be adapted for use online as part of the nurse's assessment of the caregiver. Nurses could then recommend specific online features or services for each caregiver. Web sites run by nurses could incorporate features such as message boards, chat sessions, and static media such as tips on coping as a caregiver.

Credibility

Behaviors to test credibility of information in the study sample, such as seeing if the same information exists on other sites, checking information against what the caregivers already know, and checking with their doctor are common in the larger Pew sample as well (Fox & Rainie, 2002). There is less credibility if the site lacks attribution of information or is selling something, as the sample indicated. One quarter of respondents in the Pew study checked the web site's information "most of the time," another quarter every time, and half less often. As with this study sample, those in the Pew study were often looking for specific information for specific questions.

Nurses are well positioned to teach family caregivers ways to systematically evaluate content found online and determine the credibility and quality of the information. Caregivers in the study were already using some of these ways such as examining content for attribution and authorship. Nurses could include features which increase content and site credibility for caregivers and avoid features which decrease credibility.

Web Site Design

Related to aim 3, to identify perceived benefits and limitations of Internet use by family caregivers, is the issue of information design for caregivers. Caregivers mentioned a number of web site features that were desired during the interviews. Such features are recommended as usability considerations in web design such as minimizing animation and graphic elements and insuring that links are identified consistently with brief descriptions (Spiezle, 2002). This study pilot-tested the usability of the study's web pages with people in the school of nursing. In future, usability might be improved by first using tools for user testing and user task analysis such as those found on Usable Web (2003). Pilot testing with more novice web users might have increased their participation in the study.

Caregiver needs and desired information varied in the study, sometimes within and sometimes across caregivers. Several caregivers indicated a desire for a centralized clearinghouse of information for caregivers. There are some features that can be added to sites to help caregivers find the information and other resources they require. Clear labeling by topic with current, functional links to take them further into a particular area would enable caregivers to find what they are looking for more quickly. Definitions of terms and pronunciations can also be helpful features for caregivers. Links to other sites that address related caregiving problems can also be helpful. Attribution, high-quality summary articles with links to the full text or more information on the topic, and lack of commercialized sales pitches can increase site credibility.

A Pew Internet and American Life report indicates that those surveyed reported few harmful effects from acting on health information found online (Fox & Rainie, 2002). Study participants interviewed indicated few negative experiences with the Internet technology and only one negative experience related to the caregiving–buying a piece of equipment that did not prove helpful.

Typical searchering behavior was to start with a search engine, not a medical site, for both the Pew study (Fox & Rainie, 2002) and this study sample. A study with a sample of 25 students by (Lazonder, Biemans, & Iwan, 2000) found that subjects who were more experienced searchers were able to find web sites more quickly than novice searchers. However, finding specific information on the web resulted in equivalent performances by experienced and novice searchers. The participants varied on Internet Self Efficacy but most perceived themselves as fairly skilled Internet users. More novice users might report more difficulties finding information they needed online than those in this study sample. Measuring Internet self- efficacy alone may not be sufficient to get an accurate picture of caregiver activities. Developing other ways to measure Internet skill level and Internet-based activities such as time spent on site and what was done online would provide a more complete picture than the data collected in this study generated. The participants in this study indicated that they searched briefly for information and then moved on to other sites if they did not find it. Whether this behavior would be typical of more novice users is unknown and should be studied further.

Typical behavior for the most recent Pew study (Lenhart, 2003) subjects was for searchers to visit 2 to 5 sites per visit and spend at least 30 minutes on a given search. A study by Eysenbach & Kohler (2002) found that the average searcher spent 5 minutes and 42 seconds to find desired health information online per query. Study participants were concerned about the time it took to find information. Future studies might examine length of time spent online and on any given site as part of caregiving. Paid services exist to put information about a web page or a link to a web page on a certain number of search engine lists. Using such services and adding embedded key words in the web code for the page could increase the number of family caregivers who access a particular caregiver web site. A well developed caregiving portal could also provide associative links or a thesaurus of sorts among web sites and terms. Additional studies examining specific

Internet features and content in more depth would help determine features and content to be included in the design of sites for caregivers in the future.

The Internet Self Efficacy instrument is self-report. Caregivers were not asked to provide examples of how they would troubleshoot a problem or observed in troubleshooting when they had problems with hardware or software. Sample scenarios could be used in future studies to more accurately determine actual rather than perceived skill level. The caregivers' perceptions of their skills are still important and should be assessed in future studies. Two of the central constructs (social support and information) had only one item each on the Eastin and LaRose scale. Based on the interviews and literature, in future studies the instrument should be modified to examine more aspects on how the Internet and social support or information seeking are perceived by caregivers. Items related to products, emotional support, and finding resources online should also be added. For example, the addition of specific items about seeking practical or specific information online could be helpful to further differentiate efficacy.

Health Care Interactions

Caregivers in previous studies have described caregiving as a growth or empowering experience. Caregivers in this study did as well. Changes in how caregivers interacted with the health-care system and their more assertive attitude toward finding treatment and other options for their ill family member were evident. A future study with caregivers who do and do not use the Internet might be a way to determine whether or not the Internet has an additional empowering effect on caregivers.

Caregivers provided examples of how they were able to find, comprehend and use complex medical information to advocate for their ill family member. Such caregivers may be unsatisfied with traditional approaches to health care in which the provider is the source of information and the patient and caregiver follow instructions unquestioningly. More sophisticated family caregivers may work better in a collaborative relationship with the provider rather than a recipient to authoritative source relationship. The nurse sees the patient and caregiver intermittently whereas the caregiver is providing care for greater periods of time and more consistently. Practice models with the nurse as authority and the patient or caregiver as recipient of information rather than participant and valuable source of information are not adequate to meet the needs of caregivers. Nurses can use the Internet as one way to help caregivers find more complex information and to make caregiving decisions safely. As discussed earlier, nurses can also use the Internet to help caregivers find emotional and social support.

Trajectory

The researcher's ideas about the importance of illness trajectory were off target. Before the study began, the researcher thought that online activities and caregiver needs would vary by the phase in the illness trajectory the ill family member was experiencing. While caregiver needs and online behaviors did vary over time, interviews indicated that the caregivers followed similar Internet use patterns regardless of illness trajectory. When analyzing the data, the researcher did not find patterns that fit the trajectory proposed in chapter two. The researcher looked for patterns and asked questions about what got the caregiver started using the Internet and what had changed over time. Regardless of the point of the illness trajectory for the ill family member, the caregivers almost all began looking for information. For a few caregivers, that remained their focus. Others began looking for other things such as products or emotional support although the degree and timing of the search for other things varied widely.

The researcher's focus on disease aspects of the trajectory was too narrow and care-recipient focused. The phenomenon of caregiver Internet use was more complex than initially thought. Many factors influenced caregiver Internet use, including geographic proximity, phase of the family member's illness, individual caregiver needs, contextual factors in the caregiving situation and how comfortable caregivers felt using the Internet. With this small a sample, it is possible that there were insufficient numbers to identify any trajectories that might or might not exist. This will be an area to focus on more specifically in future studies.

Caregivers initially searched broadly with search engines, gradually found trustworthy sites they felt comfortable with and returned to and narrowed their searches over time. It is possible that the more important factor was not trajectory—although needs did change with changes in family member's disease status—but rather patterns of seeking information, resources, social support, and products online. This should be explored in future studies.

Additional Implications

A number of areas for future research have been described in this chapter. The phenomena of caregiver experiences online has many areas yet to be explored. The number of caregivers online will only grow in future as trends of an aging, increasingly ill, and medical technology dependent population cope with fewer resources. There are also implications from this study for administration, education, and practice.

Caregivers are going online. It is already happening and health-care providers need to catch up with what consumers are doing in order to provide services appropriately. Policies need to be developed to address how nurses will use and interact with caregivers who are online. When educating the caregiver, questions such as whether or not the nurse should provide particular web sites as part of her practice need to be addressed. Certainly nurses should provide information on searching and evaluating web content.

Internet site content is fluid, not static as printed handouts or booklets are. Identification of nurse responsibility and accountability for providing a link to a site with such fluid content must be made. What happens if the web site provides information or caregiving suggestions which are inaccurate or harmful? Policies also could be developed if the nurse/organization decides to host a web site caregivers will use. Reasons providers are not referencing the Internet in patient and caregiver education can be explored and addressed in future studies, policies, and practice as well as staff education. Protocols, legislation, and procedures will need to be developed to assure quality and accessibility of care and define scope of practice for nurses dealing with patients, caregivers, and the Internet in their practices.

Nurses will be seeing more caregivers coming to them with information acquired from the Internet. Some ways nurses can modify their practice with Internet using caregivers have been suggested earlier in this chapter. Nurses need to become knowledgeable about the Internet, its strengths and limitations, and what it has to offer caregivers. The majority of nurses do not need to be able to set up a web site for caregivers or actually perform more complex tasks. However, they should know the appropriate information technology resources to consult. Being able to refer caregivers to specific sites, teach them what to look for in terms of quality of information, and what cautions to observe are areas in which nurses can assist caregivers.

The Internet is emerging as a new practice arena for nurses. Some sites have nurses or other health-care providers who give advice to queries from patients or caregivers online. Given the expressed desire of this sample for practical caregiving tips and ways to live with a family member's chronic illness, nurses may be ideally suited to providing online services to caregivers. Nurses can also use their knowledge of case management and community resources to the benefit of caregivers.

Methodological Implications

Online Data Collection

The study design used online data collection and telephone interviews. A body of literature about conducting research using online surveys in health sciences is emerging. Concerns tend to focus on several areas: (a) access to subjects who are appropriate for the study, (b) protection of human subjects, and (c) quality of the data collected in addition to traditional concerns of survey design. Yun (2001) found that there were no differences in response rates among a survey conducted using mail, e-mail, and web data collection strategies. Both Yun's study and another study (Dillman, Phelps et al., 2003) examining mixed mode surveys with mail, telephone, interactive voice response, and the Internet found that the method of collecting data can influence survey responses by study participants. How selection of an online and telephone interview of data collection may have influenced respondents in the current study is unknown. It is possible that caregivers would have described their experiences differently with a different data collection method. It is also possible that response rates both to individual items and the study in general were diminished by the method of questionnaire administration. Completing or finding the survey online may have been too difficult for potential participants, particularly novice users, who were underrepresented in this sample.

The study did attempt to take into account cautions and recommendations for designing surveys online (Dillman & Bowker, 2003; Dillman, Tortora, & Bowker, 2003). Design and layout decisions were made such as using a "scroll" feature rather than a "click to the next page" feature for the survey. Because the survey was brief and information in one part of the survey should not have influenced later answers, the scroll feature had the advantage of letting participants know how close they were to the end of the survey. The web site included e-mail and phone contact information. Readability of content, layout of web pages, amount of content per page, font, ease of navigation, range of browser speed, and faster loading times resulting from a simpler design without animation or effects and only one picture were some considerations in site design gleaned by the researcher from the articles cited here. During the course of the study, only one potential participant contacted the researcher with a request for information about navigating the site. None of those interviewed mentioned any problems with the online survey questionnaire.

Human subject protection is another concern in the design of the study. A recent article (Im & Chee, 2002) discusses the rising rates on research conducted online and issues with human subject protection when conducting online research. Several areas were of concern:

- anonymity,
- confidentiality,
- security,
- the right to self-determination,
- full disclosure and
- fair treatment

The study was designed so that those completing phase one could be anonymous. There was no tracking of web sites they responded to the survey from. The survey did not ask for a name unless the participant was willing to be interviewed. Most of those who responded with an e-mail address if interested in being interviewed used a screen name and not their proper name. The data were kept on secure, password-protected computers. Only the researcher had the password.

Study participants were not given any inducement to participate beyond adding to existing knowledge. Brief messages were posted on web sites with a family caregiver focus. The potential participants were able to choose whether or not to then visit the research web site. More subjects may have been recruited for this study if more aggressive recruitment techniques were used. For example, there could have been an incentive offered to participate in the study. It was felt that this might compromise the study as some who were not caregivers might be more inclined to participate for remuneration. The possibility exists that some of those who completed the survey were not, in fact, eligible for the study. While the potential exists in any survey, the culture of anonymity on the Internet makes this of special concern because anyone could pretend to be a caregiver on the Internet. There was no way to validate that those participating in the study were actually caregivers. The researcher tried to minimize this by carefully selecting sites to post information about the study and by clearly listing eligibility criteria.

An additional area of concern was the informed consent form. The researcher had no way of knowing if the participants actually read the form. There was also no signed consent form. Consent was by e-mail or web site. The researcher tried to ensure informed consent by making a separate page with the consent form, putting the link to the survey questionnaire at the bottom of the consent page, and only linking to the study from the consent page. The researcher also included questions about the consent for phase two subjects in the call script. The study was felt to be minimal risk and no one contacted the researcher with any concerns. Researchers who conduct research online must pay special attention ways in which the Internet can be used to minimize risks and maximize protections of human subjects.

Telephone Interview

The telephone interview had benefits and limitations as a method of data collection. At the time the study was designed, Internet connections were less stable, e.g. the interviewee could be "bumped" off their Internet Service Provider during the interview. The researcher decided that collecting data in an online chat might be less efficacious at that time than collecting the data by telephone. Until the study data were analyzed, the researcher did not realize that all but one phase one subject had Internet access at home. The researcher felt that a telephone interview could occur in the home and thus afford more privacy for the interview. More privacy could increase the willingness of the participant to disclose information and thus improve the quality of the data. Two of the interviewees chose the workplace as the site for the interview but the rest were all at home. One of the two work site interviewees did not allow for privacy and there were work-related interruptions. Three of the caregiver at home interviews had interruptions, so home or work as a site of data collection may not have mattered much in terms of an uninterrupted interview time. Collection of data by telephone also allowed for hearing tone of voice, pauses, and other verbal cues that could be helpful in during the interview and data analysis. Those verbal cues were helpful in the analysis and the researcher believes outweighs the benefits of conducting an online interview unless emoticons or probes to assess emotional tone and meaning are developed and used during the interview. However, the online chat interview format has the advantage of immediate and 100% accurate transcription. It might be possible in future studies to conduct the entire study online using online questionnaires and chat interviews.

As much as possible, the study design minimized areas of weakness and capitalized on strengths of using communication technology to collect the data. Quality and validity of data were also an important issue. For example, because data were collected online, the researcher can be sure that survey respondents were Internet users. The researcher could not be sure, however, that everyone who participated in the study was actually a family caregiver.

Recommendations for Future On-line Studies

Based on the response rate per e-mail mail out, larger numbers of phase one solicitation to web sites to post study information on their site could yield a more rapid response rate. Sufficient time should be set aside to screen selected sites and send out requests. During this study, approximately 1 to 2 hours was needed to obtain every 10 sites that were eligible to participate in the study. A smaller percentage of those sites actually agreed to post a link to the research site. Generating a large pool of potential sites can lead to a more representative sample, but also leads to less relevant sites having to be eliminated by the researcher. Given the responses in this study, although creating it would be time and effort consuming, a larger site pool would probably yield better responses from caregivers.

Giving sites approximately 10 working days to respond worked best in the study: more time and the request was ignored, less time and vacations and other issues came up in return e-mail responses indicating that the time was insufficient. Posting for only 1 month may not allow sufficient time to capture potential participants. Future studies might find posting for 2 to 3 months more successful at recruiting a larger sample.

Based on the timing of web site postings and the responses afterward, sites of a variety of sizes attracted participants. The sites that agreed to post information on their web page about the study also varied in size. Randomizing the list was a way to increase the representativeness of the sample and should be used in future studies. Relevance ranking did not necessarily indicate that the site was actually family caregiver focused or that the site would agree to post information about the study. Relevance ranking was of limited utility in the study search for caregiver web sites.

The researcher noted that many sites specifically requested information about study findings. Sites were given assurances that a summary would be made available to them. Caregivers interviewed also asked about the results. After several interviews where this occurred, at the end of each interview, the researcher asked the participant is they would like a summary of study findings. All participants wanted to see the results. While the participants did not know they would be offered the results before participating, it may encourage more participation in other web-based studies if they can see how their contribution could be used to help others.

Assurance of technical support is an issue for this and other studies. The periods of time where the study web site was down could have resulted in an unknown number of potential subjects being unable to participate. The researcher checked the site several times a day but was unable to immediately identify and rectify some of the downtimes. After the hosting site upgraded hardware and software, the study site became more stable. How the data and findings were affected by these downtimes is unknown.

The results from this study, like the sample, had some areas that were consistent and other areas that were not consistent with previous knowledge. New information also emerged.

Strengths and Limitations of Intensive Interviewing

One of the strengths of Intensive Interviewing was that it is possible to get considerable breadth or depth of information. There was a balance between depth and breadth. For the purposes of this study, sampling techniques such as maximum variation sampling were used to obtain as much breadth as possible across multiple participants. Intensity sampling added more depth. There was less depth in the study than would have existed in a study that focused more deeply on fewer participants. This was viewed as an acceptable tradeoff in this study because the phenomenon of interest was fairly narrow and the goal was to understand the experiences of a variety of family caregiver Internet users. Because use patterns were variable and centered around care needs, and because observation of actual internet use was not feasible or very enlightening, Intensive Interviewing provided a way to understand the experiences of family caregivers' Internet use.

Generalizability was not one of the goals of the Intensive Interviewing method used in the study. Information gained from the study had temporal and contextual limitations (Schwandt, 2000). However, the findings do apply to other people who share similar contextual frames with study participants.

A strength of Intensive Interviewing was the rich, contextually based findings that emerged from the study data. Intensive Interviewing data analysis procedures helped keep the researcher close to the data so that study findings were grounded in the data and authentically reflected the participants' experiences. Some aspects of the experience may not have been communicated to or understood accurately by the researcher. The participants may not have been able or willing to express parts of their experiences. However, the study did deal with controversial or deeply personal issues, so the participants' willingness to share their experiences was less limited than with other studies of social phenomena that are more sensitive. The researcher made every effort to put the interviewee at ease during the interview.

While efforts were made by the researcher to be sensitized to and sensitive to the experiences participants described, language had some inherent limitations as a tool for understanding. What either the participant or researcher said during the interview was shaped by their own understanding, agenda, and context. Language could also have been inadequate to capture the full expression of the phenomenon. Because the data obtained using Intensive Interviewing were language based, the limits associated with language as a tool affected data collection, analysis, and findings. In addition, because the participants were not observed directly, the researcher had to rely on their recollections of prior events and how they conveyed those recollections in their narrative accounts.

A final limitation was that people say and do different things in different situations. The research experience, however much the researcher tries to make it conversational, was still not entirely natural (Bogdan & Taylor, 1998). The participants were aware that they were participating in a research study and that affected what they said and how they behaved

Trustworthiness

In ensuring trustworthiness in the phase two qualitative research portion of the study, the researcher selected from a variety of techniques to strengthen the quality of the research. Qualitative research has been criticized for having superficial descriptions as study results, missing key aspects of the data, or getting completely lost in all the data. This section will describe trustworthiness procedures and rationales used in this study.

Persistent observation related to being immersed in the data collection and analysis long enough and deeply enough to be able to identify the salient aspects of the study, determine which aspects were relevant and important, and set aside the trivial. The amount of time spent conducting the interviews and going back and forth between data collection and data analysis was an important part of satisfying the persistent observation criterion. Persistent observation can help the researcher avoid premature closure, a danger in qualitative research. Data were collected from August 2002 to June 2003.

According to Lincoln & Guba (1985), member checks are the most critical technique for establishing trustworthiness. Because member checking is critical, and because it was used at multiple points in the study, member checks are discussed in more detail here. Member checks helped clarify and guide both data collection and data analysis. Member checks were conducted during an interview when the researcher asked the participant to clarify something said or rephrased and repeated back what the researcher believed the participant said, then asked for confirmation. The participant then verified the accuracy of the researcher's understandings or elaborated on those understandings.

A more difficult issue was the process of member checking emerging data analysis. After multiple interviews, it was possible to begin asking participants to respond to emerging understandings. For example, the researcher could say " Some other people I have talked with have mentioned X. Have you also experienced that?" While this was a valuable way to check the accuracy of understandings about the phenomena, it could also lead to responses that did not accurately reflect the experiences of the participant. This could happen either because the participant was trying to give the researcher what the participant thought the researcher wanted or because the understanding was not yet fully developed or may not prove to be salient in later analysis. Member checks were done very carefully. The last three interviews in particular provided opportunities to summarize and check emerging researcher understandings.

When data are reported, *transferability* must be addressed by providing enough data for the reader to determine whether the study findings apply to their context and situation. Demographic data provided helped describe the sample so that readers can make informed decisions as to whether or not study participants and their context were similar enough to apply in another setting with different people. Reporting findings with as much depth of contextual information as possible helped the reader make that judgment.

Confirmability is the final criterion for trustworthiness that was used in this study. Confirmability relates to the procedures followed during the research so that someone looking at the study could follow how the researcher conducted the study, why decisions such as whom to interview were made, how data were analyzed, and how conclusions were developed. In order for a reader to place credence in study findings, it was necessary to have sufficient evidence that procedures such as field note taking and the use of an audit trail were part of the study. That evidence was included in the research log, on transcripts, and in field notes.

Summary & Conclusion

Caregivers in the study were primarily female, well educated, white and experienced in both caregiving and Internet use. Future studies with other groups would add to knowledge about caregiver Internet experiences and help to design Internet sites that could be useful for caregivers. Themes identified in the study can be helpful in identifying content and features that are useful to caregivers. Further studies have been suggested to explore the experiences of online caregivers.

Appendix A

Banner Script

The description to be placed on the web site will read: "I am a doctoral student named Danita Ewing studying family nursing at Oregon Health and Science University. I am conducting a study of family caregivers who use the Internet to support their care-giving. The purpose of the study is to learn how using the Internet is or is not benefiting family caregivers in order to design web sites for caregivers which can help meet their needs. Please visit the study web site at http://www.familycaregiverinternetstudy.net/ to learn more about the opportunity to participate in this study."

Appendix B

Web-Site E-Mail Contact Script

My name is Danita Ewing. I am contacting you because you have a web site relating to family caregiving. I am a doctoral student in family nursing studying how family caregivers use the Internet and what effect it has on them as caregivers and on their caregiving. I would like to ask you to post a few sentences about my study on your site for a month.

What I would like you to post would read as follows: "I am a doctoral student named Danita Ewing studying family nursing at Oregon Health and Science University. I am conducting a study of family caregivers that use the Internet to support their care-giving. The purpose of the study is to learn how using the Internet is or is not benefiting family caregivers in order to design web sites for caregivers which can help meet their needs. Please visit the study web site at http://www.familycaregiverinternetstudy.net/ to learn more about the opportunity to participate in this study."

Please feel free to visit my site and take a look to help you decide on adding this to your web page. If you have any questions about the study, please contact me at ewingd@ohsu.edu. Thank you for taking the time to consider adding this to your site. It would be very helpful if you could return e-mail me to let me know by (date) if you agree to have this information posted on your site.

Appendix C

Study HomePage

Study Home Page URL: www.familycaregiverinternetstudy.net

Welcome to the Family Caregiver Internet Experiences Study HomePage.

What is this study about and why is it important?

Family caregivers in the U.S. are increasing in number, with about a quarter of U.S. households having at least one family caregiver. Many factors are adding to the growing number of family caregivers. At the same time, the demands on family caregivers are getting more complex while the traditional health care system is offering fewer resources. Some family caregivers are turning to the Internet to help them in their caregiving. Family caregivers experiences when they use the Internet and how those experiences affect them and their caregiving has not yet been studied. By taking part in the study, you would help add knowledge about what kind of caregivers are using the Internet, the kinds of caregiving problems caregivers go online to solve, caregiver needs that can or cannot be met by going online, how going online impacts your caregiving, and the kinds of Internet based tools (chat rooms, e-mail, search features) that are used by caregivers. In addition to generating a description of caregiver experiences going online, the study will serve as a starting point for future research and the development of web based services for family caregivers.

What happens in the study?

The study is in two parts. Taking part in the first part does not mean that you agree to take part in the second part of the study. The first part of the study involves filling out a questionnaire on-line. You can chose to be completely anonymous when you send in the questionnaire. The questionnaire will take about 15 to 20 minutes to fill out and includes a few questions about you (such as your age and gender), questions about your experience on the Internet (such as how long you have used the Internet) and questions about your caregiving situation (such as types of activities that you do for your ill family member).

At the end of the questionnaire, there is an option for you to enter an e-mail address to find out more about the second part of the study. The second part of the study will involve telephone interviews with a smaller number of people. The goal of the telephone interviews is to learn more about what is going on in the caregiver's situation when they use the Internet and what things are or are not helpful to caregivers. Since one of the goals of the study is to gain as broad a picture of caregivers as possible, people from different groups who are willing to participate in interviews will be selected. For example, people with different levels of Internet experience and caring for different family members would be selected.

Am I eligible to be in the study?

To be eligible to participate in this study, you must be:

1) at least 18 years of age,
2) a family caregiver for a family member who has been ill for at least 3 months,
3) currently using the Internet and a family caregiver web site as part of caregiving,
4) an English-speaking U.S. citizen or resident alien, and
5) willing to complete a research questionnaire for the first part of the study and to potentially participate in the second interview phase of the study.

If you would like to participate in the study, please click here to find out more information. If you have additional questions about the study, please contact me at ewingd@ohsu.edu or contact my dissertation committee chair, Dr. Christine Tanner at tannerc@ohsu.edu. If you would like more information about my background, please click here to view my biosketch (link).

Appendix D

Phase One Consent

Oregon Health & Science University

The title of the study is the Family Caregiver Internet Experiences study.

Principal Investigator: Danita Lee Ewing, RN, MS, Doctoral Candidate

(503) 494-3865

Sponsor: Dr. Christine Tanner RN, PhD

(503) 494-3742

Purpose:

The purpose of the study is to learn about the experiences of family caregivers who go on line and to describe which family caregivers are using the Internet. You have been invited to participate in this study because you are caring for an ill family member and using the Internet to support your caregiving.

Procedures:

If you agree to participate in the first part of this study, you will be asked to fill out a questionnaire that should take about 15 minutes. The questionnaire will ask you for information in three areas; information about yourself, your Internet experience and your caregiving situation.

Potential Risks and Benefits:

It is not anticipated that there are any risks to you for taking part in the study. Some of the questions may seem personal and deal with private information. If you do not wish to provide that information you do not have to. Further, if you decide you do not wish to take part in the study, you can leave the web site at any time. While it is not anticipated that you will benefit directly from taking part in the study, your participation will add to the knowledge about family caregivers and their experiences using the Internet.

The information you provide in the questionnaire will be grouped together with other people's information so that your identity is protected. Neither your name nor identity will be used for publication or publicity purposes. There is no cost to you if you chose to take part in the study.

Danita Lee Ewing (503) 494-3865 has offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health & Science University at (503)- 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health & Science University. You may print out or save a copy of this information.

Please click here if you agree to take part in the study and you will be taken to the questionnaire.

Appendix E

Biosketch

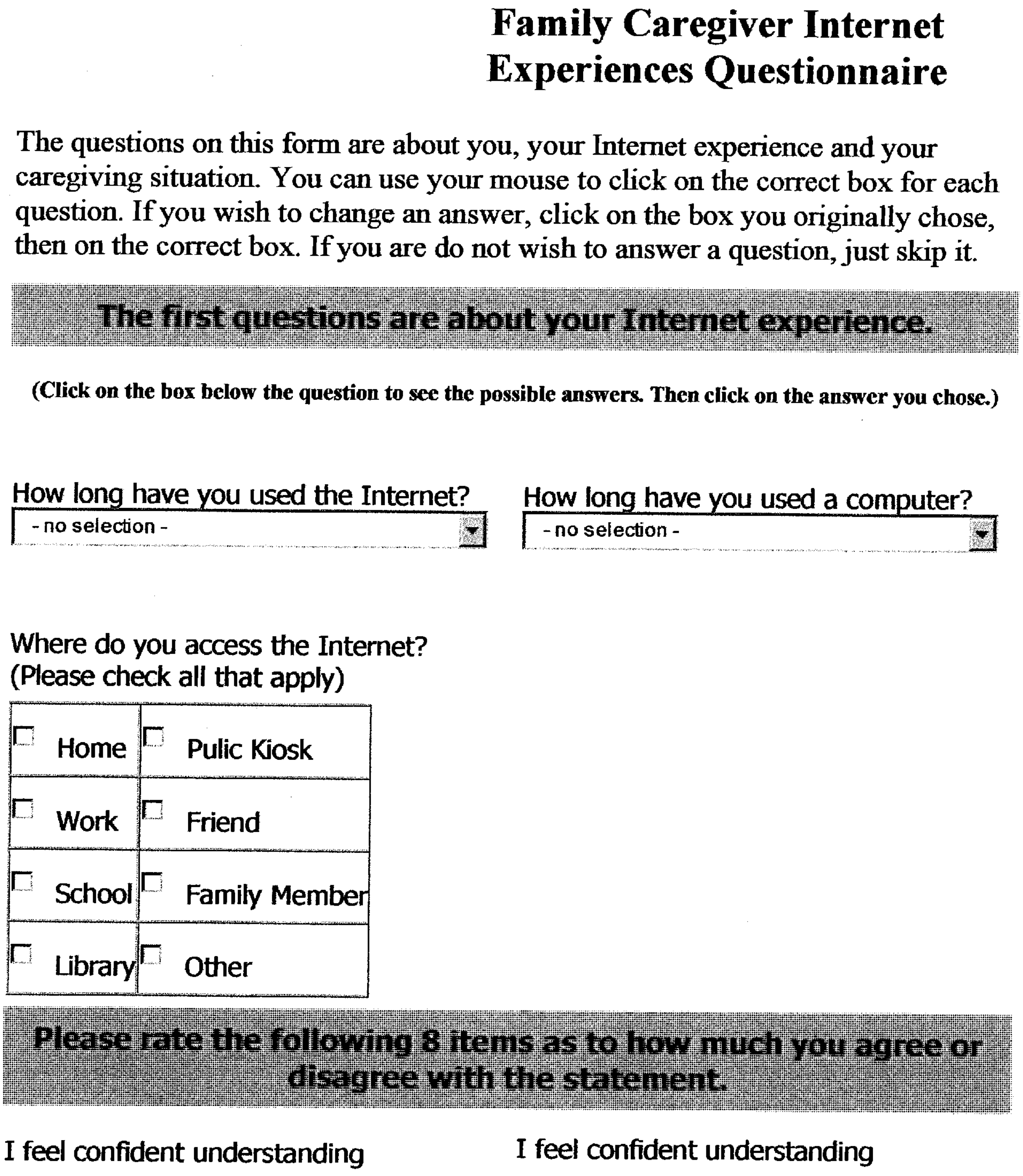
I am a doctoral student completing my fourth year of doctoral study. The chair of my dissertation committee is Dr. Christine Tanner. My program of study has been supported in part by an institutional National Research Service Award and by Sigma Theta Tau International, Beta Psi Chapter. Sigma Theta Tau is a nursing honor society of which I am a member. I am also a member of the American Association of Critical Care Nurses.

Most of my clinical background is in critical care, home health and hospice. I have also taught Medical and Surgical Nursing, Critical Care and Community Health Nursing. While working in those areas, I worked with a lot of families. I was very impressed by what family caregivers were able to do for their ill family members. I was also worried by some of the trends I was seeing in the health care system and wondered about finding ways to better support family caregivers.

An encounter with a patient who was using the Internet lead me to wonder about what caregivers might be doing online and how their experiences was affecting them and their caregiving. That led me back to school for a doctorate specializing in family nursing and minoring in informatics. (Nursing informatics is blending nursing science with information and computer science.) My goal is to eventually design web pages that are helpful to family caregivers taking care of family members with different kinds of chronic illnesses.

Appendix F

Web Questionnaire



Family Caregiver Internet Experiences Questionnaire

The questions on this form are about you, your Internet experience and your caregiving situation. You can use your mouse to click on the correct box for each question. If you wish to change an answer, click on the box you originally chose, then on the correct box. If you are do not wish to answer a question, just skip it.

The first questions are about your Internet experience.

(Click on the box below the question to see the possible answers. Then click on the answer you chose.)

How long have you used the Internet?
- no selection - ▾

How long have you used a computer?
- no selection - ▾

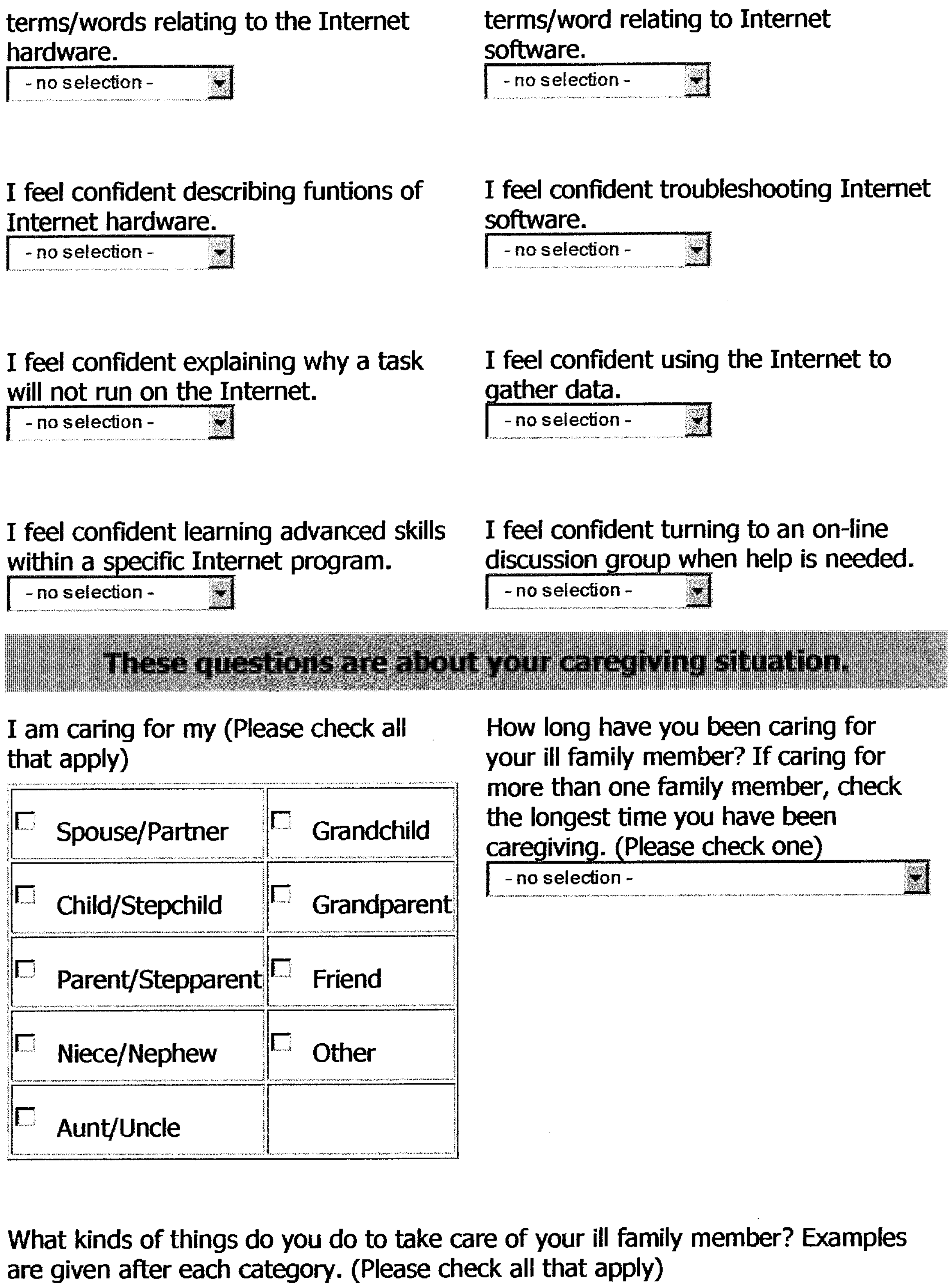
Where do you access the Internet?
(Please check all that apply)

☐ Home	☐ Pulic Kiosk
☐ Work	☐ Friend
☐ School	☐ Family Member
☐ Library	☐ Other

Please rate the following 8 items as to how much you agree or disagree with the statement.

I feel confident understanding

I feel confident understanding



terms/words relating to the Internet hardware.

- no selection -

terms/word relating to Internet software.

- no selection -

I feel confident describing funtions of Internet hardware.

- no selection -

I feel confident troubleshooting Internet software.

- no selection -

I feel confident explaining why a task will not run on the Internet.

- no selection -

I feel confident using the Internet to gather data.

- no selection -

I feel confident learning advanced skills within a specific Internet program.

- no selection -

I feel confident turning to an on-line discussion group when help is needed.

- no selection -

These questions are about your caregiving situation.

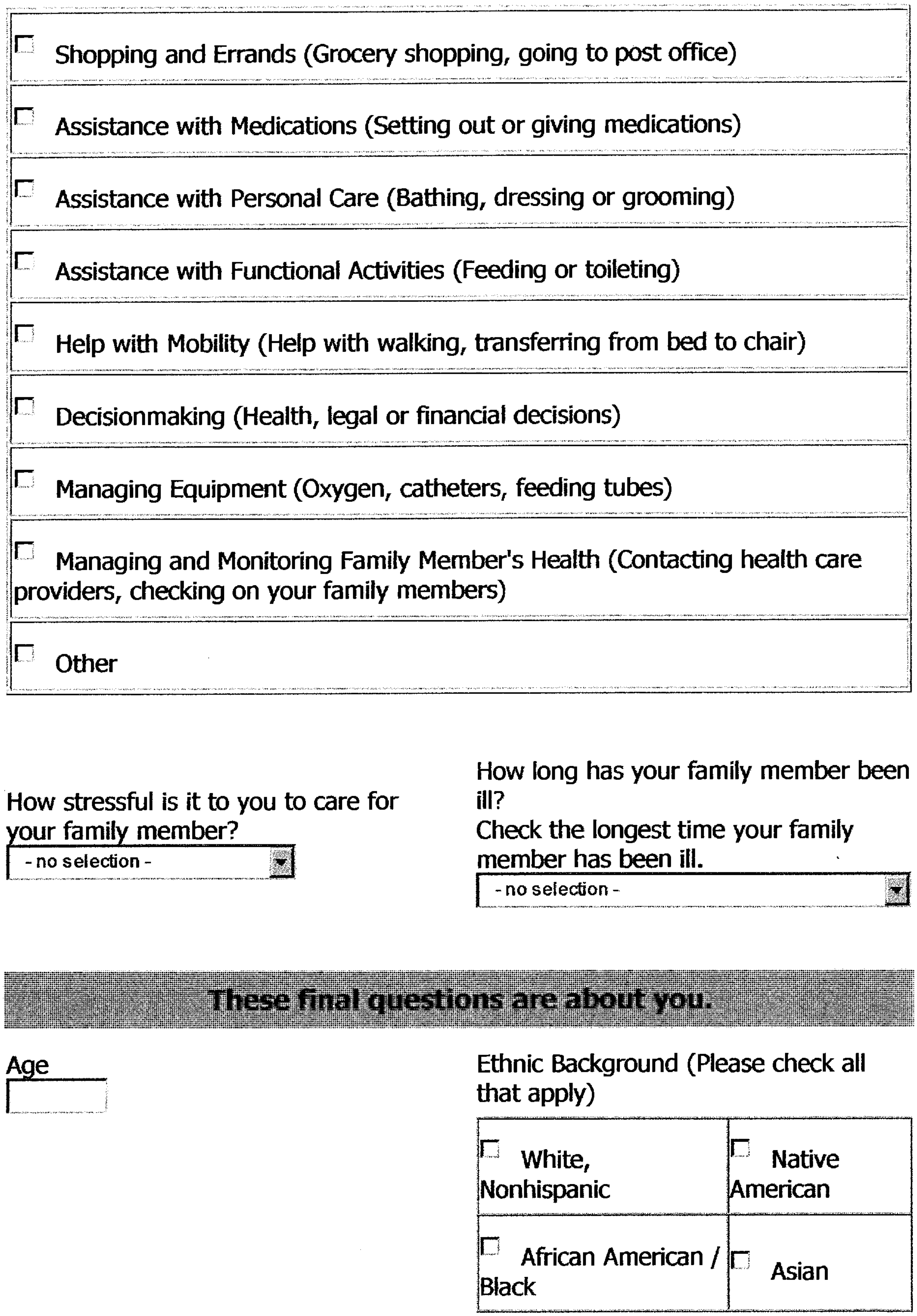
I am caring for my (Please check all that apply)

☐ Spouse/Partner	☐ Grandchild
☐ Child/Stepchild	☐ Grandparent
☐ Parent/Stepparent	☐ Friend
☐ Niece/Nephew	☐ Other
☐ Aunt/Uncle	

How long have you been caring for your ill family member? If caring for more than one family member, check the longest time you have been caregiving. (Please check one)

- no selection -

What kinds of things do you do to take care of your ill family member? Examples are given after each category. (Please check all that apply)



☐ Shopping and Errands (Grocery shopping, going to post office)

☐ Assistance with Medications (Setting out or giving medications)

☐ Assistance with Personal Care (Bathing, dressing or grooming)

☐ Assistance with Functional Activities (Feeding or toileting)

☐ Help with Mobility (Help with walking, transferring from bed to chair)

☐ Decisionmaking (Health, legal or financial decisions)

☐ Managing Equipment (Oxygen, catheters, feeding tubes)

☐ Managing and Monitoring Family Member's Health (Contacting health care providers, checking on your family members)

☐ Other

How stressful is it to you to care for your family member?

- no selection -

How long has your family member been ill?
Check the longest time your family member has been ill.

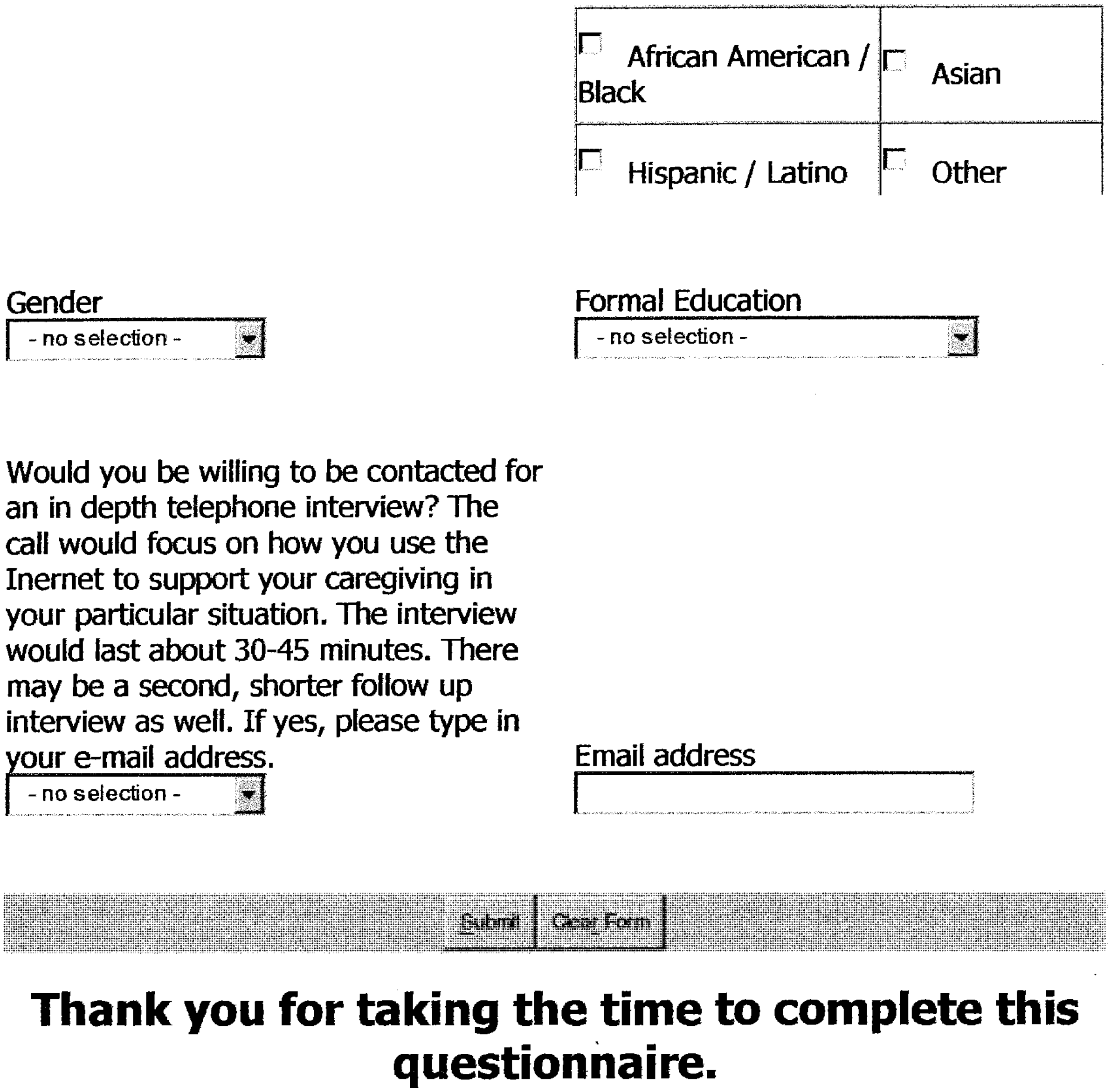
- no selection -

These final questions are about you.

Age

Ethnic Background (Please check all that apply)

☐ White, Nonhispanic	☐ Native American
☐ African American / Black	☐ Asian



☐ African American / Black	☐ Asian
☐ Hispanic / Latino	☐ Other

Gender
- no selection -

Formal Education
- no selection -

Would you be willing to be contacted for an in depth telephone interview? The call would focus on how you use the Inernet to support your caregiving in your particular situation. The interview would last about 30-45 minutes. There may be a second, shorter follow up interview as well. If yes, please type in your e-mail address.
- no selection -

Email address

Thank you for taking the time to complete this questionnaire.

Appendix G

Script E-mail Contact with Phase Two Participants

Thank you for your interest in this study. Below is information about the study in more detail. If you have any questions please contact me by phone or e-mail at the number or address listed below. If you would like to participate in the study, please send me an e-mail so we can set up a convenient time for the call.

Oregon Health & Science University

The title of the study is the Family Caregiver Internet Experiences study.
Principal Investigator: Danita Lee Ewing, RN, MS, Doctoral Candidate
(503) 494-3865
Sponsor: Dr. Christine Tanner RN, PhD
(503) 494-3742

Purpose:

The purpose of the study is to learn about the experiences of family caregivers who go on line and to describe which family caregivers are using the Internet. You have been invited to participate in this study because you are caring for an ill family member and using the Internet to support your caregiving.

Procedures:

If you agree to participate in the second part of this study, you will be asked to provide a phone number where you can be contacted and times that are convenient for you to be interviewed. The interview should take about 45 minutes. During the interview, you will be asked questions such as how you started using the Internet as part of your caregiving, what features of the Internet you use (chat-rooms, e-mail, search engines) and how they affect your caregiving, and what is happening with your caregiving situation that led you to use the Internet.

Potential Risks and Benefits:

It is not anticipated that there are any risks to you for taking part in the study. Some of the questions may seem personal and deal with private information. If you do not wish to provide that information you do not have to. If you become upset by any of the questions, a referral will be made to your health care provider. Further, if you decide you do not wish to take part in the study, you can stop the interview at any time. While it is not anticipated that you will benefit directly from taking part in the study, your participation will add to the knowledge about family caregivers and their experiences using the Internet.

Neither your name nor identity will be used for publication or publicity purposes. The interviews will be audiotaped and the audiotapes erased at the end of the study. Under Oregon law, suspected child or elder abuse must be reported to appropriate authorities. There is no cost to you if you chose to take part in the study.

Danita Lee Ewing (503) 494-3865 has offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health & Science University at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health & Science University. You may print out or save a copy of this information.

Appendix H

Telephone Script and Interview Guide with Probes

The interview guide will begin with a script for the researcher to start the interview.

Initial Phone Script:

Call will be made at mutually agreed upon time from a location where the interviewer can be assured of privacy.

Phone Rings.

Hello, is this (name person has asked to be called)?

<u>If no,</u>

ask if that person is available to come to the phone. If not, thank the person for their time and say good bye. E-mail the potential interviewee later and set up another appointment.

<u>If yes,</u>

Hello, this is Danita Ewing. I am the researcher with the Family Caregiver Internet Experiences study. We had set this as the time for our interview. Is now still a good time for you?

<u>If yes,</u> continue.

<u>If no,</u> reschedule.

Did you have a chance to read the consent form I sent you?

<u>If yes,</u> continue script.

<u>If no,</u> ask if they would like the consent read to them. If they would, read.

Do you have any questions about participating in the study?

If yes, answer all their questions until none remain.

If no, continue.

Do you agree to participate in the study?

If yes, continue.

If no, thank them for their time and say good bye

I just wanted to remind you before we get started that I will be tape recording the call but the tape will be erased at the end of the study.

Appendix I

Interview Guide Questions and Sample Probes

I would like to ask you some questions about your experiences using the Internet as a family caregiver. Some of the questions will be about your caregiving and some about how the Internet fits in with your caregiving.

1. What got you started using the Internet in your family caregiving?

What was happening with X (care recipient) at the time you started to use the Internet?

What were you looking for when you first went online?

Has your caregiving situation changed since you first went on-line, and if so, how? Have the ways you use the Internet also changed? Can you give me an example?

The first question gives the person a place to start the interview with a fairly neutral question. The question also gathers contextual data about the factors that started the caregiver using the Internet and how long ago it was.

2. What are the benefits of using the Internet to you as a family caregiver?

You told me earlier that you have been caring for you ______for _______? What kinds of things do you do for _____? Can you give me some examples of how using the Internet helped you do those things?

What do you value most about going on-line?

Where do you find what you are looking for on-line?

What features make a good site on the Internet for you? Can you give me some examples of what makes a good site for you?

How do you decide what information to trust? Can you describe a situation where you were looking for information on-line and how you decided what to do with what you found?

The second question provides data about what the caregivers gain by using the Internet in their caregiving and identifies what caregivers find useful or helpful about going online.

3. What are the limitations of using the Internet to you as a family caregiver?

Have you had any problems using the Internet?

Can you give me an example of something you need as a caregiver that you sought but couldn't get on-line?

Please give me an example of a time using the Internet didn't help you as a caregiver.

What other resources had/have you tried?

Who else do you talk to or rely on?

The third question provides data about what caregivers are not gaining by using the Internet and identifies technical problems and other barriers to Internet use.

4. What kinds of things do you do when you are on-line as a caregiver?

The fourth question provides data about the kinds of activities (e-mail, searching, chat rooms) that caregivers use as part of their caregiving.

What do you do most often when you are on-line as a caregiver?

Describe for me what you would typically do when you are online as a caregiver.

How do you evaluate what you find on-line?

5. What would you tell a family caregiver that hasn't used the Internet before about using the Internet?

The fifth question provides an opportunity for caregivers to share practical tips and advice that could be used for other caregivers.

6. Is there anything else you want to tell me about using the Internet to support your caring for your family member?

The final question is an open-ended question to let the caregiver add anything else about caregiving experiences on the Internet that has not already been covered in the interview.

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