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ALZHEIMER'S DISEASE AND RELATED DISORDERS CAREGIVER'S ACCEPTANCE OF A WEB-BASED STRUCTURED WRITTEN EMOTIONAL EXPRESSION INTERVENTION

by

Ji Woon Ko

An Abstract

Of a thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Nursing in the Graduate College of The University of Iowa

December 2011

Thesis Supervisor: Associate Professor Howard K. Butcher

ABSTRACT

Alzheimer's Disease and Related Disorders (ADRD) are a major public health problems. Major sources of care provision are family members in the community and these ADRD caregivers encounter a variety of stressor. Currently there continues to be a need to develop and test Internet based interventions designed to reduce stress for caregivers for persons with ADRD. The web-based Structured Written Emotional Expressions (SWEE) was developed to manage ADRD caregivers stress related to caregiving experiences through writing about their thoughts and feelings. However, differences between provided services by researchers (the web-based SWEE) and the desired services of ADRD caregivers could be a barrier to ADRD caregivers' acceptance and use of the web-based SWEE.

The purpose of this study was to assess the acceptability of implementing a webbased nursing intervention for ADRD caregivers and to describe participants' experiences in using the website to understand ADRD caregivers' website usage.

An experimental design was used to determine whether the web-based SWEE helped to manage ADRD caregivers' stress through writing interventions. In addition, the UTAUT model was employed for a theoretical framework to explain and predict the web-based SWEE usage behavior by ADRD caregivers. The Finding Meaning Through Caregiving Scale (FMTCS) was used to evaluate finding-meaning related to caregiving experiences as a mediator between performance expectancy and behavioral intention to use in the UTAUT model. Furthermore, the web-based research methods were assessed throughout the web-based SWEE implementing process.

Both web-based and paper-based methods were used for recruiting potential participants. Most people who contacted the researcher were recruited by the web-based method. Structural Equation Modeling (SEM) was used for test ADRD caregivers' acceptability of the web-based SWEE and direct content analysis was used for describing participants' experiences in using the web-based SWEE.

Fifty people completed the study out of the 90 people who enrolled. Of these 50 participants, 31 completed the study as intended and on schedule. The research showed a good model fit with a Chi-square value (df=43) of 57.191 (p>0.05). The findings showed that performance expectancy had a significant effect on participants' behavioral intention to use (β =0.620, p<0.01) and that effort expectancy also affected the behavioral intention to use the web-based SWEE (β =0.293, p<0.01). Performance expectancy showed stronger effects than effort expectancy. This model explained 52% of variance in behavioral intention to use. However, the effects of facilitating conditions on actual usage and effects of behavioral intention to use on actual usage were not supported by this research. The finding-meaning measure did not show a significant mediating effect on the relationship between performance expectancy and behavioral intention to use.

Findings suggested that recruitment methods which use the Internet were an effective way to find potential study participants. Regardless of the topic, the writing intervention helped ADRD caregivers to express stress related to caregiving experiences. In addition, the perceived usefulness of this nursing intervention (performance expectancy) and the perceived ease of use (effort expectancy) were two important constructs which predicted and explained the acceptance of the web-based SWEE by ADRD caregivers. Finally, even though the UATAUT model was only partially supported by a good model fit, this study's findings showed the potential of the UTAUT model for providing health consumer information systems in nursing.

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Thesis Supervisor: Associate Professor Howard K. Butcher

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CERTIFICATE OF APPROVAL

PH.D. THESIS

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ABSTRACT

Alzheimer's Disease and Related Disorders (ADRD) are a major public health problems. Major sources of care provision are family members in the community and these ADRD caregivers encounter a variety of stressor. Currently there continues to be a need to develop and test Internet based interventions designed to reduce stress for caregivers for persons with ADRD. The web-based Structured Written Emotional Expressions (SWEE) was developed to manage ADRD caregivers stress related to caregiving experiences through writing about their thoughts and feelings. However, differences between provided services by researchers (the web-based SWEE) and the desired services of ADRD caregivers could be a barrier to ADRD caregivers' acceptance and use of the web-based SWEE.

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An experimental design was used to determine whether the web-based SWEE helped to manage ADRD caregivers' stress through writing interventions. In addition, the UTAUT model was employed for a theoretical framework to explain and predict the web-based SWEE usage behavior by ADRD caregivers. The Finding Meaning Through Caregiving Scale (FMTCS) was used to evaluate finding-meaning related to caregiving experiences as a mediator between performance expectancy and behavioral intention to use in the UTAUT model. Furthermore, the web-based research methods were assessed throughout the web-based SWEE implementing process.

Both web-based and paper-based methods were used for recruiting potential participants. Most people who contacted the researcher were recruited by the web-based method. Structural Equation Modeling (SEM) was used for test ADRD caregivers'

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Findings suggested that recruitment methods which use the Internet were an effective way to find potential study participants. Regardless of the topic, the writing intervention helped ADRD caregivers to express stress related to caregiving experiences. In addition, the perceived usefulness of this nursing intervention (performance expectancy) and the perceived ease of use (effort expectancy) were two important constructs which predicted and explained the acceptance of the web-based SWEE by ADRD caregivers. Finally, even though the UATAUT model was only partially supported by a good model fit, this study's findings showed the potential of the UTAUT model for providing health consumer information systems in nursing.

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CHAPTER I

INTRODUCTION

Health care consumers are increasingly using the internet to search for health information (Evangelista et al., 2006; S. Fox & Jones, 2009; Hassling, Babic, Lonn, & Casimir-Ahn, 2003; Schlachta-Fairchild & Elfrink, 2004; H. Taylor, 2010). Studies estimated that 61 % of adults with access to the Internet have searched for medical information or other information relevant to their health care in 2009 (S. Fox & Jones, 2009). The Harris Poll reported percentage increased from 27% to 76% from 1998 to 2010 of adults who have ever searched the Internet for health or medical information (H. Taylor, 2010)

The growth of seeking health information on the Web is primarily due to the value of convenience, anonymity, and volume of on-line information, often at significantly reduced cost and inconvenience compared to traditional care (Baehring, Schulze, Bornstein, & Scherbaum, 1997; Flatley-Brennan, 1998; S. Fox et al., 2000; Houston, Chang, Brown, & Kukafka, 2001; Kirsch & Lewis, 2004; Powell & Clarke, 2002; Ritterband et al., 2003). For example, anonymity can reduce consumers' embarrassment and anxiety associated with face-to-face interaction so health consumers individually may express their feelings more openly. In addition, computer networks have 24-hour-a-day availability that supports timely access to psychosocial support for consumers when they need it (McKay, King, Eakin, Seeley, & Glasgow, 2001). Because communication over a computer network is written rather than spoken, the sender and receiver do not need to be present at the same time. Messages of emotional and spiritual support and critical information are stored on the network and can be easily retrieved and read (Brennan & Moore, 1994; Brennan, Moor, & Smyth, 1995; Gallienne, Moore, & Brennan, 1993).

Information technologies have an evolving role in creating a connection between patient-to-patient, professional-to-patient support, and self-help approaches. Information technology also has the ability to facilitate highly specialized psychological interventions for people all over the world (Ritterband et al., 2003). Evidence of the growth of the public's use of information technologies can be found in computer networks that are realistic in bridging the gap between self-care deficits and self-care capacity, especially in situations where nursing interventions are required on an intermittent and unpredictable schedule (Dew et al., 2004; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006; Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004; Wilson & Lankton, 2004).

There is growing evidence of the need for health care interventions for caregivers of persons with Alzheimer's Disease and Related Disorders (ADRD) (Beauchamp, Irvine, Seeley, & Johnson, 2005; Flatley-Brennan, 1998; Glueckauf, Ketterson, Loomis, & Dages, 2004; Hsu, 2001; E. Marziali, Donahue, & Crossin, 2005). ADRD are a major public health problem for as many as 4.5 million Americans (Alzheimer's Disease Education & Referral (ADEAR) Center, 2006) with unpredictable clinical courses (Acton & Miller, 1996) and is characterized by memory loss, behavior and personality changes, and a decline in thinking abilities. The major sources of care provision for most persons with ADRD are family members in the community, and the expectation of care will increase significantly as the population ages (White & Dorman, 2000). ADRD caregivers who take care of a seriously impaired person encounter a variety of stressors. Adamiak and Juczynski (2003) found in their research that caregivers of persons with ADRD suffered from chronic stress.

The concept of on-line support groups for caregivers began in the mid-80s and numerous on-line support groups have been created since the late-80s (Brennan et al., 1995; K. A. Smyth & Harris, 1993). As the number of on-line support groups have rapidly grown exponentially, currently there are literally thousands of links to caregiver online support groups including online ADRD caregiver support groups that can be found through internet searches (K. A. Smyth, Rose, McClendon, & Lambrix, 2007).

The internet technology provides ADRD family caregivers a means for social support benefits through online sharing of health information, sharing of emotional support, and the delivery of internet based interventions which help improve psychological outcomes of ADRD caregivers (Beauchamp et al., 2005; Glueckauf et al., 2004; E. Marziali et al., 2005). Participants of online support groups expressed generally positive attitudes to this type of service and got help through an online support group to cope with the stresses of caregiving (Marziali, Donahue, & Crossin, 2005; Rotondi, Sinkule, & Spring, 2005; Wright, 2000). Providing information related to ADRD itself and caregiving strategies including managing stress, enhancing interpersonal communication and family relationships, promoting emotional well-being, and setting and implementing personal caregiving goals decreased caregivers' subjective burden and stress as well as increased perceptions of positive aspects of careigiving (Glueckauf, Ketterson, Loomis, & Dages, 2004; Glueckauf & Loomis, 2003; Beauchamp et al., 2005). On-line ADRD support programs provide an opportunity for caregivers to express their emotions to empathetic listeners when they want (Brennan, 1996). Through this sharing and "venting" process caregivers' burdens can subside (White & Dorman, 2000).

A specialty of web-based applications is designed to deliver nursing interventions to community dwelling populations. For example, the CHIPs program (Computer for Homebound and Isolated Persons) is a program that provides an online community for isolated individuals including elderly citizens, disabled individuals and caregivers (Bradley & William, 2003). Another example is an internet-based psychosocial intervention for heart recipients and their families (Dew et al., 2004). The Internet peer support group for cancer patients in Denmark is a self-guided Internet support group following a week-long rehabilitation program on mood disturbance and adjustment to cancer (Hoybye et al., 2010). ComputerLink, Caregivers' Friend, and AlzOnlin are specialized computer networks designed to provide systematic assistance to ADRD caregivers (Brennan, Moore, Smyth, 1995; Brennan et al., 1991; Beauchamp et al., 2005; Glueckauf, Ketterson, Loomis, & Dages, 2004; Glueckauf & Loomis, 2003).

Statement of Problem

Informal caregivers for ADRD patients meet several challenges and experience a variety of stressors while they provide care for patients with ADRD (Brennan & Ripich, 1994; Pearlin, 1994). Continuing demands from a chronically ill relative without a progressing condition may lead to a high degree of ADRD caregivers' stress and feelings of caregiver burden (Browning & Schwirian, 1994; Farran, 1997; Vitaliano, Young, & Russo, 1991). Traditionally, many community-based and formal health interventions are designed to meet the social, spiritual, emotional, and informational requirements of family caregivers of ADRD patients (Alexy, 2000). However, at least one-half of informal caregivers did not use social support resources even though they could benefit from them. This failure to use resources is because of geographical distance, stigma, time constraints, and inadequacy of professional resources. (Brennan & Moore, 1994; Brennan et al., 1995; Gonyea, 1989; Hekelman, Niles, & Brennan, 1994). The non face-to-face computer network gives them an opportunity to express their feelings while overcoming obstacles related to caregiving situations (Sheese, Brown, & Granziano, 2004). Even though ADRD caregivers desire non-face-to-face services through computer networks, it is not known whether a web-based written emotional expression intervention designed to reduce caregiver stress and burden is a health service desired by ADRD caregivers. Gaps between provided services and desired services could be barriers to ADRD caregivers' acceptance and use of health services. Currently there continues to be a need to develop and test innovative, effective, easy to administer, cost and time effective Internet based interventions designed to reduce ADRD caregivers stress and burden. ADRD caregivers

provide physical, emotional, and environmental support for their loved ones who are cognitively impaired (Brennan, Moore, & Smyth, 1991).

One promising intervention designed to reduce the stress of traumatic experiences is written emotional expression (Pennebaker & Beall, 1986; Pennebaker, 1997; Richards, Beal, Seagal, & Pennebaker, 2000; J. M. Smyth, 1998). Written emotional expression is an intervention in which participants write about their deepest feelings about a traumatic experience in their life (J. M. Smyth, 1998). Writing about traumatic experiences converts the traumatic experience into a linguistic structure, so expressing emotions helps people understand a traumatic experience as an event and then reduces the negative effect which comes from thinking about a traumatic experience (Pennebaker & Beall, 1986). Expressing emotion is very important for mental and physical health (Pennebaker & Beall, 1986; Pennebaker, 1997; Seley, 1976; J. M. Smyth, 1998) in a variety of groups(Pennebaker, 1982; Pennebaker & Beall, 1986; Pennebaker, 1993; Pennebaker, 1997; Sheese et al., 2004; J. M. Smyth et al., 1999; J. M. Smyth, Stone, Hurewitz, & Kaell, 1999). Butcher (2004) found that Structured Written Emotional Expression (SWEE) in a non-internet version of the intervention significantly reduced stress in ADRD caregivers which was measured by cortisol level. SWEE is a writing intervention that is designed to manage stress in ADRD caregivers. In Butcher (2004) study, data collection occurred by visiting the caregivers in their home since ADRD caregivers are often home-bound, however, the writing intervention is also ideally suited to delivery as a web-based nursing intervention (Butcher, 2007).

It is essential to evaluate the reasons why or how end-users accept new information technology systems for developers and/or researchers to successfully implement systems. However, different ideas about useful information systems have appeared among developers and/or researchers and end-users. These differences may be caused by lack of developers' consideration of key factors related to acceptability regarding end-users' aspects. In this proposed study investigating the user acceptance of a web based intervention, the UTAUT (Unified Theory of Acceptance and Use of Technology) from Venkatesh and colleagues (2003) will be used as a means to predict which health care consumers will use web-based nursing interventions and explain what features are related to their choices. The UTAUT also allows for a way to plan and evaluate the feasibility of specific web-based nursing interventions toward fulfilling the needs and wishes of general and specific populations or to seek help from Internet based services. Therefore, despite the excellent potential of the Internet as a nursing delivery medium, its value will not be realized if consumers do not accept it for nursing interventions. Clearly, there is a need to investigate the patients' acceptance of an Internet-based nursing intervention in order to understand the various drivers influencing acceptance (M. K. O. Lee, Cheung, & Chen, 2005; Venkatesh et al., 2003).

Purpose and Aims of Study

The purpose of the study was to assess the acceptability of implementing a webbased nursing intervention for ADRD caregivers and to describe participants' experiences in using the website based to understand ADRD caregivers' website usage. The specific aims for this study were as follows:

Aim 1: Test end-user acceptability of a web-based SWEE intervention designed to reduce the stress and burden in ADRD caregivers (See Figure 1).

The research hypotheses guiding this study were:

- The performance expectancy of the web-based SWEE intervention will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE
- 2) The effort expectancy of the web-based SWEE intervention will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE
- The facilitating conditions will have a positive effect on ADRD caregivers' actual use of the web-based SWEE

- ADRD caregivers' behavioral intention to use the web-based SWEE intervention will have a positive effect on the actual use of the web-based SWEE.
- 5) The effect of performance expectancy on behavioral intention will be mediated by finding-meaning such that performance expectancy will have a positive effect on finding meaning through using the web-based SWEE which in turn will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE.
- 6) The combined scores for performance expectancy, effort expectancy, facilitating conditions and behavioral intention to use will have a significant influence on ADRD caregivers' actual usage of the web-based SWEE.

Aim 2: Describe participants' experiences in using the website to understand ADRD caregivers' website usage behavior.

Theoretical Framework

This study was designed to test acceptance by ADRD caregivers of the web-based SWEE intervention. The UTAUT was used to evaluate the extent to which ADRD caregivers accept the web-based SWEE intervention which was designed to reduce caregiver stress and burden. The UTAUT provides a framework for explaining and predicting computer usage behavior (Venkatesh et al., 2003). The framework integrates the eight models of technology acceptance and use: Theory of Reasoned Action (TRA), Technology Acceptance Model (TAM), Motivational Model, Theory of Planned Behavior (TPB), a combined TAM and TPB model, Model of PC Utilization, Innovation Diffusion Theory, and Social Cognitive Theory. The UTAUT is based on the constructs of: performance expectancy, effort expectancy, social influence and facilitating conditions. Performance expectancy, effort expectancy, and social influence are particular beliefs primarily related to intention to use a computer system, and has been used as a determinant of actual computer usage. Facilitating conditions is another core construct directly influencing actual computer usage (Venkatesh et al., 2003). Within this framework, ADRD caregivers' performance expectancy is shaped by caregivers' belief that SWEE usage improves managing their stress related to caregiving experiences and is similar to or superior to original paper based SWEE intervention. Effort expectancy of ADRD caregivers is considered as their perception of ease of use associated with the use of the SWEE system. Social influence is an individual caregiver's perception of important others, his or her family members and primary health care providers (e.g., physicians, nurse practitioners, physician assistants, or nurses) belief that he or she should use the new system. Facilitating conditions for ADRD caregivers is influenced by their beliefs of existing technical infrastructures including time that would support actual usage of SWEE (Venkatesh et al., 2003). Behavioral intention is considered as a measure of the strength of ADRD caregivers' intention to use the web-based SWEE intervention. Behavioral intention was proposed as significantly predicting action while other factors except facilitating conditions influence user behavior indirectly through behavioral intention (Davis, Bagozzi, & Warshaw, 1989; Hill, Smith, & Mann, 1987). Actual usage of the web-based SWEE is defined as completeness of the web-based SWEE for ADRD caregivers as designed. The goal of the UTAUT model is to "provide a useful tool for managers needing to assess the likelihood of success of new technology introductions..." (Venkatesh et al., 2003, p.426). ADRD caregivers' completion of the study as designed is considered a measure of success for the web-based SWE which provide theoretical evidence of acceptance of the Web-based SWEE for ADRD caregivers. Intention to use the SWEE and facilitating conditions are predictors of actual use of SWEE among ADRD caregiviers. In this study, social influence was not be used as a variable to predict and explain user acceptance. Social influence has significant influence in user acceptance in mandatory settings, but is not supported as a strong determinant in voluntary situations (Venkatesh et al., 2003) in which ADRD caregivers did not have any obligation to use the web-based SWEE for their stress management. In addition, each construct of the

UTAUT model was used as a predictor or explainer for understanding user acceptance of new technologies (Venkatesh et al., 2003). This study hypothesized that ADRD caregivers who completed the web-based SWEE as designed would have higher performance expectancy, effort expectancy, facilitating conditions and behavioral intention to use. Therefore, the sum scores of four constructs would be positively related to actual usage of the web-based SWEE by ADRD caregivers, which would be an indicator of acceptance of the web-based SWEE intervention which was a new information system for voluntary situations.



Figure 1. Theoretical framework (Modified UATUT mode) by Ko (2011)

Output quality, which is evaluated by observing intermediate end products of using an information system, can be considered an important determinant of performance expectancy (Davis, Bagozzi, & Warshaw, 1992; Venkatesh, 2000).

Constructs	Definitions	Measures
Performance expectancy	The degree to which an individual believes that using the system will help him or her to attain gains in job performance (Venkatesh et al., 2003, p.447)	Performance expectancy (UTAUT) (Venkatesh, Morris, Davis, & Davis, 2003)
Effort expectancy	The degree of ease associated with the use of the system (Venkatesh et al., 2003, p.450)	Effort expectancy (UTAUT) (Venkatesh et al., 2003)
Facilitating conditions	The degree to which an individual believes that an organizational and technical infrastructure exists to support use of the system (Venkatesh et al., 2003, p.453)	Facilitating conditions (UTAUT) (Venkatesh et al., 2003)
Output quality	Observing intermediate end products of using an information system can be considered an important determinant of performance expectancy (Davis, Bagozzi, & Warshaw, 1992; Venkatesh, 2000)	Finding Meaning Through Caregiving Scale (FMTCS) (Farran, Miller, Kaufman, Donner, & Fogg, 1999)
Behavioral intention to use	A measure of the strength of one's intention to perform a specified behavior (Fishbein & Ajzen, 1975, p.288).	Behavioral Intention to use (UTAUT) (Venkatesh et al., 2003)
Actual use	One specific behavior of interest performed by individuals with regard to some information technology (IT) system (Holden, 2010, p.160)	Completion of the web- based SWEE as designed

Table 1. Definitions and measures

In this study, finding-meaning is an output quality which is an intermediate end product of the Web-based SWEE. Finding-meaning is developed to measure the meaning of caregiving experiences (Farran & Keane-Hagerty, 1991). It is the intermediate product of SWEE intervention for finally reducing stress related to caregiving experiences with ADRD patients. This finding-meaning could also influence their intention to use the system. Perceived usefulness (performance expectancy) has been hypothesized to mediate the effects of output quality on intention use (Davis et al., 1992; Venkatesh, 2000). In other words, there is an assumption that there is a direct association between output quality and behavioral intention to use the system. Output quality has been hypothesized as an important determinant of performance expectancy (Holmbeck, 1997). Therefore, finding-meaning, which is output quality, is able to be supported as a mediator in this study.

Significance

This study tested the level of acceptance of the web-based SWEE intervention among ADRD caregivers. The web-based SWEE was a writing intervention on the Internet to find meaning through caregiving experiences, and therefore help ADRD caregivers' stress management. This study generated important knowledge concerning the issue of user acceptability for a web-based nursing intervention. Information technology including web-based interventions showed benefits for end-users, but there was a gap between the benefits of the information system and user acceptability of it. The results of this study also provided insight into the development of future web-based interventions as well as how web-based interventions could be designed to be more accepted and therefore more useful to health care consumers. Furthermore, the information could be utilized for future research for improving caregiver outcomes using web-based interventions.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter includes a review of the literature on the consumer health informatics, conceptual framework: Unified Theory of Acceptance and Use of Technology (UTAUT) conceptual framework including finding meaning as a mediator; ADRD caregivers; characteristics of ADRD caregivers; Internet-based interventions for ADRD family caregivers; research testing web-based interventions; the Structured Written Emotional Expression (SWEE) web-based intervention; and caregiver outcomes...

Consumer Health Information

Consumer health informatics is defined variously as "information supplied to patients using advanced information and communication technologies" and is the "study, development, and implementation of computer and telecommunications applications and interfaces designed to be used by health consumers" (Klein-Fedyshin, 2002, p. 36). Consumer health informatics (CHI) has spread because of its benefits as tools that are easy to use. The objectives of CHI are to provide health information to lay persons, encouraging self-care, facilitating educated decision-making, supporting health behaviors, and helping information exchange and social support (Klein-Fedyshin, 2002).

The key people using health information are not only health care professionals but also lay persons who are interested in health information. A consumer health information system is necessary for both the administrators of health care professionals and for the active involvement of patient and informal caregivers in the achievement of health care goals (Eysenbach, 2000; Klein-Fedyshin, 2002).

There are differences between patients and health information consumers. Patients are "lay people engaged in a care partnership with a specific health professional," while health information consumers are "persons who seek information about health promotion, disease prevention, treatment of specific conditions and management of various health conditions and chronic illnesses for promoting optimal health" (Brennan & Safran, 2005, p.9). Health information consumers have more independent and active roles in health care systems; for this reason, the name change from "patient" to "consumer" means a real change in health care work distribution from "a professional model of service delivery" to "a collaborative model of care engagement" (Lewis, Chang, & Friedman, 2005). Examples of CHI are personal health records, clinical use of e-mail with patients, e-forms, online pharmacies/electronic prescribing, shared decision-making, health-related web sites, Internet-based health delivery services, and so on (Brennan & Safran, 2005; Klein-Fedyshin, 2002).

The growth in health information-seeking behavior encourages consumers to have a more active role in their care and develop a sense of control and a support (Jimison, Adler, Coye, Mulley, & Eng, 1999). The Internet may crucially influence patients in the way they approach health, such as how they manage their overall health care and how they comply, through their online health-seeking behavior, with prescribed treatments (Evers et al., 2003; Harris Interactive, 2002). Consumers may use the Internet to seek information concerning illnesses, nutrition and fitness, and to learn about medications and their interactions. They might research providers and hospitals, as well as seek online support groups in order to improve health knowledge and health behaviors (Kalichman, Weinhardt, Benotsch, & Cherry, 2002). In many cases, consumers can be motivated to be involved in their health care decisions and to improve their health behavior (Kalichman et al., 2002). It is clear that health care consumers desire a variety of online services to improve or maintain their own health. It is important to ascertain whether the services offered via online are services that health care consumers really want. Discrepancies between the services desired by consumers and those offered online could be a barrier to health care consumers' acceptance and use of the technology (Nguyen, Carrieri-Kohlman, Rankin, Slaughter, & Stulbarg, 2004; Timpka, 2001; Wilson & Lankton, 2004).

Characteristics of Health Information Consumers

Generally, online users are more likely to be better educated, female, European-American, earn a high income, and younger (Dickerson et al., 2004; O'Connor & Johanson, 2000). More educated and more Internet experienced users are more likely to search for medical advice than searching general health information online (S. Fox & Rainie, 2002). Not surprisingly, patients with fair to poor health (compared to those with good or excellent health) are more likely to seek general health information on the Web (Baker, Wagner, Singer, & Bundorf, 2003; Dickerson et al., 2004). European-Americans are more likely to use the Internet than African-Americans in the US (57 versus 43 percent). This gap may be caused by a function of income (Cline & Haynes, 2001). However, African-Americans rely more on the Internet as an informational tool, including for health information (45 versus 35% of Internet users) because African-Americans may have difficulty to access traditional health information sources (Cline & Haynes, 2001). According to Pew Internet & American life, Internet usage decreases gradually with age (S. Fox, 2004). Seventy-seven percent of the age group between 18 to 29 years uses the Internet and 75% of the 30-49 age group. Whereas, 58% of Americans age 50-64 utilize the Internet and only 22% of people aged over 65 years or older accessed the Internet by February 2004. However, usage over age 65 increased from 15% in 2000. The gender ratio also shifted from 60 % of men and 40% of women in 2000 to 50% and 50% in 2004, which is the same ratio as the typical Internet population (Fox, 2004). Comparing the general population of Internet users, a Health on the Net Foundation (HON) survey found that 65% of respondents using the net to locate health information were women which was increased from 50% in 2005 (Pletneva, Cruchet, Simonet, Kajiwara, & Boyer, 2011). This may indicate that women are much more likely than men to search online health information in part because of a care-taking role (Cline & Haynes, 2001). Even though generally younger people make more use of Internet information, seventy-one percent of Internet users between 50 and 65 years old have

experience using the Internet for health information, compared with 53% of those between 18 and 29. Unlike the younger age groups, many users aged over 65 are ill or have ill spouses and could benefit from the health information resources for these illnesses. Also, family history is significantly related to use of Internet for health information (Health on the Net Foundation, 1999).

Consumer Health Informatics System Applications

The growth of seeking health information, intervention delivery and research on the Web is because users report that they value the convenience, anonymity, and volume of online applications and information, often overcoming barriers of traditional care and at significantly reduced cost (Baehring et al., 1997; Houston et al., 2001; Kirsch & Lewis, 2004). The online applications include public screening for depression online (Houston et al., 2001), physicians use e-mail to communicate with their patients (Kane & Sands, 1998), and other healthcare providers online support groups (Bass, McClendon, Brennan, & McCarthy, 1998; Brennan et al., 1991; Ripich, Moore, & Brennan, 1992). In addition, nurses educate older adults on Internet topics such as how to use the Internet to find health information (Leaffer & Gonda, 2000). The Internet affects not only person-toperson communication, but also the economy, healthcare, access to health information, and insurance reimbursement for health services (Goldsmith, 2000); in addition to primary patient care (Bischoff & Kelley, 1999; Bond, 2006).

The online support group has been one of the applications most used and valued. It can offer - via the Internet - effective support and psychosocial services to homebound adults over the age of sixty. Participants of online support groups expressed generally positive attitudes to this type of service and got help through online support groups to cope with the stresses of caregiving (E. Marziali et al., 2005; Rotondi, Sinkule, & Spring, 2005). For example, caregivers who participated more in the online community showed lower perceived life stress (Wright, 2000). The CHIPs program (Computer for Homebound and Isolated Persons) was a program that motivated an online community for isolated individuals including elderly citizens, disabled individuals and caregivers. The participants who regularly used this intervention showed a trend toward less loneliness, less depression, more positive attitudes toward computers and more confidence as well as finding a new sense of friendship. These results suggested that the participants use computer networks to communicate with others. More communication means more social contact which leads to increased participant satisfaction (Bradley & Poppen, 2003).

Another example was an internet-based psychosocial intervention for heart recipients and their families that was developed focusing on stress and medical regimen management workshops, a monitored bulletin board to check for appropriateness of comments, electronic communication with the transplant team, and information about patients' health issues. As a result of this nursing intervention, patients' depression and anxiety symptoms and caregivers' anxiety and hostility symptoms were reduced significantly as well as QoL in social function increased compared to patients and their families who received only usual care (Dew et al., 2004).

The effects of an Internet peer-support group were examined through a selfguided Internet support group for cancer patients affected by mood disturbance and adjustment to cancer. The Internet support group provided self-guided spaces for communication such as Internet discussion forum, a live chat room and a personal message system but did not provide any therapeutic information. Participants of this Internet support group reported less reduction in anxious preoccupation, helplessness, confusion, and depression (Hoybye et al., 2010)

Barriers of Consumer Health Informatics

Barriers exist for some. The term Digital Divide related to the unequal opportunity to access information technology, particularly the Internet, for racial and

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ethnic minorities, persons with disabilities, rural populations, and persons with low socioeconomic status. In other words, it is referred to as differences between desired and available e-health services because of computer literacy, health literacy, and so on (Chang et al., 2004). Online participants must have at least the ability to read and write as well as have access to a computer and the Internet. In addition, they must have a willingness to adapt to new technologies. These requirements may even restrict users of web-based nursing interventions to highly-educated people in middle to upper social economic groups (White & Dorman, 2000).

A massive amount of health information is on the Internet, but the quality of the information is not guaranteed. Too much available information makes it difficult for health information consumers to make competent health care decisions (Eysenbach & Kohler, 2002). Health information on the Internet is beneficial to health care consumers and health care professionals when they have to urgently search for information. However, the quality of health information has been an issue because of inaccuracy, erroneous information and misleading or fraudulent information. Inappropriate health information could be a threat to public health (Fallis & Fricke, 2002). Selecting good quality health information is challenging to health care consumers (J. G. Anderson, 2004).

Several ethical issues also need to be considered when implementing web-based interventions. Obtaining informed consent prior to providing web-based services may be a challenge for health care providers given the need to maintain anonymity (Childress, 2000; E. Marziali et al., 2005; Serafini, Damianakis, & Marziali, 2007). It is hard to guarantee privacy and confidentiality in the Internet environment. For example, written based communication can be freely accessible to others utilizing the Internet services. Health information messages may be misdirected to the wrong person by health care providers (Childress, 2000) if not accurately verifying the person's demographic data. Finally, the lack of face-to-face interaction means health care providers may not be able

to assess potential risks to health care consumers (Childress, 2000; E. Marziali, Damianakis, & Donahue, 2006; Serafini et al., 2007).

Conceptual Framework

Unified Theory of Acceptance and Use of Technology

Designing a computer information system with the proper function and humanmachine interface has been shown to be a challenging and delicate process by developers. Computer information systems developers such as researchers, designers, and practitioners are supposed to have the ability of predicting the new system acceptability to end-users. Designers should evaluate system acceptability through the design and implementation process as early as possible. Practitioners and researchers analyze the causes of the unacceptability to users of a given system and take appropriate action to overcome problems and improve user acceptance by changing the nature of the implementation of systems and processes (Davis et al., 1989; Davis, 1989).

The Unified Theory of Acceptance and Use of Technology (UTAUT) has been developed to explain and predict computer usage behavior (see figure 1). Technology acceptance is defined as "an individual's psychological state with regard to his or her voluntary or intended use of a particular technology" (Hu, Chau, Sheng, & Tam, 1999, p. 96). The goal of UTAUT is to "provide a useful tool for managers needing to assess the likelihood of success for new technology introductions and helps them understand the drivers of acceptance in order to proactively design interventions" (Venkatesh et al., 2003, p.426). UTAUT was developed by integrating eight models of technology acceptance and use: Theory of Reasoned Action (TRA), Technology Acceptance Model (TAM), Motivational Model (MM), Theory of Planned Behavior (TPB), Combined TAM and TPB (C-TAM-TPB), Model of PC Utilization (MPCU), Innovation Diffusion Theory (IDT), and Social Cognitive Theory (SCT) (Venkatesh et al., 2003). The developers of UTAUT did a review, compared, and synthesized the eight models and then defined four core constructs as determinants of intention to use/or usage which are posited as the key dependent variables (Venkatesh et al., 2003). The TRA, originating from social psychology, was designed by Fishbein and Ajzen (1975) to predict and explain almost any human behavior across a variety of disciplines. The TRA contains attitude toward behavior and subjective norm as the main constructs (Fishbein & Ajzen, 1975). The TAM is an extension of the TRA for modeling of user acceptance in information systems. Perceived usefulness and perceived ease of use are core constructs for TAM and subjective norm is included for TAM2, which is an extended form of TAM (Davis et al., 1989). MM has been mainly utilized in psychology to explain human behavior by using constructs of extrinsic motivation and intrinsic motivation (Davis et al., 1992). TPB is another theory which extended from TRA. TPB has been widely and successfully used in technology acceptance settings to understand and explain individual acceptance and usage of technologies. Like TRA, TPB includes attitude toward behavior and subjective norm as core constructs as well as perceived behavioral control as a new construct (S. Taylor & Todd, 1995b). C-TAM-TPB is a hybrid model which has predictors of attitude toward behavior, subjective norm, and perceived behavioral control from TPB, as well as perceived usefulness from TAM (S. Taylor & Todd, 1995a). MPCU is derived from Theory of Human Behavior by Triandls' (1977) and then modified to predict PC utilization. Core constructs of MPCU to predict intention to use are job-fit, complexity, long-term consequences, affect toward use, social factors, and facilitating conditions (Thompson, Higgins, & Howell, 1991). IDT is a grounded in sociology (Rogers, 1995) since 1960s and has been used in a variety of areas including information systems. Moore and Benbasat (1991) modified constructs of IDT to predict and explain individual technology acceptance behavior. Modified constructs of IDT have relative advantages, ease of use, image, visibility, compatibility, results demonstrability, and voluntariness of use (Moore & Benbasat, 1991). SCT, one of the fundamental and influential theories of human behavior, was extended and refined by Compeau and Higgins (1995) to apply in

context of computer usage. Its core constructs are outcome expectations - performance, outcome expectations - personal, self-efficacy, affect and anxiety (Compeau & Higgins, 1995).

Research Based on the UTAUT Conceptual Framework

UTAUT provides an explanation of and predicts user acceptance and use of information technology (IT). UTAUT was found to be valuable and useful for explaining and predicting user acceptance of IT among students and faculty in a university, business organization context, professionals in health care context as well as chronic illness patients in community (Hennington & Janz, 2007; Kijsanayotin, Pannarunothai, & Speedie, 2009; Li & Kishore, 2006; OR, Karsh, Severtson, & Brennan, 2008; Oshlyansky, Cairns, & Thimbleby, 2007; Schaper & Pervan, 2007) (Table 2).

A personal response system (Clicker) which was a handheld device for students was evaluated for the system acceptance by UTAUT. The acceptance of Clicker was explained 56% (R²) by UTAUT with perceived enjoyment, performance expectancy, social influence and effort expectancy (Taneja, 2009). The acceptance of Blackboard which was an educational Web-based software system was examined for students in a business administration undergraduate level course. The results showed that UTAUT explained 40% of students' acceptance of Blackboard system (Sundaravej, n.d.). However, a similar system with the same name (Blackboard®) was not significantly supported by a UTAUT model which was examined in a different university (Marchewka, Liu, & Kostiwa, 2007).

Venkatesh and colleagues (2003) conducted longitudinal studied at four organizations for persons with new technology implementation. UTAUT model was able to explain 69% of technology acceptance behavior while other previous models gave explanations for approximately 40% of technology acceptance. The findings of the acceptance of tablet PC by faculty in a college of business showed that UTAUT model explained 44.6% (\mathbb{R}^2) of the variance in usage of tablet PC by using four constructs (J. E. Anderson, Schwager, & Kerns, 2006).

Study	Technology studied	Population studied and setting	Analyzed sample size (N)	Variance explained
Venkatesh et al (2003)	A new technology in the workplace at four organizations	Heterogeneity across technologies, organizations, industries, business, and nature of use	215	AU: adjusted R ²⁼ 70 %
Anderson et al (2006)	Tablet PC	The faculty of a College of Business at a large university	50	BIU:R ² - =69%
Schaper (2007)	Information and communication technology (ICT)	Occupation therapists in Australian	1605	BIU: $R^2 = 63\%$
Or et al (2008)	Consumer health information technology (CHIT)	Home care patients with chronic illness	102	-
Kijsanayot in (2008)	Health information technology	Thailand's community health centers	1323	BIU: R ² 54% AU:R ² =27 %
Taneja (2009)	Personal response system (clickers)	A handheld device for Students	125	BIU: $R^2=56\%$
Sundaravej (n.d.)	An educational Web- based software system (Blackboard)	Students in a business administration undergraduate level course	262	BIU:R2 = 40%

Table 2. Summary of reviewed studies of UTAUT

BIU: Behavioral Intention to Use; AU: Actual Usage

The adoption of health information technology in Thailand's community health center was examined by UTAUT model which was explained by 54% of the variance (Kijsanayotin et al., 2009). UTAUT was also used to assess the information and communication technology acceptance of Australian occupational therapists. The direct effect only model explained 63% of the variance in behavioral intention to use the system (Schaper & Pervan, 2007). The modified UTAUT model, Patient Technology Acceptance Model, was applied to examine technology acceptance for chronic illness, especially congestive heart failure, for the web-based health system to record and review vital signs and assess health-related resources (OR et al., 2008).

Four Core Constructs of UTAUT

Based on these eight theories or models, UTAUT posits four core constructs: performance expectancy, effort expectancy, social influence, and facilitating conditions. Performance expectancy, effort expectancy and social influence are beliefs that primarily affect behavioral intention to use technology which is asserted as a significant determinant of technology use behavior. Facilitating conditions are hypothesized to directly influence technology use behavior (Venkatesh et al., 2003).

Performance Expectancy

Performance expectancy is defined as "the degree to which an individual believes that using the system will help him or her to attain gains in job performance" (Venkatesh et al., 2003, p.447). This definition captures constructs embodied by perceived usefulness (TAM/TAM2 and C-TAM-TPB), extrinsic motivation (MM), job-fit (MPCU), relative advantage (IDT), and outcome expectations (SCT). The performance expectancy construct has been demonstrated the strongest predictor of behavioral intention to use technology in individual theory/model. Venkatesh and colleagues (2003) found performance expectancy was the strongest predictor of behavioral intention to use new technology (R2= .49- .59, p<.001) through conducting longitudinal study at four organizations for persons with new technology implementation. The adoption of health information technology in Thailand's community health center showed intention use health IT was predicted when health IT was useful (performance expectancy, β =.43, P <.001) (Kijsanayotin et al., 2009). Perceived usefulness (performance expectancy) was a
significant predictor of intentions to use the web-based health system by home care patients with chronic illness (r = .77, p<.01) (OR et al., 2008). Performance expectancy was demonstrated to have a significant effect on behavioral intention both in voluntary and mandatory situations. It has been moderated by gender and age. Men and younger adults would be influenced by the performance expectancy (Venkatesh et al., 2003). However, unlike these studies, the influence of performance expectancy to intention to use was not statistically supported by UTAUT model for students in both Web-based blackboard use and personal response systems (Marchewka et al., 2007; Taneja, 2009).

Effort Expectancy

Effort expectancy is defined as the "degree of ease associated with the use of the system" (Venkatesh et al., 2003, p.450). The effort expectancy is represented as perceived ease of use (TAM/TAM2), complexity (MPCU), and ease of use (IDT). UTAUT hypothesizes the impact of effort expectancy is varied depending on experiences, gender and age (Li & Kishore, 2006; Venkatesh et al., 2003). The effort expectancy has more significant effect in early stage of a new technology implementation. In addition, it has been shown to be a stronger determinant for women and older adults (Venkatesh et al., 2003). A personal response system for students demonstrated that effort expectancy had a small but statistically significant effect on intention to use ($\beta = .12$) (Taneja, 2009). A longitudinal study at four organizations for persons with new technology implementation showed that effort expectancy indicated a weak but positive relationship to intention to use the system (Venkatesh et al., 2003). The adoption of health information technology in Thailand's community health center was examined by UTAUT model. According to results, intention use health IT was predicted when it exhibited ease of use (effort expectancy, $\beta = .20$, P < .001) (Kijsanayotin et al., 2009). In addition, the Web-based health system for chronic illness, especially congestive heart failure reported that perceived ease of use (effort expectancy) was the significant factor related to intention use (r = .36, p<.01) (OR et al., 2008).

Facilitating Conditions

Facilitating conditions are the only core construct directly related to actual usage rather than behavioral intention to use technology (Venkatesh et al., 2003). The facilitating conditions are defined as the "degree to which an individual believes that an organizational and technical infrastructure exists to support use of the system" (Venkatesh et al., 2003, p.453). The root constructs of facilitating conditions include perceived behavioral control (TPB, C-TAM-TPB), facilitating conditions (MPCU), and compatibility (IDT). These constructs contain the idea that the environment of organization or/and technology implementation is designed to remove the barriers to use technology/system. Facilitating conditions for persons with new technology implementation (R2= .05- .18, p<.05) (Venkatesh et al., 2003). The Thailand's community health center health information technology usage was significantly affected by facilitating conditions on usage is asserted to be moderated by age and experiences. It is stronger with older adults with increasing experiences (Venkatesh et al., 2003).

Behavioral Intention to Use

Another foundation of UTAUT theory is the notion of behavioral intention as a determinant of actual computer usage (Davis et al., 1989). Behavioral intention is defined as "a measure of the strength of one's intention to perform a specified behavior" (Fishbein & Ajzen, 1975, p.288). Behavioral intention was proposed as able to significantly predict action while other factors influence user behavior indirectly through behavioral intention (Davis et al., 1989; Hill et al., 1987) except facilitating conditions (Venkatesh et al., 2003). The adoption of health information technology in Thailand's community health

center showed that IT use was determined by intention to use IT (β =.13, P <.001), (Kijsanayotin et al., 2009).

The sum scores of each construct of UTAUT model, performance expectancy, effort expectancy, facilitating conditions, and behavioral intention can represent the level of the Web-based acceptance such as with the SWEE for ADRD caregivers. Each construct has been used as predictor or explainer to understand users' technology acceptance in various settings (Kijsanayotin et al., 2009; Li & Kishore, 2006; Marchewka et al., 2007; OR et al., 2008; Oshlyansky et al., 2007; Schaper & Pervan, 2007; Venkatesh et al., 2003). A high level of each construct has been associated with willingness to use the new technology, which is the user acceptance (Schaper & Pervan, 2007; Venkatesh et al., 2003). Therefore, the sum scores of four constructs will represent whether ADRD caregivers' acceptance of the web-based SWEE, a new information system, is well received in voluntary situations.

Among those core constructs, social influence will not be included in the webbased SWEE study framework. Social influence is defined as the "degree to which an individual perceives that important others believe he or she should use the new system" (Venkatesh et al., 2003, p.451). The social influence is derived from subjective norm (TRA, TAM2, TPB and C-TAM-TPB), social factor (MPCU) and image (IDT). UTAUT suggests that social influence is more salient for women or/and older adults in mandatory settings with the effect declining with experience. No root constructs of social influence were supported as a significant determinant in voluntary research contexts (Venkatesh et al., 2003) which is the case of the web-based SWEE for ADRD caregivers. Compliance, internalization, and identification are three mechanisms for the social influence working process. Internalization and identification are influenced by an individual's belief formation and/or potential social status gain while compliance is related to the social pressure. This compliance which means reliance on others' opinions is consistently significant only in mandatory contexts of the technology acceptance research (Hartwick & Barki, 1994a; Venkatesh & Davis, 2000). The above examples provide the evidence that the UTAUT is comprehensiveness with high explanatory power (Schaper & Pervan, 2007) and may be used in a variety of contexts.

Venkatesh et al. (2003) state:

While the variance explained by the UTAUT model is quite high for behavioral research. Future work should attempt to identify and test additional boundary conditions of the model in an attempt to provide an even richer understanding of technology adoption and usage behavior. This might take the form of additional theoretically motivated moderating influences, different technologies... different user groups... and other organizational context.... Result from such studies will have the important benefit of enhancing the overall generalizability of UTAUT and/or extending the existing work to account for additional variance in behavior (p.470).

The validity of the model has rarely been tested in application use for caregivers. Conceivably, such caregivers may differ from students or other subjects commonly studied in previous research due to a host of factors including age, gender general competence, intellectual and cognitive capacity, specialized training, and type of work and accomplishment. Hartwick and Barki (1994b) emphasize the increasing importance of theory testing for Information Systems (IS) research, for which examination or validation of existing findings of user technology acceptance is desirable, particularly when findings involve different technologies, user populations, or organizational contexts (Hu et al., 1999).

UTAUT core constructs: Definition	Root constructs	Definitions	
Performance expectancy: The degree to which an individual believes that using the system will help him or her to attain gains in job performance (Venkatesh et al., 2003, p.447)	Perceived usefulness (TAM/TAM2, C-TAM-TPB)	The degree to which a person believes that using a particular system would enhance his or her job performance (Davis, 1989,p 320)	
	Extrinsic motivation (MM)	The perception that users will want to perform an activity because it is perceived to be instrumental in achieving valued outcomes that are distinct from the activity itself, such as improved job performance, pay, or promotions (Davis, Bagozzi, & Warshaw, 1992, p.1112)	
	Job-fit (MPCU)	How the capabilities of a system enhance an individual's job performance (Thompson, Higgins, & Howell, 1991, p.129)	
	Relative advantage (IDT)	The degree to which using an innovation is perceived as being better than using its precursor (Moore & Benbasat, 1991, p.195)	
	Outcome expectations (SCT)	Performance- related the consequences of the behavior. Specifically, performance expectations deal with job related outcomes	
		Personal- the personal consequences of behavior. Specifically, personal expectations deal with individual esteem and sense of accomplishment (Compeau & Higgins, 1995; Venkatesh & Davis, 2000, p.432)	
	Perceived ease of use (TAM/TAM2)	The degree to which a person believes that using a system would be free of effort (Davis, 1989, p.320)	
	Complexity (MPCU)	The degree to which a system is perceived as relatively difficult to understand and use (Thompson et al., 1991, p.128)	
	Ease of use (IDT)	The degree to which using an innovation is perceived as being difficult to use (Moore & Benbasat, 1991, p.195)	

Table 3. Definitions of UTAUT core constructs

Social influence: The degree to which an individual perceives that important others believe he or she should use the new system (Venkatesh et al., 2003, p.451)	Subjective norm (TRA, TAM2, TPB, C-TAM-TPB)	The person's perception that most people who are important to home think he should or should not perform the behavior in question (Fishbein & Ajzen, 1975, p.302)	
	Social factor (MPCU)	The individual's internalization of the reference group's subjective culture, and specific interpersonal agreements that the individual has made with others, in specific social situations (Thompson et al., 1991, p.126)	
	Image (IDT)	The degree to which use of an innovation is perceived to enhance one's image or status in one's social system (Moore & Benbasat, 1991, p.195)	
Facilitating conditions: The degree to which an individual believes that an organizational and technical infrastructure exists to support use of the system (Venkatesh et al., 2003, p.453)	Perceived behavioral conditions (TPB, C- TAM-TPB)	Reflects perceptions of internal and external constrains on behavior (Taylor & Todd, 1995, p.149) and encompasses self-efficacy, resource facilitating conditions, and technology facilitating conditions (Venkatesh et al., 2003, p.454)	
	Facilitating conditions (MPCU)	Objective factors in the environment that observers agree make an act easy to do, including the provision of computer support (Thompson et al., 1991, p.129)	
	Compatibility (IDT)	The degree to which an innovation is perceived being consistent with existing values, needs, and experiences of potential adopters(Moore & Benbasat, 1991, p.195)	

Mediator: Finding-meaning

Output quality which is evaluated by observing intermediate end products of

using an information system can be considered an important determinant of performance

expectancy (Davis et al., 1992; Venkatesh, 2000). In this study, finding-meaning will be

used to assess an output quality (Farran & Keane-Hagerty, 1991). Finding-meaning is the intermediate product of SWEE intervention. When able to find meaning with SWEE, a person is reducing stress related to caregiving experiences with ADRD patients (Butcher, 2004). In these previous studies, output quality was considered an external variable which was mediated by perceived usefulness (performance expectancy). However, it is hypothesized a mediator exists between performance expectancy and intention of using SWEE. The effect of performance expectancy on intention using technology is mediated by finding-meaning through caregiving experiences. The mediator indicates how or why a given effect occurs (Baron & Kenny, 1986). More specifically, it is defined as "the generative mechanism though which the focal independent variable is able to influence the dependent variable of interest ... (and) Mediation ... is best done in the case of a strong relation between the predictor and the criterion variable" (p, 1173, 1178). The important prerequisite is a significant association between the independent variable and the dependent variable prior to test a mediated effect (Holmbeck, 1997).

The Finding Meaning Through Caregiving Scale (FMTCS) is used as an instrument for finding-meaning for Alzheimer's caregivers (Farran et al., 1999). This instrument is designed to measure the meaning of caregiving experiences (Farran & Keane-Hagerty, 1991). Nolan, Grant, & Ellis (1990) reported that a caregiver's burden is more associated with the subjective meaning of specific events and tasks. The key to transforming traumatic losses into something positive lies in the effort to give one's losses meaning to learn and gain insight from the losses and imparting to others positive effects based on the experience (Harvey, 1996). Therefore, finding positive meaning may give new value to caregivers from their stressful situations (Folkman, 1997). The FMTCS consists of three subscales that are Loss/Powerlessness (LP), which refers to caregivers' feeling of loss and powerlessness for their family members, concerning themselves, and associated with caregiving; Provisional Meaning (PM), which explains what is viewed as positive, what keeps caregivers going, and what is positive about their

daily experiences; Ultimate Meaning (UM), defined as a higher power, a philosophical or religious/ spiritual structure (Farran, 1997). FMTCS has been tested though home-based dementia caregivers and spouse caregivers to establish reliability and validity. Caregivers' depression and role strain were positively associated with LP, (r= .61, p <.01; r= .70, p <.01) respectively, but had negative relations to PM and UM. PM had positively related to caregiver satisfaction (r= .64, p <.01) and personal gain (r= .57, p <.01). UM is mostly associated with non-organized religion (r= .61, p <.01) as well as religious participation(r= .53, p <.01) (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilkin, 1991).

Lee and colleagues (2003) implemented FMTCS to populations with different cultures/ethnicity, Korean-Korean caregiver, Korean-American caregiver and European-Caucasian caregivers for understanding their finding-meaning experiences. Among three caregiver groups, Korean-Korean caregivers showed a high level of depressive symptoms with high feeling of LP as well as low levels of PM and UM especially spouse caregivers. In addition, cultural appropriateness was evaluated through semi-structured interviews by comparing Korea-born female family caregivers, five living in Korea and five living in the US. Mostly FMTCS was tool to assess finding-meaning of this particular population (E. E. Lee et al., 2003).

Finding-meaning was considered the intermediated output of SWEE intervention in this study and would be positively related to ADRD caregivers' performance expectancy of the web-based SWEE intervention which was defined as caregivers' belief that SWEE usage improved managing their stress related to caregiving experiences. The disclosure of their feelings, which was designed in this study as finding-meaning by using web-based SWEE, had a positive relationship with improving distress, depression, subjective wellbeing, anger, and anxiety as well as positive attitude toward intervention in health (Frattaroli, 2006). This finding-meaning also could influence their intention to use the system. Perceived usefulness (performance expectancy) was hypothesized to mediate the effects of output quality on intention use (Davis et al., 1992; Venkatesh, 2000). In other words, there was an assumption that there was a direct association between output quality and behavioral intention to use the system. Output quality had been hypothesized as an important determinant of performance expectancy (Holmbeck, 1997). Therefore, finding-meaning, which was output quality, was able to be supported as a mediator in this study.

ADRD Family Caregivers

As the percentage of the elderly population increases, so does the number of Alzheimer's Disease and Related Disorders (ADRD) patients (Alzheimer's Disease Education & Referral (ADEAR) Center, 2006). Its unpredictable clinical courses average 8-10 years, though the disease can last for up to 20 years (Acton & Miller, 1996). It is the fourth leading cause of death in adults. It is characterized by memory loss, behavior and personality changes, and a decline in thinking abilities. The major source for providing care for most ADRD patients are family members in the community, and the expectation of care will increase significantly as the population ages (White & Dorman, 2000). Family caregivers are resources which provide extensive support to their relatives who have illness or disabilities (National Academy on an Aging Society, 2000). According to the Administration of Aging and the US Census Bureau, 1997, 66% of older noninstitutionalized persons and 47% of those 85 and older lived in a family setting. Approximately 13% of older persons were living with children, siblings, or other relatives instead of a spouse. Additionally, 776,000 older adults lived with nonrelatives, such as friends, roommates, and neighbors (Administration on Aging, 2007). The annual cost of caring for ADRD patients at home is estimated to be \$354 billion in the US (Gibson & Houser, 2007).

ADRD caregivers provide physical, emotional, and environmental support for their loved ones (Brennan et al., 1991). Informal caregivers for ADRD patients meet

several challenges while they provide care for their loved ones. Those challenges are: accessing peer support and professional consultation and gaining adequate information to make choices about care as well as information related to issues of themselves (Brennan & Ripich, 1994; Chambers, 2002; Rotondi et al., 2005). Traditionally, many communitybased and formal health interventions are designed to meet the social, spiritual, emotional, and informational requirements of family caregivers of ADRD patients. These interventions provide social support including face-to-face groups and educational activities (Alexy, 2000). However, at least one-half of informal caregivers do not use social support resources even though they could benefit from them. This is because of geographical distance, stigma, time constraints, and inadequacy of professional resources. Lack of substitute caregivers, transportation problems, and inconvenient meeting times and locations comprised three of the greatest obstacles to support group attendance (Brennan & Moore, 1994; Brennan et al., 1995; Gonyea, 1989; Hekelman et al., 1994; Rotondi et al., 2005; Steiner & Pierce, 2002). Computer-based and web-based interventions have been used as another method with the advantages of having ability to reach homebound and geographically isolated people, having barrier of transportation, or having home-care responsibilities that make it hard to attend face-to-face meetings.

Characteristics of ADRD Caregivers

Caregivers of persons with ADRD could benefit from technologically based nursing interventions (Brennan et al., 1991; Gallienne et al., 1993). More than 57 % of the participants in Internet-based nursing intervention for ADRD caregivers were spouses of the person to whom they were providing care except one study whose participants were mostly adult children. The remaining caregivers were adult children (29% to 38 %) of the care recipients and other relatives such as siblings, relatives, friends etc. Most caregivers' mean age was over 60 years except one study in which it was 46.5 years old.

Study	Age (year)	Gender (%) Male/ Female	Race (%)	Length of Caregiving (range)	Education Employme (year) (%) (%)		Relationship (%)
			(ComputerLin	k		<u> </u>
Brennan et al., 1991	68	49/59	White 80 Black 18	3.1 years (1-10 years)	14	Retired 45 Full time 23 Part time 14	Spouse 85 Other 15
Brennan, Moore, & Smyth, 1992	60.3	32/68	None	30 months (4M – 10Y)	None	None	Spouse 57 Adult children 29 Other 13
Brennan, Moore, Smyth, 1995 Brennan, Moore, 1994 Malcolm et al., 2001	60.8	33/67	White 72 Black 28	34 months	< 12 (33) > 12 (66)	Full/part time 33	Spouse 58 Adult children 35 Other 7
AlzOnline							
Glueckauf, Ketterson, Loomis, & Dadges, Pat, 2004 Glueckauf & Loomis, 2003	64.4	10/90	White 95 Black 5	3.25 years	14.38	Full time 71 Part time 29	Spouse 62 Adult Children 38
Caregiver Friends							
Beaucham p et al., 2005	46.9	27.73	White 80 Black 4 Hispanic 8 Other 8	None	< 14 (10) >14 (90)	None	Spouse 7 Adult children 67 Other 26
	1	21	nternet-ba	sed Intervent	ion progran	ns	
Marziali & Garcia, 2011	65,51	50/50	None	4.55 years	<14 (40) >14 (60)	None	Spouse 74

Table 4. Demographic characteristic of ADRD caregivers for Internet-based interventions

This result supports the acceptance and use of a computer network by those who are not typical computer users. Only one intervention, Caregiver' Friend, reported that the average age was 46.5 years old because it was focusing on the specific worksite caregivers, so adult child caregivers were a majority in this study while the majority of caregivers in the other two interventions were spouses.

Length of time of caregiving ranged from 2.5 to 4.55 years. More than 72% of the caregivers in the studies were white. Four studies reported about African-Americans while only one study reported having a Hispanic population. The caregivers' education averaged more than 12 years. Less than half of caregivers were employed in full or part time jobs.

Internet-based Interventions for ADRD Caregivers

Finding respite care for several hours while caregivers attend a meeting is difficult. Alzheimer's caregivers need many kinds of support (Gallienne et al., 1993; McClendon, Bass, Brennan, & McCarthy, 1998; Pratt, Aono, Lehman, Hammar, & Risser, 1985) such as finding appropriate information, sharing experiences and opinions, and providing encouragement (White & Dorman, 2000), but traditional face-to-face support groups for caregivers, constituting a staple recommendation for families faced with Alzheimer's disease, make attendance at in-person meeting untenable (McClendon et al., 1998). They may be limited in their abilities to travel to another place because Alzheimer patients generally do not live alone; that is, caregivers have to stay with them in their houses (McClendon et al., 1998). Another reason is that caregivers could become frustrated with their situation at any time, so they may have a desire to share their feelings and stress, and receive emotional support regardless of the time of day or night (McClendon et al., 1998; White & Dorman, 2000). Thus, the non face-to-face computer network gives them an opportunity to express their feelings (Gallienne et al., 1993). Lack of substitute caregivers, transportation problems, and inconvenient meeting times and locations comprised three great obstacles to support group attendance (Gonyea, 1989).

Computer networks make it possible for users to stay at home and use nursing services any time that they want to keep their anonymity. Thus, users may better express their feelings and have improved interpersonal interaction via computer networks during a time of stress than in small support groups and face-to-face services (Gallienne et al., 1993; McClendon et al., 1998; Ripich et al., 1992). Through their writing, caregivers who use online services can share with other caregivers their feelings of grief, frustration, anger, and helplessness. Through this sharing and "venting" process caregivers' burdens subside (White & Dorman, 2000). The writing provides an opportunity to express their emotions to empathetic listeners, and probably serves a therapeutic purpose (Brennan, 1996).

According to White et al. (2002), the Internet allows the elderly social support benefits in terms of expanding their social networks that help them to avoid social isolation. Also, they gain advantages from using computers or the Internet for some physical limitations such as using typing as a way to overcome age-related unreadable handwriting (Furlong, 1989; McMellon & Schiffman, 2002; Wright, 2000).

Use of technologies such as computer networks can help caregivers' participation in services that are expected to be beneficial (Brennan et al., 1995). Computer networks, which are defined as "technologic supports that create electronic links between remote sites," (Brennan et al., 1991, p.15) can help nurses in assisting family caregivers of persons with ADRD. They can link ADRD caregivers to professionals and peers familiar with their situation and needs, permit clinicians to reach caregivers in a timely and convenient manner, and have the particular advantage of reaching large numbers of individuals easily (Brennan et al., 1995). They help family caregivers for ADRD patients access emotional support plus practical information and resources to promote skill development and improve their knowledge related to ADRD (Brennan et al., 1991) while enhancing the quality of life of caregivers as well as patients (Monnier, Laken, & Carter, 2002). Several studies have demonstrated the efficacy and effectiveness of helping Alzheimer's caregivers via the internet services.

ComputerLink, a specialized computer network designed to provide systematic assistance to ADRD caregivers, was easily accessible without requiring extensive training or time to access. The content of the system was created to be practical, to address concerns relevant to caregivers, and to encompass features such as peer contact found to support caregivers. ComputerLink consists of three functional areas: the Electronic Encyclopedia, the Decision Support system, and the Communication Pathway. Caregivers access the ComputerLink from their homes via telephone lines using computer terminals (Brennan et al., 1991; Brennan et al., 1995).

Caregiver's Friend: Dealing with Dementia is a web-based multimedia intervention that provides text material and videos with caregiving strategies. This intervention provides services emphasizing problem-focused techniques and social support skills including: Guide Me which is a personalized program regarding particular situations; Being a Caregiver, which educates the caregivers about common caregiver issues; Coping With Emotions, which helps caregivers cope with common emotions by using video demonstrations of caregivers discussing cognitive and behavioral strategies; and Common Difficulties, which addresses common concerns and is tailored by the severity of dementia (Beauchamp et al., 2005).

AlzOneline services include: 1) on-demand, audiovisual presentations on current developments in dementia care, treatment research, community resources, and pharmacological interventions; 2) a Message Board and Chat Room to build a caregiver community, facilitate exchanging tips and suggestions, and provide support; 3) an Electronic Library offering information on the basics of dementia, caregiving techniques, and research developments; and 4) Helpful Links to federal, state, and community resources. The important service of AlzOnline is its series of six 45-minute live interactive classes that focus on managing stress, enhancing interpersonal communication and family relationships, promoting emotional well-being, and setting and implementing personal caregiving goals. The Positive Caregiving classes within this series consist of a brief educational presentation combined with group discussion and recommended outside activities (Glueckauf & Loomis, 2003; Glueckauf et al., 2004).

Access to Caregiver's Friend and AlzOnline positively affected caregiving psychological outcomes. Caregiver's Friend helped to improve depression, anxiety, level and frequency of stress, caregiver strain, self-efficacy, and intention to seek help, as well as perceptions of positive aspects of caregiving (Beauchamp et al., 2005). Likewise, participants of AlzOnline noticed a decrease in subjective caregiving burden (Glueckauf & Loomis, 2003; Glueckauf et al., 2004). Both Internet-based interventions reported improvements in caregivers' perceptions of self-efficacy in performing many of the demands of caregiving and coping with facing care recipient behavioral problems. In addition, Caregiver's Friend also significantly and positively impacted caregivers' appraisal of their situation while AlzOnline or didn't change on the positive dimensions of the caregiving experience (e.g., stress-related growth and positive caregiving appraisals), or caregivers' perceptions of time burden in providing care to their care recipients (Beauchamp et al., 2005; Glueckauf & Loomis, 2003; Glueckauf et al., 2004). Caregiver's Friend's users also expressed intention to access help from others. An important finding is that only 32 minutes total exposure significantly influenced the results, which represents quite a minimal intervention. More time spent using Caregiver's Friend was significantly associated with greater outcomes (Beauchamp et al., 2005).

Internet-based interventions such as ComputerLink provided instrumental, emotional, and spiritual support to ADRD caregivers by offering general information regarding caregivers' condition and care needs to enhance decision support; encouraging network members to post problems for discussion; and encouraging maintenance of caregivers' own religious beliefs (Brennan, Moore, & Smyth, 1992). Therefore, they served as either a substitute for face-to-face support groups or a supplement to support groups depending on specific circumstances. A key variable is the caregiver's level of use of a support group before specifying whether substitution or supplementation took place (McClendon et al., 1998).

Two Internet-based clinical support interventions were developed for ADRD caregivers to improve their experienced stress and health status. One intervention was a text-based Chat Group intervention allowing access to a caregiver information handbook and videos on managing caregiving tasks. The other intervention was an online video conferencing psychotherapeutic support group (Video group) intervention by a clinician and access to a caregiver information handbook. Compared to the Chat group, the Video group reported a significant improvement in mental health conditions (E. Marziali & Garcia, 2011)

Research Testing Web-based Interventions

Several studies showed the feasibility and efficacy of web-based interventions for family caregivers of various diseases (Table 5). Cancer caregivers also were interested in the internet-based cancer services webs regardless of group differences. Their interventions of most interest were information related to treatment, conversations with physicians on the Internet, and online support groups as well as home health services delivered through individual computers (Monnier et al., 2002). Caring-web, in-home support for caregivers with stroke patients, demonstrated the potential to facilitate caregivers' well-being through providing health related care to persons with strokes in home setting (Steiner & Pierce, 2002). Caregivers of people with a mental illness used Web-based self-help groups for discussion of emotions and finding information associated with diagnosis of their relatives (Perron, 2002). Family caregivers of persons with neurodegenerative disease showed positive responses to an internet-based psychotherapeutic support group intervention (E. Marziali et al., 2006).

Study	Sample	Design	Interventions	Results
Perron, (2002)	Caregivers of persons with a mental illness N = 36 Male=6	A case study: 18 months of an on-online self-help group.	Online self-help group: Open group without moderator	Purpose of using the website: Disclosure (N=164) Providing information and advices (N=89)
	Female=26 Unknown= 4		Bulletin board and e-mail for communication	Content of messages: Discussion of emotions (42 %) Diagnosis (34. 6 %)
Marziali, Damianakis, & Donahue (2006)	Family caregivers of persons with neurogenerativ e diseases N = 34 Male=8 Female=26 (wives, daughters and daughter in law)	Qualitative study: Explore the feasibility of Internet video conferencing environment	Internet based psychotherapeuti c support group: Internet video conferences (including one- on-one and a group format)	Positive responses (78%): Learning to use computers Negotiating the website links Obtaining disease specific information from the websites Using technology to communicate Bonding with groups members Providing mutual guidance and support Benefiting in terms of coping with the stress of caregiving
Rotondi, Sinkule& Spring (2005)	Female significant others/spousal caregivers of persons with Traumatic brain injury (TBI) N =17	Descriptive study: Identify the feasibility of offering 6 months in- home adjunctive and supportive services	WE CARE: Online support groups Ask our experts your questions Questions-and- answers library Reference library, and Community resources library	Most used: Electronic support group (68.6%) Community resource library Evaluation of the website: Moderately to extremely easy to use (84%) Very to extremely satisfying the web site (75%) Very to extremely helpful (75%)
Sander et. al (2009)	Caregivers of persons with medically documented TBI N=15	Feasibility study with satisfaction and perceived utility assessed	Six web-based videoconferencin g sessions (including didactic education with interactive problem solving)	Satisfaction with education modules: 82% - 100% Perceived utility: gain knowledge that was applicable to everyday lives

Table 5. Research testing Web-based Interventions

Family caregivers of persons with Traumatic Brain Injury used the on-line support groups to have social support, information, and guidance after returning home (Rotondi et al., 2005). A Web-based video conferencing training program for caregivers of adults with traumatic brain injury in rural areas was developed to manage cognitive and behavioral changes in the care recipients (Sander, Clark, Atchison, & Rueda, 2009). Likewise, ADRD caregivers are a particular population of caregivers who use consumer informatics and who are in tremendous need of access to information and the delivery interventions designed to reduce their stress.

Given the stress that ADRD caregivers experience, the development and implementation of web-based interventions designed to reduce stress and caregiver burden and promote health and well-being may be of great benefit to caregivers, their family members as well as persons with ADRD. However, evaluating user acceptance of internet interventions is essential in order to ensure that the type of intervention system offered fits the users' needs and requirements. The focus of this study is to evaluate the acceptability of a web-based writing intervention, structured written emotional expression (SWEE) designed to reduce stress in ADRD family caregivers.

Structured Written Emotional Expression

Written emotional expression is an intervention in which participants are asked to write an essay that expresses their deepest feelings about a traumatic experience in their life (J. M. Smyth, 1998). Originally, Pennbaker & Bell (1986) suggested that written emotional expression, writing an essay about traumatic experiences, converts a traumatic experience into a linguistic structure, and therefore helps people understand a traumatic experience as an event and reduces the negative effect which comes from thinking about a traumatic experience.

According to an experiential model, directly experiencing facets of an emotionladen memory, including its psychological and affective components, along with associated thoughts and images, enables a person to reassess the affective and cognitive schemas involved in that memory. This re-experiencing is the key to its resolution. This process allows for an examination of different facets of the experience that the person may otherwise block from awareness (Rice, 1974). In reprocessing a past stressor more slowly and completely, the person may become aware of dimensions of the experience not previously realized and come to see it in a different way (Rice & Greenberg, 1984). A central feature of this process is cognitive reorganization, which might be facilitated when schema activation is accompanied by new information that is incompatible with previously existing cognitive-affective structures (Safran & Greenberg, 1991). This process can lead to insight or a change in perspective (reorganization of the schema), decreased distress (Gendlin, 1984; L. S. Greenberg & Safran, 1989; Rice & Greenberg, 1984), and decreased bodily tension (Wexler, 1974).

Written expression is based on inhibition and disclosure of emotion (Pennebaker, 1997). Inhibition of emotional expression causes long-term low-level stressors that can cause and exacerbate stress-related diseases; thus, expressing emotion is very important for mental and physical health (Pennebaker & Beall, 1986; Pennebaker, 1997; Seley, 1976; J. M. Smyth, 1998). The findings of a meta-analysis of experimental disclosing indicated positive and significant effects on participants, with an overall effect size of 0.257 (J. M. Smyth, 1998), 0.084 (Frisina, Borod, & Lepore, 2004) and 0.075 (Frattaroli, 2006). The disclosure of their feelings had influence on improving psychological health including distress, depression, subjective wellbeing, anger, and anxiety as well as physiological health such as immune parameters, HIV viral load, liver function, and dopamine. In a random effects analysis, groups of experimental disclosing showed improvement in health, disease specific outcome and illness behaviors, positive attitudes toward interventions and treatments, and improvement in social relationships, cognitive functioning, outcomes concerning work and school (Frattaroli, 2006). The study of written emotional expression via e-mail showed significant overall health benefits, F

(2,486) = 3.80, p<.05, 5 weeks after the intervention to an undergraduate population which were measured by self-reported health (Sheese et al., 2004). Interestingly, writing about emotions about traumatic and upsetting events had higher positive expectancies, which was defined as "the generalized expectancy that positive things happen in the future" (p.175), than writing about trivial events for emotional impact, t(54) = 6.28, p <.001 and physical symptoms, t(90) = 2.93, p <.01. These expectancies of written emotional expression showed statistical trends of decreasing emotional impact from upsetting events as well as physical symptoms (Langens & Schuler, 2007). Effects of written disclosure of feelings were conducted in neurodegenerative caregivers to compare among three protocols: writing about thought and feelings related to a distressing event, writing about perceived benefits related to a distressing event, or writing about neutral stimuli. Writing about a distressing event showed more reduction in distress and perceived burden of caregiving than writing about neutral stimuli (Pennebaker & Beall, 1986; Pennebaker & Francis, 1996; Pennebaker, 1997; Sheese et al., 2004). Even though writing about traumatic experiences has a tendency to make participants unhappy and distressed in the hours after writing because short-term distress may be required for cognitive repair, written emotional expression produces health benefits in a variety of groups including cancer patients, PTSD patients, students with trauma history, asthma/arthritis patients and etc. (Kiecolt-Glaser, Maruch, Amlarkey, Mercado, & Glaser, 1995; Pennebaker, 1982; Pennebaker & Beall, 1986; Pennebaker, 1997; Sheese et al., 2004; J. M. Smyth et al., 1999).

Outcomes Related to ADRD Caregivers' Stress

The outcomes are the multidisciplinary character of stress research, so they suggest some questions as to whether it can be a comprehensible field of study. The outcomes in a social study usually include the well-being of people, their physical and mental health, and their ability to sustain themselves in their social roles (Pearlin, 1994).

Among those outcomes, mental and physical health are selected as outcome measures of stress process because several studies report that providing care to ADRD patients can increase physical and emotional health problems (Acton & Kang, 2001; Bergman-Evans, 1994; Browning & Schwirian, 1994; Dura, Stukenberg, & Kiecolt-Glaser, 1991; Fuller-Jonap & Haley, 1995; Grafstrom, Fratiglioni, Sandman, & Windblad, 1992; Kiecolt-Glaser et al., 1995; Pearlin, Mullan, Semple, & Skaff, 1990; Pearlin, 1994; R. A. Pruchno & Potashnik, 1989; Schulz, Visintainer, & Williamson, 1990; Vedhara et al., 1999). Regarding physical health, caregiver spouses reported higher morbidity of diabetes, arthritis, ulcers and anemia with fewer doctor visits than expected (Bergman-Evans, 1994; R. A. Pruchno & Resch, 1989). Elderly caregivers of ADRD patients reported delayed wound-healing process because psychological stress can adversely affect the immune system (Kiecolt-Glaser et al., 1995). Also, they have shown more activated the hypothalamic-pituitary adrenal axis and less response to influenza vaccine antibody; that is, ADRD caregivers have a higher chance of getting infectious diseases than non-caregivers (Vedhara et al., 1999).

Depression and burden have been established as consequences of caregiving stress. The sense of hopelessness and loss of control of ADRD caregivers may influence the presence of depression (Bergman-Evans, 1994). Depression could be often increased in caregivers by the physical and emotional demands of caregiving (Fuller-Jonap & Haley, 1995; Schulz & Williamson, 1991). Not surprisingly, chronic strain of caregiving for a spouse with progressive dementia relates to the onset of depressive disorder in spite of no evidence of prior diagnosis of depression (Dura et al., 1991). In addition, spousal caregivers of ADRD patients expressed higher levels of negative affect, were more likely to use psychological drugs, and experience more psychological distress symptoms (Bergman-Evans, 1994; R. A. Pruchno & Resch, 1989).

Burden is defined as "the degree to which caregivers see their physical and emotional health, social life, and financial status affected as a result of caregiving" (Browning & Schwirian, 1994, p.19). Stress of caregiving often leads to a high level of caregiver burden (Zarit, Todd, & Zarit, 1986). Especially, caregiver burden is very important for ADRD caregivers because caregiver duties continue for a prolonged time (Acton & Kang, 2001). Patients' characteristics, caregiver characteristics, and caregiving context are considered as factors relating to caregiving burden (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Farcnik and Persyko (2002) and demonstrated treatment interventions to reduce caregiver burden. These treatment interventions include pharmacological treatment, Acetylcholinesterase inhibitors, psychosocial intervention, counseling, respite care and educational activities. The result of these treatments reduced caregiver burden; in addition, researchers suggested that combined intervention could be more effect to reduce caregiver burden.

Summary Summary

The SWEE intervention was tested in a home based study and its finding indicated that implementation of Web-based SWEE may provide a more convenient way than face-to-face methods for ADRD caregivers who have generally several barriers to access health care interventions or support for themselves. Fortunately several earlier studies demonstrated positive results of web-based intervention for ADRD caregivers. However, there is gap between heath care services that are provided by health care providers and health care services that are desired by health care consumers. In spite of the excellent potential of the Internet as a nursing delivery medium, its value will not be realized if patients do not accept it for nursing intervention. Therefore, there is a need to investigate the patients' acceptance of an Internet-based nursing intervention in order to understand the various drivers influencing acceptability along with the history of information technology system development. UTAUT will be utilized to predict the patients' acceptance of an Internet-based nursing intervention and to explain the various drivers influencing acceptance.

CHAPTER III

METHOD AND PROCEDURE

The purpose of this study was to test end-user acceptability of a web-based SWEE intervention designed to reduce stress in ADRD caregivers and to describe participants' experiences in using the website in order to better understand ADRD caregivers' website usage behavior. Previously, an in-home paper-based SWEE was performed to evaluate its efficacy but little is known about the efficacy of SWEE as a Web-based intervention for Alzheimer's caregivers.

Design of the Study

An experimental design was used because it is very well suited for testing the web-based SWEE for ADRD caregivers and its ability to help manage ADRD caregivers' stress through writing interventions (Pedhazur & Schmelkin, 1991). Participants were randomly assigned to either an experimental group or control group when they completed the consent form. Each participant was scheduled for a pre-test. Both experimental and control groups used the web-based writing system three times, spending twenty minutes every other day writing about their experiences as caregivers. Two post-tests were scheduled on the 4th and 30th day after the intervention to assess participants' perception of the system.

In addition to testing the web-based SWEE for ADRD caregivers, the primary purpose of this study was to test end-user acceptability of a web-based SWEE intervention. This was determined by sum scores of four UTAUT constructs, including behavioral intention to use, performance expectancy, effort expectancy, and facilitating conditions (Venkatesh et al., 2003). For finding-meaning, output quality was a mediating factor between performance expectancy and behavioral intention to use web-based SWEE. Actual usage was measured by completion of the web-based SWEE as designed.

Table 6. Research design

	Pre-tests I		Interv	Intervention		Post-tests	
Group						4 th day	30 th day
Experimental	R	Demographics	X ₁	X ₂	X ₃	CES-D	CES-D
(SWEE)		CES-D				BI	BI
Comparison	R	BI	C ₁	C ₂	C ₃	PILL	PILL
		PILL				FMTCS	FMTCS
		FMTCS				Post- writing	User acceptance

R = Randomization; 0 = observation point; X = experimental intervention points (every other day); C = Comparison intervention points (every other day); CES-D: Center for Epidemiological Studies Depression Scale; BI: Burden Interview; PILL: Pennebaker Inventory of Limbic Languidness; FMTCS: Finding Meaning Through Caregiving Scale

Development and Design of the Website

The research website was duplicated from the original study and included everything except the cortisol instruction in the original study. The original study was designed to evaluate the feasibility of an internet version of SWEE, a paper-based writing intervention which aimed to decrease the emotional and physiological burdens of caregiving in family caregivers of persons with ADRD. To evaluate the effective ness of the intervention, the original study included several measures to assess physiological and psychological responses to caregiving stress (Butcher, 2007). The cortisol level measurement in the original test was excluded from this study of web-based SWEE because checking cortisol levels increased withdrawal rates in the original study and added financial problems. ITC (Instructional Technology Centers) had been managing the website, programming and data server since the original study. The new server was tested several times to repair problems caused by incompatibility with the older program. This process was repeated several times until most known problems were resolved. However, even though we tested the website several times before launching, several issues appeared again. The biggest problem was that the web site did not work the way we designed it to. Although much effort was made to fix these problems, website managers determined that they could not be fixed due to outdated and complicated website design programming. Therefore, the researchers and website managers decided to rewrite the program using JAVA and JSP (JAVA Server Pages) backend instead of the ASP (Active Server Pages) used in the original website design framework.

Procedures: Website Operation

On-line journaling (SWEE) was implemented so that caregivers could access the intervention from their home computers. The intervention consisted of three twentyminute writing sessions scheduled every other day. The use of a web-based intervention allowed researchers to accept a much larger number of participants due to the elimination of time and area limitations (Sheese et al., 2004).

The homepage appeared with a greeting and a brief description of the study. It linked to the introduction to the study, frequently asked questions, eligibility criteria, and the informed consent form (Appendix C, p. 122). The introduction included a general explanation of the study (Appendix C, p. 123). Then FAQ (Frequent Asked Questions) gave more details about the purpose, how to participate in the study, procedures, required time, eligibility criteria, and participants' rights (Appendix C, p. 124-125). When a participant decided to participate in the study, he/she contacted the researcher by e-mail or phone. Then, a participant directly accessed the web-site to complete the on-line consent form which was an upgraded version of the paper-based consent form (Appendix C, p. 126-129). The on-line consent form had the same content as the paper format but it was much easier to complete. For example, for the paper format, a participant printed the form, signed up and mailed the signed consent form to a researcher. However, for the online consent form, a participant only needed to click the box "I agree" and fill out the blank field with his/her e-mail address. The e-mail address was needed to send the access code to a participant. When a participant completed the on-line consent form, the researcher and a participant received a confirmation e-mail which was automatically generated on the SWEE website. Then, the researcher randomly assigned the participant to either experimental or comparison groups by tossing a coin and the provided a participant with an access code which was required to create an ID and a password. The website had a scheduler function which helped participants to anticipate their scheduled study dates. The scheduler calculated the date automatically when the first date of the writing and clicked the icon 'update.' Then, the scheduler displayed the date of the pretest, the dates of the three writing sessions, and the two post-tests (Appendix C, p. 131). A participant completed the pre-test questionnaires for baseline information before starting the writing intervention on the web-site. Between the pretest and the interventions, a time gap of any amount was allowed. However, once the writing started, the time line was strictly controlled, with writing scheduled every other day. Both the experimental and comparison groups participated in the intervention on-line every other day on three separate occasions, writing and then submitting their writing samples each times. On the 4th day following the last writing session the participant was contacted and asked to complete the first set of post-test measures. Lastly, one month after completing the writing interventions, a participant was contacted again via e-mail to complete the last set of post-test measures including the web-based SWEE user acceptance measure. Pretest questionnaires included demographics, FMTCS (Finding Meaning Through Caregiver Scale), CES-D (Center for Epidemiological Studies Depression Scale), BI (Burden Interview), PILL (Pennebaker Inventory of Limbic Languidness). The first posttest questionnaires had FMTCS, CES-D, BI, PILL and Post writing questionnaires. The last questionnaires had FMTCS, CES-D, BI, PILL and User acceptance. Each questionnaire consisted of several pages, so whenever a participant finished each page, he/she clicked the "continue" button to go on to the next page. If any questionnaire was uncompleted, an error message appeared notifying participants to review their answers. The website allowed participants to come back to previous pages at any time before

clicking the "complete" button. When a participant came back to previous pages, a warning sign popped up to indicated that the data on the current page was not saved (Appendix C, p. 132-145). Also, the website provided a progress report page which displayed the completeness and availability of the each questionnaire and each writing. For example, if a participant completed only CES-D among the pre-test questionnaires, the progress report pages showed CES-D was "Complete" but demographics, BI, FMTCS, and PILL were "Incomplete." In addition, the website did not allow a participant to access the pages before the scheduled date. For example, if the first posttest questionnaires were scheduled on 7/14/2011, a participant could not access this page until this date (Appendix C, p. 130). For the writing interventions, both the experimental and the control groups had the same general writing instructions as well as specific and different instructions for each group. The webpages for writing had a timer which started when a participant clicked the "Start writing" button (Appendix C, p. 146-149). After twenty minutes, the timer stopped and writing contents were automatically saved on the database. When a participant completed the whole study, the website showed a thank you message. Appendix C included the webpages of the web-based SWEE (http://swee.its.uiowa.edu/swee/pages/home/index.jsp). Although the website provided a scheduler to help participants keep track of the dates of the study, the researcher also sent a personal reminder by e-mail the day before the pre and post-tests as well as before each of the three writing sessions.

Human Subject Protection

Microsoft SQL (Structured Query Language) server 2005 was used for the database which is secured by ITS –SPA (Instructional Technology Centers- Service Planning Area). In addition, SSL (Secure Sockets Layer) was utilized for security of the participants. Data was kept confidential. First, the researcher provided the participant with an access code which was required to create an ID and a password independently.

Second, data was stored in the secure server without individual identity information including all questionnaires and written narratives from the SWEE and comparison groups. Third, the key to the code was kept separate from the data, and was accessible to only members of the research team for the purpose of the study. Fourth, paper-based consent forms were located in locked cabinets.

Even though potential risks of this study were minimal, participants may have experienced increased physical symptoms and negative psychological symptoms because writing about a traumatic experience can exacerbate emotions associated with a difficult experience. If participants had any adverse psychological symptoms during the course of the intervention or following the intervention, the researchers offered supportive counseling as needed and referral of participants to a mental health professional if necessary. Any participant with a negative experience was able to withdraw from the study at any time. The website approved by the IRB.

Sample/Setting

The population of this study was made up of home based ADRD caregivers who could access and use the Internet. The major sources of care providers for most ADRD patients are family members such as spouses, children, siblings, or other relatives in the community (Administration on Aging, 2007; White & Dorman, 2000). Likewise, most participants for web-based studies for ADRD caregivers were spouses and adult children (Beauchamp et al., 2005; Brennan et al., 1991; Brennan et al., 1992; Brennan & Moore, 1994; Brennan et al., 1995; Glueckauf & Loomis, 2003; Glueckauf et al., 2004).

Inclusion criteria were: 1) caring for someone who was living at home and who had a memory loss due to any form of dementia like Alzheimer's Disease, Parkinson's or Huntington's disease; 2) were 18 years of age or older; 3) not paid for the care they provide; 4) were persons who spends on average 4 hours of day helping their relatives or friend. This included anytime that they spend watching, monitoring, assisting, or simply being available in case help was needed (even during hours that they are sleeping); 5) be able to read and type English on a computer; 6) had the ability to connect to the internet using home computers and be computer literate.

In addition, potential participants were excluded if they were: 1) seriously ill, requiring hospitalization or extended bed rest in the last 3 months or 2) depressive and experiencing anxiety, requiring the use of medications.

Recruitment of Participants

Recruitment was conducted through the Internet and several other methods. Information about the research including the study website and PI contact information was announced on these support group websites. Potential participants contacted the PI through e-mail or by phone. The setting for all comparison group activities and all experimental group SWEE interventions was in the participants' home using computers with Internet access.

The first trial to recruit participants was to release the study information in a news format to local media (Eastern Iowa plus Des Moines) and also to all daily and weekly papers in Iowa two times.

Next, I sent 138 e-mails to the National Alzheimer Association local chapters except local chapters that did not provide e-mail addresses on their websites and then sent them e-mails again after one month when there was no response the first e-mail. I asked them to disseminate the study information at their local support group meetings, or to post the study information on their local support group newsletters, on their websites or local chapter Facebook. The majority of responses from local chapters suggested contacting the central chapter or provided direct information about the TrialMatchTM, which is a collection of clinical trials for people with Alzheimer's, caregivers, families and researchers from the Alzheimer's' Association. Four of them were posting and disseminating the study information at local chapter meetings, local newsletters, or Facebook. Four local chapters chose not to disseminate the study information by themselves because they had not enough capacity to disseminate and conduct the study in their local chapters. At the same time, I tried to contact several caregiver websites to ask them to post the study information on their websites which were wellspouse.com, NFCA (National Family Caregivers Association: www.thefamilycaregiver.org), the ElderCare online (www.ec-online.net), and the network of cares senior and people with disabilities (www.networkcare.org). They allowed us to post study information on the discussion boards. NFCA posted the study information on the e-newsletters three times. Among those, the e-newsletter from NFCA was the most effective method for recruiting potential participants through the Internet. The mass mail system of the University of Iowa was employed to recruit people two times. Most of the potential participants contacted when e-newsletters were sent by NFCA and study information was disseminated by the mass mail of the University of Iowa.

In addition to these web-based recruitments, the STAR registry sent mails including brochures to 23 people who were listed on the database. During the recruitment, some people who were contacted about the study were willing to post the study information on their private blogs. Also, they disseminated information about the study to their relatives and friends.

Intervention

Experimental Group

The SWEE intervention for each participant consisted of three individual 20 minute writing sessions in their home computer settings. Pennebaker (1994) suggested that the best effects are created when the writing sessions are applied on consecutive days. We chose every other day because the caregivers were undergoing an on-going current stressor in being an ADRD caregiver and were therefore not writing about a past trauma like in most of the writing studies, but a current trauma. The consecutive

implementation had been reported to increase concentration in emotionally expressed writing and to decrease the potential missing data (Pennebaker, 1994). The family caregiver was asked to write for 20 minutes, expressing their deepest thoughts and feelings about their caregiving experiences (Appendix B).

Pennebaker and colleagues found that, over a short-time, participants may have experienced negative effects because writing about traumatic events may have intensified their emotions about the experience (Pennebaker, Colder, & Sharp, 1990; Pennebaker & Francis, 1996; Pennebaker, 1997). For this reason, any participant was free to withdraw from the study at any time when they experienced negative effects.

Comparison Group

In SWEE studies, the participants in the comparison group were asked to write for the same length of time as the participants in the experimental group. However, comparison participants were given a different writing assignment that did not involve the expression of the deep thoughts and feelings related to traumatic or stressful experiences (Pennebaker, 1994). Instead, participants in the comparison group were asked to write about topics more removed from the caregiving role because topics related to the caregiving role could be emotionally laden and potentially confuse the post-test measures (Appendix B).

Both Groups

For each writing session, confidentiality of written materials was emphasized. Data were automatically reserved in the main server that PI only could access with the authorized access code.



Figure 2. Internet study design

Website Instruments

User acceptance: The user acceptability was assessed by the sum scores of four constructs in the UTAUT model; behavioral intention to use, performance expectancy, effort expectancy, and facilitating conditions (Venkatesh et al., 2003). The measures for performance expectancy, effort expectancy, facilitating conditions, and behavioral intention to use were measured using modified versions of scales developed by McDaniel and Ko. Behavioral intention to use is influenced by performance expectancy and effort expectancy as well as by FMTCS directly. In addition, performance expectancy affects behavioral intention use through FMTCS indirectly. Actual use of web-based SWEE was measured in this study by whether or not the participant completed the web-based SWEE as designed or not. Actual use of the web-based SWEE was expected to be predicted by behavioral intention to use and facilitating conditions.

Variables	Construct (LV) definition/ Item (MV) in questionnaire			
Performance expectancy ^a : Caregivers' belief that SWEE usage improves managing their stress related to caregiving experience				
PE1	I found the web-based writing system useful for managing my stress related to caregiving			
PE2	Using the web-based writing system made it easier to deal with my stress related to caregiving			
PE3	Using the web-based writing system helped me express my issues related to caregiving at any time			
Effort expectancy ^a : ADRD caregivers' perception of ease of use associated with the use of the SWEE				
EE1	Leaning use the web-based writing system was easy for me			
EE2	I found the web-based writing system easy to use			
EE3	Using the web-based writing system tool too much time			
Facilitating conditions a: ADRD caregivers' beliefs of existing technical infrastructures including time that would support actual usage of SWEE				
FC1	I had the resources I needed to use the web-based writing system			
FC2	The web-based writing system was not compatible with other ways I manage my caregiving related stress			
Behavioral intention to use a: a measure of the strength of ADRD caregivers' intention to use the web-based SWEE				
BIU	I would use the system again for managing my stress related to caregiving			
Actual usage b: The web-based SWEE was completed of the study as designed				
AU	Completion of the web-based SWEE as designed			
^a Four-point scale: 1= strongly agree, 2=agree, 3=disagree, and 4=strongly disagree				

Table 7. Each item in the questionnaire related to the research model constructs

^b Dichotomous: 1= fail to complete the study as designed and 2= succeed to complete the study as designed

Measures of performance expectancy, effort expectancy, facilitating conditions and intention to use were reviewed and refined by Vesentash in 2003 and have been validated in several subsequent studies. Each consists of a four-point Likert scale, from 1= strongly disagree to 4 = strongly agree. According to Vekentash (2003) the reliability (Cronbach α) of these constructs are as follows: performance expectancy = .91- .92, effort expectancy = .90-.94, facilitating conditions = .83-.87, behavioral intention = .90.92. In addition, various studies have demonstrated the validity of constructs in various areas including in the healthcare field as well as in general populations. The results of studies that have examined the explanatory power and measurement validity of UTAUT suggest that UTAUT has an adequate ability to explain and predict user acceptance of new information technology. Participants were also asked open-ended questions about the positive and negative aspects of their experience using the web-based SWEE.

Finding Meaning Through Caregiving Scale (FMTCS) was used as an instrument for measuring meaning-making by Alzheimer's caregivers (Farran et al., 1999). This instrument was designed to measure the meaning attributed to caregiving experiences (Farran & Keane-Hagerty, 1991). The FMTCS consists of three subscales; Loss/Powerlessness (LP), which refers to caregivers' feeling of loss and powerlessness for their family members and themselves associated with the need for caregiving; Provisional Meaning (PM), which measures what is viewed as positive, what keeps caregivers going, and what is positive about their daily experiences; Ultimate Meaning (UM) is defined as a higher power, a philosophical or religious/ spiritual structure that caregivers use to attribute meaning to their experiences (Farran, 1997). The LP subscale includes 19 items and score ranges from 19 to 95 (M=64.86, SD=11.45). Caregivers high scores on LP have more feelings of Loss/Powerlessness. The PM subscale is composed of 19 items and has a score range from 19 to 95 (M=75.85, SD=8.88). The UM have 5 subscale items that scored of 5 to 25 (M=19.36, SD=4.22). Caregivers who report high scores on either PM or UM experience more feelings of provisional and ultimate meaning (Farran et al., 1999).

The Internal reliability of these scales has been shown to be .91 for Total Meaning (TM) and .89, .88, .91 for each subscale of the FMTCS (Farran et al., 1999). Construct and discriminated validity were established using general measures which were the Grief Experiment Inventory-Form B, the Life Attitude Profile-Revised (LAP-R), and other specific caregiver measures. In addition, an inverse relationship has been found between

PM (-.37) and UM (-.28) and depressed measure, CES-D (Farran et al., 1999). The Provisional Meaning subscale was most likely sensitive to the SWEE intervention scale (Butcher, 2004). For this study, the differences between the second posttest measure (30 days after the writing intervention) and the baseline measure for finding meaning was used to identify any mediating effects. One previous study of a writing disclosure intervention reported long-term positive effects of disclosure of thoughts and feelings as well as short term negative effects of the writing interventions (Pennebaker & Beall, 1986).

Pennebaker Inventory of Limbic Languidness (PILL): the PILL has commonly been used in SWEE studies to measure health complaints and physical symptoms with significant effects and to compare experimental and control groups (L. Greenberg, D'Andrea, & Lorence, 2004; J. M. Smyth, 1998; J. M. Smyth et al., 1999). The scores range from 0 to 54, with higher scores indicating more health complaints (Pennebaker, 1982).

Burden Interview (BI): The BI is one of the most common measures of burden for ADRD caregivers (Acton & Kang, 2001) because caregiver-stress has been strongly associated with a caregiver role (Zarit et al., 1986). The BI was designed to assess the level of burden that caregivers experience and has been developed to evaluate the relationship between caregiver stress and dementia-related behaviors, including behavior and memory problems and stages of functional and cognitive impairment (Zarit, Reever, & Bach-Peterson, 1980). It consists of 22-item self-report Likert scale (Vitaliano et al., 1991).

Center for Epidemiological Studies Depression Scale (CES-D): The CES-D was developed to assess symptoms of depression in the general population (Radloff, 1977). The CES-D has been one of the most commonly used depression scales for community dwelling adults (Irwin, Artin, & Oxman, 1999) and-also the most common scale to determine levels of depression in ADRD caregivers (Lawton, Brody, & Saperstein, 1989; Schulz et al., 1990). The CES-D has four symptom categories, including negative affect, positive affect, interpersonal problems, and somatic or retarded activities. It consisted of a 20 item self-report scale, each of which assesses current levels of depressive behavior.

Data Analysis

Quantitative data analysis

Data were analyzed using SPSS for Windows. Descriptive statistics including means, range and standard deviations were calculated for continuous variables, frequency, and proportions for categorical variables. The population distribution was assumed normality. If data violated the normality, either appropriate modifications would apply to the data or statistical analyses for non-normal data would be used.

Structural Equation Modeling (SEM) was used to specify the causal relationships of the constructs to one another as posited by underlying theoretical principles (Segars & Grover, 1993). Use of structural equation modeling was rapidly growing in psychology and the social sciences. SEM was a combination of the measurement model and the structural mode which were mathematically Confirmatory Factor Analysis (CFA) and path analysis, respectively (Kline, 1991). The measurement model evaluated the relationship between observed variables (measured variables) and hypothesized constructs (latent variables) (Weston, 2006). The structural model specified the relationships among latent variables. However, path analysis did not have the ability to represent latent variables or underlying factors. SEM had the ability to estimate an entire multivariate model with multiple and interrelated dependence relationships as well as unobserved concepts. SEM went beyond the provided information by path analysis, so it allowed for more precise estimation of the indirect effects or the latent variables (Musil, Jones, & Warner, 1998; Segars & Grover, 1993). These abilities were especially useful to this study because constructs of this model could not be measured directly (Wilson & Lankton, 2004). Mplus 5.2 was used as the primary data analysis technique. Mplus was a
flexible statistical modeling program to analyze the data which provided a wide range of selection from models, estimators, and algorithms in a program. Mplus allowed the analysis of cross-sectional and multilevel data with either observed or unobserved values. Analyses were performed for observed variables of continuous, binary, ordered categorical, unordered categorical, or a combination of these variable types. Capability of Mplus extended to Monte Carlo simulation studies, where data could be generated and analyzed according to any of the models including the program (Muthen & Muthen, 2010).

Qualitative data analysis

Qualitative content analysis has been applied in variety of data in nursing research and education. Direct content analysis was used for qualitative data analysis. This deductive method has been used for extending or validating theoretical frameworks or theories. Key themes as initial coding categories were identified based on the UTAUT model. Then, researchers highlighted all text that reflected core constructs of the UTAUT model which were usefulness of the intervention (performance expectancy), ease of use the intervention (effort expectancy), facilitating conditions, and intention to use the intervention. Text which could not be categorized into core constructs was coded in different labels related to the writing intervention. After coding, categories were examined again if they were needed to be subcategorized (Elo & Kyngas, 2008; Hsieh & Shannon, 2005).

Hypotheses	Variables	Tool/ Alpha	Data Analysis
The performance expectancy of the web-based SWEE will have a positive effect on ADRD	Performance expectancy	Performance expectancy = .91- .92	Structural Equation Modeling (SEM) Correlation
caregivers' behavioral intention to use the web-based SWEE	Effort expectancy	Effort expectancy = .9094	
The effort expectancy of the web-based SWEE will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE.	Behavioral intention to use	Behavioral intention to use = .9092	
The facilitating conditions will have a positive effect on ADRD caregivers' actual use of the wab based SWEE	Facilitating condition	Facilitating condition = .8387	-
ADRD caregivers' behavioral	Behavioral intention to use	Behavioral intention to use = .9092	
SWEE will have a positive effect on the actual use of the web- based SWEE.	Actual use	Completion of the web-based SWEE as designed	
The effect of performance expectancy on behavioral intention will be mediated by finding-meaning such that performance expectancy will have a positive effect on finding meaning through using the web- based SWEE which in turn will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE.	Performance expectancy	Performance expectancy = .91- .92	-
	Finding meaning	FMTCS = .91	-
	Behavioral intention to use	Behavioral intention to use = .9092	-
The combined scores for performance expectancy, effort expectancy, facilitating	Performance expectancy	Performance expectancy = .91- .92	-
conditions and behavioral intention to use will have a significant influence on ADRD caregivers' actual usage of the	Effort expectancy	Effort expectancy = .9094	-
web-based SWEE.	Facilitating condition	Facilitating condition = .8387	
	Behavioral intention to use	Behavioral intention to use = $90 - 92$	

Table 8. Research questions, construct, variable, measurements, and data analysis

CHAPTER IV

RESULTS

This chapter presents the results of the study. The results of recruiting participants for a Web-based study are presented first. The response rate and descriptive statistics of demographic data are described. The measures' reliability and validity are discussed, followed by the SEM (Structural Equation Modeling) analysis of the research model as well as the findings of research questions numbers one through six. Finally, the qualitative data about the web-based SWEE are described.

Analyses were conducted using Statistical Package for the Social Science (SPSS) Version 19 for descriptive data. In addition, SEM using the MPLUS version 5.2 by Muthen and Muthen was employed for the research model (Muthen & Muthen, 2010).

Results of the Web-based Recruitment Procedures

Information about the study was disseminated using both paper and web-based formats. An announcement about the study with contact information and the website address (See Appendix D) was sent to newspapers and local media in Eastern Iowa and Des Moines, to daily and weekly papers and to the newsletters of local Alzheimer's Association support groups. In addition, the study announcement was sent to individuals through the STAR registry which is a registry of persons residing in Iowa interested in participating in research studies that is maintained by the University of Iowa Center on Aging. TrialMatch[™], a registry maintained by the central chapter of the Alzheimer's Association, Alzheimer groups on Facebook, and the websites of local chapters of the Alzheimer's Association were also contacted and given study information. Study information was also disseminated via the Internet by a number of online caregiver support groups, such as: wellspouse.com, National Family Caregivers Association (www.thefamilycaregiver.org), and ElderCare online (www.ec-online.net), a network of caregivers of seniors and people with disabilities (www.networkcare.org), as well as by private blogs. The mass mail system of the University of Iowa was also employed to recruit subjects via the Internet. In addition to these paper and web-based recruitments, some people who were contacted about the study were willing to pass on information about the study to relatives and friends.

Most of the participants found out about the study through e-newsletters that were sent by NFCA and through the mass e-mailing to University of Iowa faculty members, staffs, students and employees in the listserve mailing list of the University of Iowa. A total of 125 potential participants contacted me either by e-mail or phone. 106 potential participants completed consent forms. Only a few people informed me of the reasons why they did not enroll the study. The reasons were that they lost interest in the study or did not meet the eligible criteria.

Of 90 caregivers who completed consent forms and enrolled in the study, 50 actually completed the study. Overall completion rates for the entire study were 55.6%, 54.7% (N=29 out of N=53) of those assigned to the experimental group and 56.8% (N=21 out of N=37) of the control group.

Of the 50 participants who completed the study, 29 had found out about the study through NFCA e-newsletters, nine from the mass e-mailing sent out to the University of Iowa listserve, five from friends or relatives, three from local Alzheimer Association support groups, two from local news letters, one from wellspouse.com and one from the STAR registry. Of the 90 people who enrolled the study, seven enrolled in the study but did not participate further. Seventeen people stopped participating in the study during or after the pre-intervention questionnaires. Ten participants withdrew from the study during or after the writings. Six participants completed the first post-writing questionnaires but did not complete the second set of posttest questionnaires on the 30th day after the third writing session (Table 9). Reminders were sent to participants did not show any study activity for more than a month, e-mail messages were sent to them to remind them

of the study. The e-mail messages included their study progress status and the link to the study website. In addition, an individual access code was included in e-mail to those who had completed the consent form but had not completed the enrollment process. A few people gave reasons withdrawing from the study. One care recipient passed away during the study. Two participants withdrew from the study because of health or personal problems. Six participants dropped out of the study because of technical problems. Most of these had trouble with the web-based survey forms and one had a problem with the writing section while accessing the web-page for writings. Others stopped participating in the study without any explanation even though a researcher tried to contact them to assess the reasons.

Even though reminder messages were sent the day before each scheduled study date, nineteen participants out of the 50 who completed the study did not follow the timetable established by the researchers for completing the pretest, intervention, and posttests. Reminders were sent to participants who missed a scheduled date to ask them to continue participating in the study. This study was originally designed with a precise timetable, but participants who missed dates were allowed to continue in the study and researchers assessed the actual usage of the web-based SWEE comparing the two groups of participants, those who completed the study as intended based on the designed schedule and those who completed the study but not according to the schedule.

Table 9	Particinants ²	progress	through	phases	of the	study
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The points at which subjects stopped participating in the study	Enrolled only	Pretest Intervention		tion	The 1 st posttest		Completion	
		Partial	Total	Partial	Total	Partial	Total	
# of subjects	7	4	13	5	5	0	6	50

Characteristics of the Participants

The characteristics of study participants are shown in Table 10. Their ages ranged from 29 to 82 years (mean=59.34, SD=12.18) in the experimental group and from 26 to 79 years (mean=56.95, SD=11.66) in the control group. Twenty-seven out of 29 participants in the experimental group were female (93.1%) and 17 out of 21 (61.9%) in the control group. The majority of the participants in both experimental and control groups were Caucasian (N=26, 89.7% in the experimental group; and N=20, 95.2% in the control group). The number of years of education of participants ranged from five to 20 years (mean=14.97, SD=3.32) in the experimental group and from one two 20 years (mean=15.29, SD=3.98) in the control group.

The participants reported a mean length of time since the onset of memory changes in care recipients of 56.69 months in the experimental group (SD=48.18, Minimum= 12, Maximum=192) and 63.38 months in the control group (SD=44.20, Minimum= 0, Maximum=180). The participants in the experimental group provided an average of 76.28 hours of care per week (SD=62.08, Minimum= 5, Maximum=168) and those in the control group provided care for an average 59.14 hours per week (SD=55.57, Minimum=5, Maximum=168). 89.7% of the participants in the experimental group and 85.7% of the control group had never received any caregiver training. Ten participants among 29 in the experimental and eight participants among 21 in the control group hired professionals or support staffs for an average of 20.9 hours per week (SD=15.92, Minimum=4, Maximum=50) and 19.88 hours (SD=25.27, Minimum=1, Maximum=63), respectively. The participants were spouses (N=11, 37.9% in the experimental group; N=10, 47.6% in the control group), offspring (N=12, 41.4% in the experimental group; N=8, 38.1% in the control group), friends (N=1, 3.4% in the experimental group; N=1, 4.8% in the control group), or others (N=5, 17.2 % in the experimental group; N=2, 9.5% in the control groups). There were no siblings in either group. The participants mostly

lived with care recipients only (N=13, 44.8% in the experimental group; N=8, 38.1% in the control group) or with more than one family member, one of whom was the care recipient (N=10, 34.5% in the experimental group; N=9, 42.9% in the control group). Otherwise they lived alone (N=1, 3.4% in the experimental group; N=3, 14.3% in the control group) or with one or more family members, none of whom was the care recipient (N=5, 17.2) in the experimental group; N=1, 4.8% in the control group). The majority of the participants did not attend a support group (N=24, 82.8% in the experimental group; N=18, 85.7% in the control group). The other participants in the experimental group attended a support group on average 2.0 times per month and those in the control group attended a support group an average of 2.0 times a month. Twenty-one participants (70.0%) in the experimental group and 16 participants (77.8%) in the control group did not utilize any respite care, while an average of 10.38 hours and 17.80 hours weekly of respite care was used by the other participants in the experimental and control groups respectively. The caregivers had a paying full time and a part time job (N=12, 41.4% in the experimental group; N=11, 52.4% in the control group). Participants were otherwise retired (N=8, 27.6% in the experimental group; N=6, 28.6% in the control group), laid off or unemployed (N=3, 10.3% in the experimental group; N=2, 9.5% in the control group), a full-time homemaker (N=2, 6.9% in the experimental group; N=1, 4.8% in the control group) and others. Eleven people (37.9%) in the experimental group and nine (42.9%) in the control group used \$10,000-\$30,000 of their average annual income to provide care. 20.7% of participants in the experimental group (N=6) and 28.6% in the control group spent from \$30,000-\$50,000 a year on care provision (N=6). 26.7% in the experimental group (N=8) and 14.3% (N=3) in the control group spent less than \$10,000 and 13.8% in the experimental group (N=4) and 14.3% (N=3) in the control group spent more than \$50,000 a year on care provision . Among participants, 44.8% (N=13) in the experimental group and 61.9% (N=13) in the control group stated that the caregiving role resulted in a financial burden for them. Fifteen participants in the experimental group

(50%) and 11 in the control group (52.3%) went to religious meetings or services at least once a week or more often. 72.4 % of the experimental group and 52.4% of the control group participants had never or almost never written down their thoughts and feelings in a journal or diary since becoming a caregiver. Diagnosis and medications varied. A series of t-test were conducted and showed no significant difference between groups in variables. In addition, the experimental group and the control group did not show any significant differences in finding-meaning through the writing intervention including total meaning, loss/powerlessness, provisional meaning and ultimate meaning (p>0.05).

There were some differences in baseline demographic characteristics between participants who completed the study (the completion group) and those who withdrew from the study (the non-completion group). Among the non-completion group (N=40), 32 people completed the demographic questionnaires. The average age of the completion group was 58.05 years (SD=12.54), which was older than non-completion group (mean= 53.13, SD=13.60). Most of participants in the completion and the non-completion groups were female (88.0% in completion and 87.5% in non-completion groups). The majority of the participants in both groups were Caucasians (N=46, 92.0% in the completion group; N=28, 87.5% in the non-completion group). The average number of years of education for both groups was around 15 years (mean= 15.10, SD= 3.58 in the completion group; mean=14.72, SD=5.11 in the non-completion groups).

The participants reported a mean length of time since the onset of memory changes in care recipients of 59.50 months (SD=46.18) in the completion group and 57.22 months (SD=54.01) in non-completion group. The participants in the completion group provided care to the care recipients for an average of 69.08 hours per week (SD=59.4) while those in the non-completion group provided 58.81 hours of care per week (SD=48.89). 74.6% of the participants in the completion group and 90.6% of those in the non-completion group had never received any caregiver training. Eighteen participants of the 50 in the completion group and twelve of the 32 in the non-completion

group hired professionals or support staffs for an average of 20.44 hours (SD=19.94) and 16.78 hours (SD=41.64), respectively per week. The relationship of caregivers to care recipients were mostly spouses and offspring in both groups (N=41, 82% in the completion group; N=26, 81.3% in the non-completion group). More than 40% of participants in both groups lived only with care recipients (N=21, 42.0% in the completion group; N=14, 43.8% in the non-completion group). The majority of the participants did not attend a support group (N=42, 84.0% in the completion group; N=29, 90.6% in the non-completion group). Thirty-seven participants out of 50(74.0%) in the completion group and 27 out of 32 in the non-completion group did not utilize respite care. The participants had a paying full time and a part time job (N=14, 28.0% and N=9, 18.0%, respectively) while the non-completion group had a job either full time (N=12, (140%) or part time (N=9, 28.1%). In the completion group, twenty people (40%) spent \$10,000-\$30,000 of their annual income on care-related expenses, and twelve spent \$30,000-\$50,000 (24.0%). In the non-completion group, the twelve people spent 10,000-30,000 and fourteen people spent less than 10,000 (43.8%). Almost half of the participants in both groups (N=26, 52.0% in the completion group; N=17, 53.1% in the non-completion group) stated that they had a financial burden related to their caregiving role. Twenty-six participants out of 50 in the completion group and ten participants out of 32 in the non-completion group went to religious meetings or services at least once a week or more often. 64.0 % of the completion group and 56.3% of the non-completion group had never or almost never written down their thoughts and feelings in a journal or diary since becoming a caregiver. A series of t-test were conducted and showed no significant difference between groups in variables. In addition, baseline scores for finding-meaning between the completion and the non-completion groups were not significantly different in total meaning, loss/powerlessness, provisional meaning, and ultimate meaning (p>0.05).

		Non-completion		
	Experimental group	Control group	Total	group
Variables		Mean ±SD (Mini	mum –Maximum)	
Age (years)	59.34±12.18 (29-82)	56.95±11.66 (26-79)	58.05±12.54 (26-82)	53.12±13.61 (24-84)
Education (years)	14.97±3.32 (5-20)	15.29±3.98 (1-20)	15.10±3.58 (1-20)	14.72±5.11 (1-26)
Months since memory changes of	56.69±48.14 (12-	63.38±44.20 (0-180)	59.50±46.18 (0-192)	57.22±54.01 (4-200)
care recipient	192)			
Average hours of providing care to	76.28±62.09 (5-168)	59.14±55.57 (5-168)	69.08±59.46 (5-168)	58.81±48.89 (4-168)
the care recipients (weekly)				
Hours for professional or hired	20.9±15.92 (4-50)	19.88 ±25.27 (1-63)	20.44±19.94 (1-63)	16.78±41.64 (4-168)
support in house (weekly)	N=10	N=8	N=18	N=12
Hours for utilizing respite care	10.38±9.04 (4-30)	17.80 ±19.91 (2-50)	13.23 ±13.92 (2-50)	5.2±2.18 (4-8)
	N=8	N=5	N=13	N=5
If the caregiver attend a support	2.0±0.70 (1-3)	2.0±1.00 (1-3)	2±0.76 (1-3)	$1\pm0(1-1)$
group, how many times (monthly)	N=5	N=3	N=8	N=4
Variables: Categories		Ν	(%)	
Gender:				
Male	2 (6.9)	4 (19.0)	6 (12.0)	4 (12.5)
Female	27 (93.1)	17 (81.0)	44 (88.0)	28 (87.5)
Ethnicity:				
Caucasian	26 (89.7)	20 (95.2)	46 (92.0)	28 (87.5)
African American	1 (3.3)	0 (0)	1 (2.0)	1 (3.1)
American Indian/Native American	0 (0)	0 (0)	0 (0)	0 (0)
Hispanic	0 (0)	0 (0)	0 (0)	0 (0)
Asian	1(3.3)	0(0)	1 (2.0)	2 (6.3)
Other	1 (3.3)	1 (4.8)	2 (4.0)	1 (3.1)
The caregiver live:				
Alone	1 (3.4)	3 (14.3)	4 (8.0)	5 (15.6)
With care recipient only	13 (44.8)	8 (38.1)	21 (42.0)	14 (43.8)

Table 10. Baseline characteristics of respondents-Continuous variables and categorical variables

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With more than one family member	10 (34.5)	9 (42.9)	19 (36.0)	6 (18.8)
(one of whom is the care recipient)				
With one or more family member	5 (17.2)	1 (4.8)	6 (14.0)	7 (21.9)
none of whom are the care recipient	, , ,		, , , , , , , , , , , , , , , , , , ,	、 <i>`</i>
Others	0(0)	0(0)	0 (0)	0 (0)
Receive caregiver training:				
Yes	3 (10.3)	3 (14.3)	6 (12.0)	3 (9.4)
No	26 (89.7)	18 (85.7)	44 (88.0)	29 (90.6)
Relationship to the care recipients:				
Spouse	11 (37.9)	10 (47.6)	21 (42.0)	10 (31.3)
Offspring	12 (41.4)	8 (38.1)	20 (40.0)	16 (50.0)
Sibling	0 (0)	0 (0)	0 (0)	0 (0)
Other relationship	5 (17.2)	2 (9.5)	7 (14.0)	5 (15.6)
Friend	1 (3.4)	1(4.8)	2 (4.0)	1 (3.1)
The caregiver attend a support group:				
Yes	5 (17.2)	3 (14.2)	8 (16.0)	4 (12.5)
No	24 (82.8)	18 (85.7)	42 (84.0)	28 (87.5)
Working status:				
Full-time	6 (20.0)	8 (38.1)	14 (28.0)	12 (37.5)
Part-time	6 (20.0)	3 (14.3)	9 (18.0)	9 (28.1)
Retired	8 (27.6)	6 (28.6)	14 (28.0)	2(6.3)
Laid-off or unemployed	3 (10.3)	2 (9.5)	5 (10.0)	3 (9.4)
A full-time homemaker	2 (6.9)	1 (4.8)	3 (6.0)	2 (6.3)
Other	4 (13.8)	1 (4.8)	5 (10.0)	4 (12.5)
Average annual income available for				
use to provide care:				
=< \$10,000	8 (26.7)	3 (14.3)	11 (22.0)	14 (43.8)
\$10,000 - \$30,000	11 (37.9)	9 (42.9)	20 (40.0)	12 (37.5)
\$30,000 - \$50,000	6 (20.7)	6 (28.6)	12 (24.0)	1 (3.1)
=> \$50,000	4 (13.8)	4 (14.3)	7 (14.0)	5 (15.6)

Table 10. Communed	Table	10.	Continued
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				-
The caregiving role result in a				
financial burden:				
Yes	13 (44.8)	13 (61.9)	26 (52.0)	17 (53.1)
No	16 (55.2)	8 (38.1)	24 (48.0)	15(46.9)
Frequency of attending religious				
meetings or services:				
Never or almost never	7 (24.1)	4 (19.0)	11 (22.0)	13 (40.6)
Once or twice a year	3 (10.3)	4 (19.0)	7 (14.0)	2 (6.3)
Every few months	$2(6.9)^{\prime}$	1(4.8)	3 (6.0)	6 (18.8)
Once a week	2 (6.9)	2(9.5)	4 (8.0)	3 (9.4)
More than once a week	10 (34.5)	5 (23.8)	15 (30.0)	3 (9.4)
Don't know	3 (10.3)	4 (19.0)	7 (14.0)	4 (12.5)
Prefer not to say	2 (6.9)	1(4.8)	3 (5.1)	$1(3.1)^{-1}$
Frequency of writing down thoughts				
and feelings :				
Never or almost never	21 (72.4)	11 (52.4)	32 (64.0)	18(56.3)
Once or twice a year	2 (6.9)	1 (4.8)	3 (6.0)	4 (12.5)
Every few months	3 (10.3)	4 (19.0)	7 (14.0)	5 (15.6)
Once a week	1(3.4)	1 (4.8)	2 (4.0)	4 (12.5)
More than once a week	0(0)	4 (19.0)	4 (8.0)	0 (0)
Every day	2 (6.9)	0 (0)	2(4.0)	1 (3.1)
Finding Meaning Through Caregiving		Mear	+ SD	• • • • •
Scale (FMTCS)		Wiedi		
Pretest:				
Total meaning	141.0±17.98	139.5 ±14.23	140.4 ± 16.44	127.32±22.43
Loss/powerlessness	67.87±7.03	65.45±7.10	66.90±7.08	77.39±13.23
Provisional meaning	75.80±12.17	72.9±9.62	74.64±11.21	71.03±12.12
Ultimate meaning	19.07±4.84	18.05±6.14	18.66±5.36	17.68±6.49
2 nd posttest:				None
Total meaning	129 52 124 55	134 25 + 23 24	136 82 + 23 89	
Loss/powerlessness	130.33 ± 24.33 71 52 ± 14.57	71.75+14.77	71.62 ± 14.50	
Provisional meaning	77.33 ± 14.37	73.85+11.71	75.92 ± 11.32	
Ultimate meaning	19.77 ± 5.04	18.15+6.17	18.52+5.97	
-	10.//±0.94	10110 _0117		

Statistical Analysis of Research Model using SEM

Structural Equation Modeling (SEM) was used to specify the causal relationships of the constructs to one another as posited by underlying theoretical principles (Segars & Grover, 1993). Use of structural equation modeling has been rapidly growing in psychology and the social sciences. Mathematically, SEM is a combination of Confirmatory Factor Analysis (CFA) and path analysis, respectively (Kline, 1991). However, path analysis does not have the ability to represent latent variables or underlying factors. SEM can be used to test multivariate model with multiple and interrelated dependent relationships as well as unobserved concepts. SEM goes beyond the information provided by path analysis, and so it allows for more precise estimation of indirect effects or latent variables (Musil et al., 1998; Segars & Grover, 1993). These abilities were especially useful in this study because the constructs being tested could not be measured directly (Wilson & Lankton, 2004).

Measurement Model Evaluation

The reliability as determined by Cronbach's alpha or internal consistency indicates the extent to which indicators accurately represent the underlying true score of the constructs. Through this process, measurement errors can to be identified so that better measures can be utilized or errors can be accounted for in the subsequent analysis. The reliability of performance expectancy and effort expectancy were 0.884 and 0.728 respectively, which indicated that measurement errors were relatively small. The reliability of facilitating conditions-was 0.661 but it was close to 0.7 (Fornell & Larcker, 1981).

The model also demonstrated convergent validity. As shown in Table 11, factor loadings of all items on their respective associated constructs are equal or greater than 0.70 in rounded integer while their loadings on unrelated constructs are lower (Barclay, Higgins, & Thompson, 1995; Kijsanayotin et al., 2009). For adequate discriminant validity, the diagonal elements should be greater than the off-diagonal elements in the corresponding rows and columns. The measures are highly related, but the constructs are different from other constructs, thus demonstrating discriminant validity (Kijsanayotin et al., 2009). Therefore, discriminant validity is demonstrated by this model as indicated in Table 11.

	Performance expectancy	Effort expectancy	Facilitating conditions	Behavioral intention to use	Actual usage
PE1	0.911	0.234	0.435	0.63	-0.074
PE2	0.938	0.13	0.32	0.585	-0.026
PE3	0.862	0.319	0.345	0.509	0.04
EE1	0.073	0.821	0.201	0.228	0.235
EE2	0.275	0.888	0.527	0.461	0.143
EE3	0.285	0.707	0.424	0.361	0.124
F1	0.38	0.502	0.836	0.383	0.044
F2	0.333	0.332	0.896	0.533	0.053
BIU	0.635	0.429	0.536	1	0.045
AU	-0.021	0.209	0.056	0.045	1

Table 11. Correlation matrix: Loadings and cross loadings of individual items on their constructs

*Diagonal elements: Items loadings on their theoretically associated factors are highlighted in bold.

Structural Model Evaluation

Structural model evaluation was used to assess the predictive or causal relationship between constructs in the model. The overall results are exhibited in Figure 3 and represent 50 users. Figure 3 shows the path coefficients (β) and the explained variance (\mathbb{R}^2) for each path segment in the model.



Figure 3. SEM path analytic results

Note: Finding meaning: Total meaning * p<0.01

The constructs of performance expectancy, effort expectancy and findingmeaning were predictive of ADRD caregiver's behavioral intention to use the web-based SWEE, with an R-square of around 52%. Performance expectancy and effort expectancy played a substantial role in explaining the use of the web-based SWEE by ADRD caregivers while facilitating conditions and finding-meaning played minimal roles. R^2 was slightly different depending on finding-meaning subscales. Behavioral intention to use the web-based SWEE and facilitating conditions accounted for only R^2 of .066 in predicting the actual use of SWEE. In addition, there was no significant difference between the experimental and the control group. In other words, the performance expectancy and the effort expectancy significantly influenced behavioral intention to use whether the participants wrote about their feelings/ thoughts (the experimental group) or whether they wrote about something else (the control group). Also, performance expectancy did not significantly influence find-meaning in the experimental and control groups. Finding-meaning did not significantly influence the behavioral participant's intention to use the web-based SWEE whether the writing was about feelings/thoughts or not. Actual usage of the web-based SWEE was not strongly associated with either behavioral intention to use or facilitating conditions regardless of the writing topics.

The data showed a good fit with the model, with Chi-square values (df=43) of 57.191 (p > 0.05), 55.257 (p > 0.05) and 50.994 (p > 0.05) and CFI (Comparative Fit Index) values of 0.939, 0.938 and 0.965 for total meaning, provisional meaning, and ultimate meaning, respectively. The Chi-value for loss/powerless was 61.990 (p < 0.05). RMSEA (Root Mean Square of Error Approximation) revealed a good model fit with 0.081, 0.094, 0.087 and 0.061 for total meaning, loss/powerlessness, provisional meaning, and ultimate meaning, respectively. Guidelines for acceptable fit included a non-significant Chi-square value, CFI greater than 0.9 and RMSEA less than 0.10 with a maximum upper bound of the 90% CI of 0.10 (Weston & Gore Jr., 2006).

Mediators	Total meaning	Loss/powerlessness	Provisional meaning	Ultimate meaning
Chi-square	57.191 (p >0.05)	61.990 (p <0.05)	55.257(p>0.05)	50.944 (p>0.05)
CFI	0.939	0.921	0.938	0.965
RMSEA	0.081	0.094	0.083	0.061
SRMR	0.092	0.094	0.087	0.085

Table 12. Model fit indices

*Chi-square: non-significant indicates good model fit; CFI (Comparative Fit Index): greater 0.90; RMSEA (Root Mean Square Error of Approximation): less than 0.10; and SRMR (Standardized Root Mean Square Residual); less than 0.10 are acceptable fit guidelines (Weston & Gore Jr., 2006)

The performance expectancy of the web-based SWEE intervention will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE.

Performance expectancy had a significant effect on behavioral intention to use the

web-based SWEE (β =0.612 – 0.632, p<0.01). The path coefficients were slightly

different depending on mediators even though there was no statistically significant mediating effect between performance expectancy and behavioral intention to use the system. Performance expectancy was the strongest predictor of behavioral intention to use the system. However, although it was not statistically significant, performance expectancy most strongly predicted behavioral intention to use the system when mediated by feelings of loss or powerlessness related to caregiving experiences (β =0.632), followed by meaning of total meaning, provisional meaning and ultimate meaning in β =0.620, 0.612, and 0.612, respectively. It indicated, overall, that ADRD caregivers' belief that using SWEE would help them manage their caregiving related stress was directly associated with an intention to use the web-based SWEE when they had feelings of loss or powerlessness because of their caregiving experiences. The stronger the belief that SWEE would help them manage their stress, the stronger their intention to use was.

The effort expectancy of the web-based SWEE intervention will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE.

Effort expectancy had a significant effect on behavioral intention to use the webbased SWEE (β =0.277 – 0.296, p<0.01). The path coefficients were slightly different depending on mediators even though there was no statistically significant mediating effect between performance expectancy and behavioral intention to use the system. Effort expectancy mostly strongly predicted behavioral intention to use the system when caregivers had feelings of loss or powerlessness related to caregiving experiences (β =0.296), followed by meaning of total meaning, provisional meaning and ultimate meaning in β =0.293, 0.280, and 0.277, respectively. It indicated that ADRD caregivers perception that the web-based SWEE was easy to use was directly associated with a stronger intention to use the web-based SWEE for ADRD caregivers when they had feelings of loss or powerlessness related to caregiving experiences.

The facilitating conditions will have a positive effect on ADRD caregivers' actual use of the web-based SWEE.

Facilitating conditions had no relationship to actual use of the web-based SWEE by ADRD caregivers (p>0.05). This implies that ADRD caregivers' belief in the existence of technical infrastructures supporting the system is not related to their actual use of the web-based SWEE.

ADRD caregivers' behavioral intention to use the web-based SWEE intervention will have a positive effect on actual use of the web-based SWEE.

A behavioral intention to use the web-based SWEE was not strongly associated with actual use of the web-based SWEE by ADRD caregivers (p>0.05). This indicates that measures of the strength of ADRD caregivers' intention to use the web-based SWEE did not significantly predict actual use of SWEE (which means the web-based SWEE was completed as designed).

The effect of performance expectancy on behavioral intention will be mediated by finding-meaning such that performance expectancy will have a positive effect on finding meaning through using the web-based SWEE which in turn will have a positive effect on ADRD caregivers' behavioral intention to use the web-based SWEE.

For this research model, the second post-test measure (30 days after the writing intervention), used as an indicator of finding-meaning, did not play as strong role in in mediating the association between performance expectancy and ADRD caregiver behavioral intention to use the web-based SWEE. To demonstrate, performance expectancy influences finding-meaning, which, in turn, influences behavioral intention to use the web-based SWEE. Also critically, there must be a significant association between performance expectance and behavioral intention to use the web-based SWEE before testing for finding-meaning as a mediated effect. The data show that there was a significant association between performance expectancy and caregiver behavioral intention to use the web-based SWEE. However, there was no significant relationship between performance expectancy and finding-meaning or between finding meaning and the behavioral intention to use the web-based SWEE. The FMTCS (Finding Meaning

Through Caregiving Scale) consists of three subscales which measure loss/powerlessness, provisional meaning, and ultimate meaning. Examining these subscales separately, as well as the total scale showed no statistical significance among these four scales.

The combined scores for performance expectancy, effort expectancy, facilitating conditions and behavioral intention to use will have a significant influence on ADRD caregivers' actual usage of the web-based SWEE.

There were no significant effects of performance expectancy, effort expectancy, facilitating conditions, and behavioral intention to use the web-based SWEE and composite score on actual usage of the web-based SWEE for ADRD caregivers. This suggests that completing the web-based SWEE as designed could not be predicted or explained by caregivers' belief that SWEE usage would help them manage stress related to caregiving experiences, or by caregivers perception of the system's ease of use, or by caregivers belief in existing technical infrastructures that would support SWEE, or by a measure of strength of ADRD caregivers' intention to use the web-based SWEE.

Path	Standardized Path Coefficient (β)					
	Total meaning	Loss/Powerlessness	Provisional meaning	Ultimate meaning		
$PE \rightarrow BIU$	0.620*	0.632*	0.612*	0.612*		
$EE \rightarrow BIU$	0.293*	0.296*	0.280*	0.277*		
$PE \rightarrow FM$	0.180	0.274	0.101	0.044		
$\mathrm{FM} \rightarrow \mathrm{BIU}$	0.090	-0.112	0.002	0.012		
$FC \rightarrow AU$	0.118	0.120	0.097	0.117		
$BIU \rightarrow AU$	0.045	0.043	0.056	0.045		

Table 13. Path coefficients (β) for constructs

PE: Performance expectancy; EE: Effort expectancy; BIU: Behavioral intention to Use; AU: Actual usage; FC: Facilitating conditions; FM: Finding-meaning; *p <0.01

Participants' Perspectives of the Web-based SWEE

The participants were asked three open-ended questions about their experiences using the website which were analyzed based on the UTAUT core constructs to understand ADRD caregivers' website usage behavior. Forty-eight participants provided the comments about the web-based SWEE experiences (Table 14).

The core constructs of the UTAUT model will be described by ADRD caregivers who are end-users of the Web based SWEE.

Based on the UTATU model constructs, four themes were identified including: usefulness of the intervention (performance expectancy), ease of use of the intervention (effort expectancy), facilitating conditions, and behavioral intention to use the system. Then, all transcripts were carefully reviewed and all comments relating to the four themes were highlighted. These highlighted texts were each assigned to a theme. Remaining highlighted texts related to the writing intervention were labeled as associated with the writing intervention.

The theme of usefulness of the intervention was categorized into 'the intervention was helpful' and 'the intervention was not helpful.' 'The intervention was helpful' was subcategorized into helpful; feeling better/stress relief; expressing feeling, thoughts, and problems; identifying feelings, thoughts and emotions; liking the writing tasks; no criticisms of the writing contents or topics. The category of "the intervention was not helpful' was subcategorized as follows; dislike the writing topics; dislike the contents of questionnaires such as the use of the word 'God'; waste of time. Not surprisingly, participants in the experimental group expressed opinions about the helpfulness of the intervention group. Two participants in the control group even said that this intervention was waste of time. Participants who did not like the questionnaires were found in both groups.

Theme	Categories	Subcategories	С	E
			(N)	(N)
Usefulness of	The intervention	Helpful	2	2
the	was helpful	Expressing feelings, thoughts, and	4	10
intervention	-	problems		
		Identifying feelings, thoughts and	3	6
		emotions		
		Liking the writing tasks	3	6
		Feeling better/stress relief	1	4
		No criticisms of the writing contents	4	3
		or topics		
	The intervention	Not helpful	3	1
	was not helpful	Dislike the writing topics	13	2
	1	Dislike the contents of questionnaires	5	8
		such as the use of the word 'God'	-	-
Ease of use the	Ease of use/User	None	7	9
intervention	friendly			-
	Technical		1	5
	problems (negative		-	C
	aspects of the			
	system)			
Facilitating	Time	Time constraints of writing	1	10
conditions		interventions		-
		Lack of time available to spend on the	4	2
		SWFF intervention		
	Needs feedback	None	1	2
	from the writings	None	1	2
Intention to	Continue to use the	Naga	0	2
Intention to	Continue to use the	INORE	0	3
use the	system			
Finding	Dlagging taking	None	1	0
rinding	blessing taking	INOILE	1	0
positive magning of	care of care			
ineaning of	recipient			
categiving				
through				
writings				
Consequences	Felt had feelings	None	0	2
of the writing	and frustrated		0	2
intervention	The study strassed		1	0
	the difficult and		1	U
	sad part of			
	sau part or			
	Calegrying			

Table 14. Content analysis of qualitative data

C: Control group; E: Experimental group

The next theme was ease of the use the intervention which was categorized into ease of use/ user friendliness and technical problems. Interestingly, more participants in the experimental group had technical issues. Facilitating conditions was categorized into time and needs feedback from the writings. The category of time was subcategorized into the time constraints of writing interventions; lack of time available to spend on the SWEE intervention. Most participants who mentioned time constraints were in the experimental group. Three participants expressed opinions about their intention to use the intervention. There were two additional themes related to the writing intervention. One was finding positive meaning in caregiving experiences through the writings. The other was the consequences of the writing intervention. The raw qualitative data is summarized in Appendix E.

CHAPTER V DISCUSSION

This chapter presents a discussion of the general findings of this study. After the research findings are summarized, several conclusions are presented. These conclusions describe the implications for practice (intervention web-design) and research, describe the limitations of the current study, and discuss directions for future research and the potential contribution to the field of nursing.

Demographic Characteristics

Compared to previous studies of Web-based nursing interventions for ADRD caregivers, the average age of the participants in this study was 58.05 years, which, with one exception (Beauchamp et al., 2005), was less than the average age of participants in other internet based nursing intervention studies of ADRD caregivers (60.3 to 68 years in Brennan et al., 1991; Brennan et al., 1991; Brennan et al., 1991; Brennan et al., 1992; Brennan et al., 1995; Glueckauf & Loomis, 2003; Glueckauf et al., 2004). However, most of the caregivers (65%) in this study were over 55 years which is consistent with ADRD caregivers in general (Alzheimer's Association, Thies, & Bleiler, 2011). The gender, race and relationship to care recipients of study participants were similar to prior studies; participants were mostly women, Caucasians and spouses. Participants' education levels were slightly higher than in previous studies, at 15.01 years compared to approximately14 years. This is also higher than the education level of ADRD caregivers in the general population, which is less than a college degree. Most participants were recruited via the Internet and previous studies have reported that Internet users tend to be more educate (Alzheimer's Association et al., 2011; Dickerson et al., 2004). The length of time spent caregiving was much longer in this study than in other studies at 59.50 months compared to 36 months. Almost half the participants were employed, either in full-time

or part-time jobs, and half were unemployed. The employment status of participants has varied from study to study (Beauchamp et al., 2005; Brennan et al., 1991; Brennan et al., 1991; Brennan et al., 1992; Brennan et al., 1995; Glueckauf & Loomis, 2003; Glueckauf et al., 2004). In addition, more than half of the participants in this study had not received any caregiving training or attended caregiver support groups. This is consistent with other research studies of ADRD caregiver support groups (Brennan & Moore, 1994; Brennan et al., 1995; Hekelman et al., 1994). More than half of the participants had never written down their thoughts and feelings about their caregiving experiences before this intervention. However, the qualitative comments revealed that participants in both groups were willing to write or express something related to their caregiving experiences.

Web-based Nursing Research

Research participants were recruited using both traditional and Internet formats. Traditional formats included local newspapers (from Eastern Iowa and Des Moines), daily and weekly papers in Iowa, and local support group newsletters published by the Alzheimer's Association and the STAR registry. Web-based formats included TrialMatch[™], a web-based recruitment toll used by the central chapter of the Alzheimer's Association, Facebook, the websites of local chapters of the Alzheimer's Association, and online caregiver support groups, such as wellspouse.com, NFCA (www.thefamilycaregiver.org), ElderCare online (www.ec-online.net), a network of carers of seniors and people with disabilities (www.networkcare.org) as well as private blogs. These were used to distribute study information through the Internet along with the mass mailing system of the University of Iowa. The number of participants recruited using the Internet was much higher than through the paper-based formats. This was because of the nature of the Internet communication, such as its high speed, flexibility and easy access to potential participants (Im & Chee, 2003). The responses of potential participants to study information disseminated via the internet in e-newsletters or mass mailing systems were fast. For example, most people who were interested in the study contacted me within a week from 19 states including Iowa, Florida, Illinois, California, and New York. The Internet provided more opportunities to reach a wider population and send out information about a study without time or area restrictions. In addition, potential participants were able to ask questions about the study by e-mail (Duffy, 2002; Im & Chee, 2003). The on-line consent form of the web-based SWEE was another feature which helped potential participants start the study without delay. Prior to the on-line format, a paper consent form had been used. Participants had to print the form out, sign their name and mail the paper consent form to the researcher. These steps took more than 2 weeks from the beginning of the sign-up process to the point when the researcher received the paper consent form. However, the on-line consent form took almost no time; the participant simply had to click the box to agree to the informed consent. Although participants could not compare the two systems, participants who were in the transition period between the two formats were willing to wait for the on-line version (Im & Chee, 2003; Rhodes, Bowie, & Hergenrather, 2003).

E-mail reminders were used to ensure that participants followed the study schedule which consisted of three pieces of writing, one every other day, and two posttest questionnaires on the 4th and the 30th day of the study following the last writing session. In addition, an on-line scheduler was set up on the study website to help participants schedule study days. However, surprisingly, almost half of the participants did not adhere to the recommended study schedule. (Prior to evaluating the effects of the web-based SWEE for ADRD caregivers, this study evaluated the acceptance of the webbased SWEE for ADRD caregivers by employing the UTAUT model.) Most did not explain why they missed the scheduled dates. Several participants offered reasons that were related to their caregiver situations, such as a care recipient's health problem or their own conditions, which prevented them from following the study. Although web-based nursing interventions have been developed to increase the opportunities for ADRD caregivers to participate in nursing interventions (Brennan et al., 1991; Brennan, 1995), lack of time and respite care continue to be barriers for ADRD caregivers. Often, time was not considered as a restricting factor of web-based interventions and research because of asynchronous and synchronous interaction; however, time was an important factor influencing the data collection process because some participants missed the study dates when these dates fell on weekends, holidays and/or vacations. Thus researchers should look more carefully at time issues and plan data collection processes to avoid these days (Im & Chee, 2003). Qualitative data support this observation: several participants complained about the time constraints of the writing intervention itself and the lack of time they had generally for spending on the system.

Approximately half of the participants withdrew from the study at various points, including at the enrollment stage, and during the pre-writing questionnaires, writing interventions, or post-writing questionnaires. A few people gave reasons for withdrawing from the study. These included the death of a care recipient during the study, health or personal problems and technical problems. The technology itself caused problems (Stewart, 2003). Most people had trouble with the web-based survey forms and one had a problem with the writing section. Whenever problems were reported, researchers tested the website and reported the problems to a web-master. However, in all cases, the researcher and webmaster could not find any problems with the website and advised participants to try one more time or asked them to enter information using the correct format and numeric values. Unfortunately, some participants dropped out of the study when they experienced technical problems. A web-master who was an expert in the webbased SWEE website provided support in managing technical problems (Im & Chee, 2003).

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Evaluating Acceptance of the web-based SWEE for ADRD

caregivers by the UTAUT Model

The purpose of this study was to identify factors that predict and explain ADRD caregivers' intention to use and their actual use of the web-based SWEE by employing an adapted UTAUT model. The analyses revealed that perceptions of the usefulness (performance expectancy) of the web-based SWEE and the ease of use (effort expectancy) were two significant predictors of a participant's behavioral intention to use the web-based SWEE (hypothesis 1 and 2). These two predictors were extensive and accounted for about half of the variance in the behavioral intention to use the web-based SWEE. Especially, performance expectancy was the strongest influencing factor. These findings are consistent with a number of prior studies which also demonstrated greater effects of performance expectancy than effort expectancy on behavioral intentions to use web-based intervention tools (Kijsanayotin et al., 2009; OR et al., 2008; Venkatesh et al., 2003). Even though the research findings showed no statistically significant differences between the experimental and the control groups in the effects of performance expectancy on behavioral intention to use, qualitatively, the comments of some subjects indicated differences between the two groups. Not surprisingly, participants in the experimental group reported that the writing intervention was helpful for them while participants in the control groups said that the intervention was not helpful. Participants in the control group disliked the writing topics. Similar to prior studies, effort expectancy and ease of use had a positive and significant influence on the intention to use the information systems (Kijsanayotin et al., 2009; OR et al., 2008; Taneja, 2009; Venkatesh et al., 2003). In addition, even though performance expectancy is considered to be the strongest predictor in almost any situation, effort expectancy may be moderated by age, gender, and experiences. In other words, effort expectancy is more significant for women and older people. The effects of effort expectancy on behavioral intention to use decreased for people with more experience

with computers and/or the Internet (Venkatesh et al., 2003). Also, lack of experience of writing about caregiving experiences could explain the weak relationship between effort expectancy and behavioral intention to use the web-based SWEE (Holden & Karsh, 2010). One possible reason for the weak effect of effort expectancy was the characteristics of the study participants. Compared to the general population using the Internet, this study's participants were mostly women with an average age of 58 years who often have less experience with computer and/or the Internet and therefore may generally have a higher effort expectancy. However, one of the eligibility criteria for this study was the ability to access the Internet, which indicates that all participants had some experience with and knowledge of Internet usage. This factor could explain why effort expectancy was a weaker predictor than performance expectancy of behavioral intention to use the web-based SWEE for ADRD caregivers (Li & Kishore, 2006; Venkatesh et al., 2003).

The results showed that actual usage of the web-based SWEE by ADRD caregivers was not predicted by behavioral intention to use or by facilitating conditions (hypothesis 3 and 4). Only seven percent of variance in the use of the web-based SWEE by ADRD caregivers was explained by these two factors. This outcome suggests that removing barriers and providing technical support to ADRD caregivers did not significantly influence the completion of the web-based SWEE as designed by ADRD caregivers. However, the effect of facilitating conditions may not be accurately reflected in this study because several participants withdrew when they encountered technical problems related to the website, and so they did not have opportunities to express their opinions in either UTAUT model analyses or open-ended questions. Effects of behavioral intention to use on actual usage of the web-based SWEE were not significant. ADRD caregivers' motivation or intention did not predict or explain whether or not they completed the web-based SWEE as designed. There was an inconsistent or consistently weak relationship between behavioral intention to use and

actual usage of the web-based SWEE (Holden & Karsh, 2010). Even though the results did not show that behavioral intention to use or facilitating conditions had a statistically significant effect on actual usage of the web-based SWEE by ADRD caregivers, the positive relationship between these two constructs - behavioral intention to use and facilitating conditions - and actual usage were consistent with the findings of previous IT adoption research studies (Kijsanayotin et al., 2009; Venkatesh et al., 2003). The effect of facilitating conditions decreased with more experience or knowledge of information system use (J. E. Anderson et al., 2006; Venkatesh et al., 2003). Even though this study did not ask about participants' previous experience s of the Internet or information systems, most participants received were recruited via the Internet. Therefore, it can be assumed that they had some familiarity with computers and the Internet. In addition, we hypothesized that actual usage of the web-based SWEE could be predicted by composite scores of performance expectancy, effort expectancy, facilitating conditions, and behavioral intention to use the web-based SWEE. This hypothesis assumed that ADRD caregivers who complete the web-based SWEE as designed would have higher performance expectancy, effort expectancy, facilitating conditions, and behavioral intention to use the system (hypothesis 6). However, the results showed that whether or not ADRD caregivers completed the web-based SWEE as designed was not influenced by these four constructs. This could be explained by the validity of the actual usage measure. We measured actual usage by the numbers of participants who completed the interventions as designed. In other words, participants had to complete all the sections and stay on schedule. This was seen as measure of the success the system. However, this means that actual usage had only one indicator, and even though this indicator did not have any statistical problems it may have been too restrictive to capture actual use (Weston & Gore Jr., 2006).

Another way to evaluate caregiver acceptance of this information system could be to use behavioral intention to use the web-based SWEE as the measure of acceptance instead of actual usage. Previous research has reported that the most proximal antecedent to actual use of an intervention is the behavioral intention to use it, and this is now commonly what is meant when researchers refer to acceptance. Behavioral intention to use information technology is thought to reliably predict actual use and behavioral intention to use is sometimes the only measured outcome of interest in a study using TAM (Technology Acceptance model) (Holden, 2010). UTAUT is a model with an obvious resemblance to TAM. In several empirical studies which have used TAM, behavioral intention to use the system has been the measure of user acceptance instead of actual usage (Hu et al., 1999; Mathieson, 1991; Szajna, 1996). Hill, Smith and Mann (1987) have argued that that behavioral intention can significantly predict action. Davis et al (1989) found that behavioral intention to use a system is significantly correlated with actual usage, and that behavioral intention is a major determinant of user behavior, while other factors influence user behavior indirectly by affecting intentions. According to Mathieson (Hill et al., 1987), behavioral intention can be justified as the dependent variable based on the strong causal link between intentions and actions and they conclude that "the fact that behavior was not directly assessed is not a serious limitation" (p.186). A number of prior studies have proposed that behavioral intention to use a system is a logical indicator of future system usage (Jackson, Chow, & Leitch, 1997).

Finding-meaning was a variable consisting of total meaning, loss/powerlessness, provisional meaning, and ultimate meaning. The results showed that none of these variables had mediating effects between performance expectancy and behavioral intention to use the web-based SWEE. This shows that ADRD caregivers' belief that SWEE intervention would help reduce stress related to caregiving experiences did not affect the meaning they attributed to these caregiving experiences in their writing. Nor did the finding meaning variable affect caregivers intention to use SWEE, even though performance expectancy had the strongest effect on behavioral intention to use. Even though there were no mediating variables between performance expectancy and behavioral intention to use, qualitative data showed that some participants used SWEE to identify and express thoughts and feelings. For example, one caregiver wrote that "it is a blessing taking care of the care recipient" which is an example of finding positive aspects to caregiving experiences. Frattaroli (2006) has said that disclosing thoughts and feelings helps to foster positive attitudes toward intervention and improves outcomes. However, the writing intervention may possibly have enhanced the negative aspects of caregiving experiences (Smyth, Stone, Hurewitz, & Kaell, 1999). Qualitative comments consisted of expressions of bad feelings and frustration as a result of writing. One participant commented that the study stressed the difficult and sad part of caregiving.

Overall, the UTUAT model showed a good fit with the data in spite of a small sample size. Previous guidelines for sample size have suggested 10 to 20 participants per estimated parameters (Kline, 1998) or a minimum sample size of 200 for any SEM anticipating no problem with data (Weston & Gore Jr., 2006). The sample size of this study (N=50) did not meet these guidelines which could affect the model fit (Weston & Gore Jr., 2006). This study provides further evidence for the basic validity of the UTAUT model by confirming the significant effects of performance expectancy and effort expectancy on behavioral intention to use new information technology (Venkatesh et al., 2003). However, behavioral intention to use and facilitating conditions had a weak correlation to actual usage of SWEE. Also, output quality, finding-meaning, was not supported by the modified UTAUT model. Although our model did not explain actual use of SWEE to the same extent as the original UATUA model, our modified UTUAU model provides a better understanding of the web-based SWEE acceptance by ADRD caregivers. Moreover, out study demonstrates the validity and reliability of the core constructs of the UTAUT model.

Implications of Findings

Implications for Practice (web-based Intervention)

Recruitment methods which use the Internet are an effective way to find potential participants. In this study, the number of participants contacting researchers through the Internet was higher than the number of participants contacting researchers through traditional methods. However, finding the right websites and methods for disseminating study information took an unexpectedly long time and occasionally had unexpected results. The NFCA electronic newsletters and the mass e-mails to the University of Iowa community were more effective than other Web-based methods for recruiting subjects, including TrialMatch[™], other websites, and private blogs. This was because the first two methods more actively disseminated study information than the others. NFCA sent an e-newsletter directly to family caregivers and the mass mailing sent study information to people on the University of Iowa listserve. However, the other organizations posted study information on their websites or blogs, which is a less targeted and more passive way to disseminate the study information to potential participants. Therefore researchers who plan to use the web-based recruitment methods should carefully select websites for disseminating and posting the study information.

Several comments from participants suggest that they were waiting for web-based nursing interventions that allowed them to express their feelings, thoughts and opinions related to their caregiving experiences. Evaluating the effects of the web-based SWEE is beyond this dissertation's research. However, participants reported that they liked this intervention and they would be willing to participate in this study if they had an opportunity. Even though some participants in the control group complained about the writing topics, there was no statistical difference in their behavioral intention to use the web-based SWEE. This suggests that the writing intervention itself, regardless of topic, helped participants discuss stress related to caregiving experiences and that ADRD caregivers are interested in resources which allow them to write about their experiences as caregivers. Also the qualitative comments indicated that participants liked the webbased SWEE due to the ease of use of the system.

In Web-based intervention research, technical experts have to be included. Even though the websites used in this study were tested several times and were not found to have any problems during testing periods, technical troubles can possibly occur after launching the study. Speed of feedback was crucial at this time. Therefore, a person who can respond to technical issues is necessary throughout the period of the study.

Implications to Research

The objective of this research was to understand acceptance by ADRD caregivers of the nursing intervention, SWEE. The UTUAT model posited that successful implementation of the web-based SWEE would depend on a high level of acceptance of the system. This research found partial support for this model. The research questions addressed the variable affecting the success of the web-based SWEE success. The majority of the hypotheses were supported, providing several insights into the relationships between performance expectancy and behavioral intention to use and between effort expectancy and behavioral intention to use. Several hypotheses were not supported because the effect of some variables was not statistically significant including the relationship between facilitating conditions and actual usage, and between behavioral intention to use and actual usage. There were no mediating effects between performance expectancy and behavioral intention to use. The findings indicate that all three primary constructs played important and influential roles in the success of the web-based SWEE, as measured by performance expectancy and effort expectancy. Higher performance expectancy and effort expectancy generally increased intention to use the system. The participants in this study felt that the benefits of writing about their caregiving experience were important considerations when deciding whether they would participate in writing

interventions again in the future. In addition, they would like to participate in the webbased writing intervention again when the system was easy enough to use. Writing itself is an intervention for ADRD caregivers. Even the participants in the control group reported that they would like to be in an experimental group. They were willing to participate in a writing study if performance and effort expectancy were high. Several participants described a desire for interventions that allowed them to express their opinions, feelings, thoughts and concerns related to caregiving experiences even though some participants in the control group said that they did not like the writing topics and one participant even said she/he did not like this writing intervention. However, one participant said "once they started, words poured out of me." Many participants reported that they found the web-based SWEE easy to use. Furthermore, the results indicated that performance expectancy was a much stronger predictor of intention to use the web-based SWEE than effort expectancy. This suggests that the perceived benefits of the intervention were much more important for ADRD caregivers than ease of use of webbased systems. In other words, according to this result, the contents of any web-based intervention should be considered to be more significant than the design of the website on ADRD caregivers' intention to use the system.

Facilitating conditions did not have any significant effect on actual usage of the web-based SWEE. However, time was a very important factor for ADRD caregivers, affecting whether they could participate or access the web-based SWEE as well as other Web-based nursing interventions for ADRD caregivers. Therefore, researchers should take into consideration that time is an essential factor in use of web-based nursing interventions for help participants access these systems easily.

This study primarily used the actual usage of the web-based SWEE to evaluate acceptance of the web-based SWEE by ADRD caregivers. However, only 6% of variance of actual usage only was explained by behavioral intention to use and facilitating conditions. One possible reason for this result could be that the measure of actual usage was not sensitive enough to capture this construct. Therefore, developing new measures of the actual usage may be one way to improve estimates of the variance of actual usage of the web-based SWEE by ADRD caregivers. Using behavioral intention to use instead of actual usage to evaluate acceptance of this information system could be an alternative method. Previous research has reported that the most proximal antecedent to actual use is behavioral intention to use and this is now commonly used by researches to measure acceptance of a new technology (Jackson, Chow, & Leitch, 1997).

Finding-meaning, which was an output quality, did not mediate between performance expectancy and behavioral intention to use the web-based SWEE. Findingmeaning did not show significant mediating effects between performance expectancy and behavioral intention to use. Several participants complained about the content and wording of the ultimate meaning finding scales; for example use of the term "God" was not seen as appropriate by some participants. Finding-meaning was hypothesized as an output quality and defined as intermediated end products of the web-based SWEE. Finding-meaning was considered as an intermediated product of the intervention. Previous research has reported that the SWEE improved stress, depression, burden and physical symptoms (Frattaroli, 2006; Sheese, Brown, & Granziano, 2004; Smyth et al., 1999). Therefore these could be hypothesized as the end products of the web-based SWEE. The SWEE website includes instruments to measure these end products. Therefore, these end products should be considered output quality indicators as mediators instead of finding-meaning.

Limitations

This study has some limitations.

First, the ability to generalize the conclusions is limited due to the sampling methods. In spite of random assignment to control and experimental groups, participants were self-selected, offering to participate after receiving study information. Help seeking is not a random behavior, so participants who seek or use special services are often either particularly resourceful or distressed. In addition, web-based interventions require participants to have some degree of computer literacy. That is, while web-based interventions have no time or place limitations, the computer skills needed may actually decrease access and the ability to use internet based intervention tools. Therefore, it is inappropriate to generalize finding from studies whose participants are recruited from Internet support groups.

The second potential limitation is that this study focused on a nursing intervention especially designed for ADRD caregivers. User acceptance of web-based nursing interventions for other populations may be different, depending on the characteristics of the technologies and the potential users.

Third, because there were no face to face interactions (only phone calls and/or email) between the researcher and participants, the possibility of discrepancies between participants' self-reported data and actual conditions cannot be ruled out. If, for some reason, a participant wanted entry into the study but was not a caregiver of an ADRD patient, the participant could have invented information related to caregiving experiences. Although this is unlikely, it is still a possibility

Fourth, behavioral intention to use and actual usage only have one indicator for each construct. Using a single indicator for testing constructs is strongly discouraged. Research suggests three indicators, ideally with separate measures for each latent variable (Weston & Gore Jr., 2006). Using one item for a construct limits the accuracy of the UTAUT model, and while these measures can be statistically correct, using only one item to measure a construct limits the model's ability to sufficiently explain the entire concept and increases the possibility of respondent error (Schaper & Pervan, 2007). In addition, actual usage, which was defined as completion of the web-based SWEE as designed, may have been too conservative to be a true measure actual usage of SWEE. It is
recommended that future studies revise the indicator for behavioral intention to use and actual usage of the nursing interventions.

Fifth, the expected finding meaning process from SWEE intervention may be affected by the relationship between caregivers and care recipients. There is a stronger effect in spousal relationships due to the often strong sense of commitment that characterizes many spousal ADRD caregiver relationships.

Sixth, this study aimed to capture the causal links between behavioral intention to use and actual usage of the web-based SWEE. Because these two construct were measured at the same time, the precedence relationship of behavioral intention to use was not detected. Therefore, the causal relationship between behavioral intention to use and actual usage of the web-based SWEE is less logically apparent.

Finally, the sample size (N=50) is a limitation of this study. Previous guidelines for sample size have suggested that 10 to 20 participants per estimated parameter (Kline, 1998) or a minimum sample size of 200 for any SEM anticipating no problem with data (Weston & Gore Jr., 2006). The sample size of this study (N=50) did not meet these guidelines. Therefore, the small sample size may have affected the model fit (Weston & Gore Jr., 2006).

Recommendations for Future Research

This research project addressed many issues identified in the literature on webbased nursing interventions. However, several issues remain unresolved and offer opportunities for future research.

First, this study needs to be replicated with a larger sample size. SEM is a commonly used statistical method for evaluating the UTAUT model. Previous research has advised a minimum sample size 200 for any SEM anticipating no problems with data. Even though data showed a good fit with the UTAUT model, the small sample size may have resulted in non-significant effects in several paths.

Second, a longitudinal study design can be applied to future research. Behavioral intention to use the web-based SWEE did not have a significant effect on actual usage. This suggests that ADRD caregivers' intention to use the web-based SWEE did not predict or explain their actions which were completion of the web-based SWEE as designed in the past. Therefore, a longitudinal research design which provides participants opportunities to try the web-based SWEE at least twice could more accurately measure the relationship between behavioral intention to use and actual usage of the Web-based SWEE.

Third, different measures and multiple indicators should be developed for measuring the validity of behavioral intention to use and actual usage of the web-based SWEE by ADRD caregivers. These constructs only had one indicator to capture the true meaning of the constructs, but this is not sufficient. In addition, instead of measuring actual usage by the number of participants who complete the intervention, the measure of actual usage should be designed to reflect participants' progress through the phases of the study.

Fourth, finding-meaning did not show significant mediating effects between performance expectancy and behavioral intention to use the web-based SWEE. A reduction in depression, burden and physical symptoms related to ADRD caregivers' stress (Berman & Silver, 2006; Fuller-Jonap & Haley, 1995) could be considered to be the end products of the web-based SWEE. The SWEE website includes instruments to measure these end products. Therefore, these end products could be used as output quality indicators and mediators instead of finding-meaning.

Fifth, some participants commented in their qualitative responses that the questions about ultimate meaning in the FMTCS were not appropriate to their situations. While the study results did not support finding-meaning as a mediator, there was a significant relationship between provisional meaning and performance expectancy. Thus,

researchers should consider revising FMTCS to be more appropriate to caregiver situations.

Sixth, according to Venkatesh (2003), there are few studies which evaluate the relationship between user acceptance and individual usage outcomes. Although positive outcomes are expected as a result of the web-based SWEE usage, the link between outcomes and acceptance of the system (as measure either by the behavioral intention to use or actual usage of the web-based SWEE) remains to be tested.

Finally, the design of the three 20 minute writing interventions were based on a literature review, but several participants reported that time was too constrained. Some said it was too short and others said it was too long. Flexibility of time and schedule should be considered to provide research subjects with more appropriate nursing interventions, and may improve participants' satisfaction and participation rates.

Conclusions

This chapter has discussed the findings of this study of a web-based nursing intervention, including the recruitment methods used and the writing intervention for ADRD caregivers. It has also described testing hypotheses using the UTUAT model; implications for web-based nursing interventions and research; study limitations; and recommendations for future research.

This dissertation first describes the recruitment of potential participants through the Internet implementing an online consent form, and the web-based SWEE process, from pre-writing questionnaires to second post-writing questionnaires. The UTAUT model was used to provide a theoretical framework to predict and explain ADRD caregivers' acceptance of the web-based SWEE. Parts of the research model were supported, of which performance expectancy and effort expectancy had statistically significant effects on the behavioral intention to use the web-based SWEE. These two constructs explained about 52% of the variance in behavioral intention to use the webbased SWEE. In addition, performance expectancy was the strongest construct to explain the behavioral intention to use the web-based SWEE. Actual usage was hypothesized as a variable indicating ADRD caregivers' acceptance of the web-based SWEE. However, only 7% of actual usage was explained in the study. While behavioral intention to use the web-based SWEE was not found to be a predictor of actual usage in this study, behavioral intention to use the information system was found to be a reasonable predictor of the actual usage of the information system. Therefore, performance expectancy and effort expectancy were two important constructs to explain the ADRD caregivers' user acceptance of the web-based SWEE.

This study utilized the UTAUT model to evaluate the web-based nursing intervention for ADRD caregivers. Previously, the UTAUT model has been little used for nursing information systems research or community dwelling caregivers. There have been some studies of health care professionals and one study of patients with chronic illnesses. Currently, healthcare professionals, researchers, educators as well as patients and their family members have acknowledged the need for web-based nurse intervention systems and have tried to develop systems for health care consumers. However, there is a gap between the kind of web-based nursing information systems consumers want and those that are developed by healthcare professionals, researchers, and educators. Therefore, assessing user acceptance of web-based nurse interventions for health care consumers is important to more effectively meet the needs of health care consumers. Even though the UTAUT model in this study was only partially supported by a good model fit, this study's findings show the possibility of applying the UTAUT model in nursing discipline of health consumer information systems.

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APPENDIX A : INSTRUMENTS

Demographic Questionnaires

- 1. State of data collection
- 2. County
- 3. Date (MM-DD-YY)
- 4. Caregiver's name
- 5. Phone number of the caregiver _____
- 6. Has the caregiver ever received any caregiver training? 0 = No 1 = Y
- 7. How many average hours weekly does the caregiver provide care to the care recipient? (List actual hours) (Must be more than 4)
- 8. How many hours is professional or hired support in the house every week?
- 9. What relationship is the caregiver to the care recipient? 1 = Spouse 3 = Sibling 5 = Friend 2 = Offspring 4 = Other Relation
- 10. Birth date of the caregiver (MM-DD-YY)
- 11. Gender of the caregiver: 1 = Male 2 = Female
- 12. Ethnicity of the caregiver: 1 = Caucasian 4 = Hispanic 2 = African American 5 = Asian3 = American Indian/Native American 6 = Other, specify
- 13. Highest educational level of the caregiver (list actual number of years of schooling completed).
- 14. Does the caregiver live:
 1 = Alone
 2 = With care recipient only
 3 = With more than one family member (one of whom is the care recipient)
 4 = With one or more family member, none of whom are the care recipient
 5 = Other, describe ______
- 15. Does the caregiver attend a support group? 0 = No 1 = Yes
- 16. If yes to above, how many times a month?
- 17. How often does the caregiver utilize respite care (list actual number of hours per week)?
- 18. Working status of caregiver:
 - 1 = Working at a paying job full-time
 - 2 = Working at a paying job part-time
 - 3 = Retired
 - 4 = Laid-off or unemployed, but looking for work

5 = A full-time homemaker 6 = Other

- 19. Average annual income available for use to provide care: 1 = < \$10,000 3 = \$30,000 - \$50,0002 = \$10,000 - \$30,000 4 = > \$50,000
- 20. Does the care giving role result in a financial burden for the caregiver? 0 = No 1 = Yes
- 21. Length of time since memory changes of care recipient: (List in actual months)
- 23. Medications you are taking (Please list)
- 23 Number of serious health problems you have (please list)
- 24. About how often do you go to religious meetings or services?
 - 1 = Never or almost never
 - 2 =Once or twice a year
 - 3 =Every few months
 - 4 = Once a week
 - 5 = More than once a week
 - 6 =Don't know
 - 7 =Prefer not to say
- 25. Since you have been a caregiver, do you write down your thoughts and feelings in a journal or diary?
 - 1 =Never or almost never
 - 2 =Once or twice a year
 - 3 =Every few months
 - 4 = Once a week
 - 5 = More than once a week
 - 6 = Every day

	· · ·	Strongly Agree	Agree	Disagree	Strongly Disagree
1.	I found the web-based writing system useful for managing my stress related to caregiving				
2.	Using the web-based writing system made it easier to deal with my stress related to caregiving				
3.	Using the web-based writing system helped me express my issues related to caregiving at any time.				
4.	Learning to use the web-based writing system was easy for me.				
5.	I found the web-based writing system easy to use.				
6.	Using the web-based writing system took too much time.				
7.	Using the web-based writing system is a good idea for caregivers with Alzheimer's disease and related disorders.				
8.	The web-based writing system was interesting to me.				
9.	I liked working with this web-based writing system to manage my stress related to caregiving .				
10.	I had the resources I needed to use the web-based writing system				
11.	The web-based writing system was not compatible with other ways I manage my caregiving related stress.				
12.	I could control how I used the web-based writing system.				
13.	I could use the web-based writing system even if no one was around to tell me what to do.				
14.	I felt nervous about using the web-based writing system.				
15.	It scared me to think that I might make a mistake when using the web-based writing system.				
16.	I was worried about using the web-based writing system				
17.	I would use the system again for managing my stress related to caregiving.				

User Acceptance of a web-based Written System for ADRD caregivers

We are interested in your opinion of the web-based writing system for managing stress related to caregiving . Please tell me what you liked about using the system.

Were there things that you didn't like about the system or that didn't work well for you?

Do you have any suggestions for how to make the system *more useful* to you?

Finding Meaning Through Caregiving Scale (FMTCS)

This questionnaire contains a number of statements related to opinions and feelings about yourself, your impaired relative and your caregiving experience. Read each statement carefully, then indicate the extent to which you agree or disagree with the statement. Circle one of the alternative categories.

Loss/Powerless Subscale	Strongly	Agree	Undecided	Disagree	Strongly
(LP)	Agree				Disagree
I miss the communication	SA	Α	U	D	SD
and companionship that					
my family member and I					
had in the past.					
I miss my family	SA	А	U	D	SD
member's ability to love					
me as he/she did in the					
past.					
I am sad about the mental	SA	А	U	D	SD
and physical changes I see					
in my relative.					
I miss the little things my	SA	А	U	D	SD
relative and I did together					
in the past.					
I am sad about losing the	SA	А	U	D	SD
person I once knew.					
I miss not being able to be	SA	А	U	D	SD
spontaneous in my life					
because of caring for my					
relative.					
I miss not having more	SA	А	U	D	SD
time for other family					
members and/or friends.					
I have no hope, I am	SA	А	U	D	SD
clutching at straws.					
I miss our previous social	SA	А	U	D	SD
life.					
I have no sense of joy.	SA	А	U	D	SD
I miss not being able to	SA	А	U	D	SD
travel.					
I wish I were free to lead a	SA	Α	U	D	SD
life of my own.					

I miss having given up my	SA	A	U	D	SD
job or other personal					
interests to take care of my					
family member.					
I feel trapped by my	SA	А	U	D	SD
relative's illness.					
We had goals for the future	SA	А	U	D	SD
but they just folded up					
because of my relative's					
dementia.					
I miss my relative's sense	SA	A	U	D	SD
of humor.					
I wish I could run away.	SA	А	U	D	SD
I feel that the quality of my	SA	A	U	D	SD
life has decreased.					
My situation feels endless.	SA	A	U	D	SD
	•	•		•	•

Provisional Meaning (PM)	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
I enjoy having my relative with me: I would miss it if	SA	А	U	D	SD
he/she were gone.					
I count my blessings.	SA	А	U	D	SD
Caring for my relative	SA	Α	U	D	SD
gives my life a purpose					
and a sense of meaning.					
I cherish the past	SA	Α	U	D	SD
memories and experiences					
that my relative and I have					
had.					
I am a strong person.	SA	Α	U	D	SD
Caregiving makes me feel	SA	Α	U	D	SD
good that I am helping.					
The hugs and "I love you"	SA	Α	U	D	SD
from my relative make it					
worth it all.					
I'm a fighter.	SA	Α	U	D	SD
I am glad I am here to care	SA	Α	U	D	SD
for my relative.					
Talking with others who	SA	Α	U	D	SD
are close to me restores my					
faith in my own abilities.					
Even though there are	SA	Α	U	D	SD
difficult things in my life, I					
look forward to the future.					

Caregiving has helped me learn new things about myself	SA	А	U	D	SD
Each year, regardless of the quality, is a blessing.	SA	А	U	D	SD
I would not have chosen the situation I'm in, but I get satisfaction out of providing care.	SA	A	U	D	SD
Every day is a blessing.	SA	А	U	D	SD
This is my place; I have to make the best out of it.	SA	А	U	D	SD
I am much stronger than I think.	SA	А	U	D	SD
I start each day knowing we will have a beautiful day together.	SA	A	U	D	SD
Caregiving has made me a stronger and better person.	SA	А	U	D	SD

Ultimate meaning (U	UM)
---------------------	-----

Ultimate meaning (UM)	Strongly	Agree	Undecided	Disagree	Strongly
	Agree				Disaglee
The Lord won't give you	SA	A	U	D	SD
more than you can handle.					
I believe in the power of	SA	A	U	D	SD
prayer; without it I couldn't					
do this.					
I believe that the Lord will	SA	A	U	D	SD
provide.					
I have faith that the good	SA	A	U	D	SD
Lord has reasons for this.					
God is good.	SA	A	U	D	SD

Burden Interview

The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, please circle the one that corresponds to how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There is no right or wrong answers.

Some-times Ouite Nearly ever rarely Òften Always 1. Do you feel that your relative asks for more help than he/she needs? Do you feel that because of the time 2. you spend with your relative you don't have enough time for yourself? 3. Do you feel stressed between caring for your relative and trying to see other responsibilities for your family or work? Do you feel embarrassed over your 4. relative's behavior? 5. Do you feel angry when you are around your relative? Do you feel that your relative 6. currently affects your relationship with other family members or friends in a negative way? 7. Are you afraid what the future holds for your relative? Do you feel your relative is 8. dependent upon you? 9. Do you feel strained when you are around your relative? 10. Do you feel your health has suffered because of your involvement with your relative? 11. Do you feel that you don't have as much privacy as you would like, because of your relative? 12. Do you feel that your social life has suffered because you are caring for

your relative?

- 13. Do you feel uncomfortable about having friends over, because of your relative?
- 14. Do you feel that your relative seems to expect you to take care of his/her, as if you were the only one he/she could depend on?
- 15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
- 16. Do you feel that you will be unable to take care of your relative much longer?
- 17. Do you feel you have lost control of your life since your relative's illness?
- 18. Do you wish you could just leave the care of your relative to someone else?
- 19. Do you feel uncertain about what to do about your relative?
- 20. Do you feel you should be doing more for your relative?
- 21. Do you feel you could do a better job in caring for your relative?
- 22. Overall, how burdened do you feel in caring for your relative?

/		
/		
/		

Pennebaker Inventory of Limbic Languidness (PILL)

Several common symptoms or bodily sensations are listed below. Most people have experienced most of them at one time or another. We are currently interested in finding out how prevalent each symptom is among various groups of people. On the page below, write how frequently you experience each symptom. For all items, use the following scale:

А	В	С	D	E
Have never or	Less than 3 or 4	Every month or	Every week	More than
almost never experienced the symptom	times per year	SO	or so	once every week

For example, if your eyes tend to water once every week or two, you would answer "D" next to question #1.

1. Eyes water	<u>28. Swollen joints</u>
2. Itchy eyes or skin	29. Stiff or sore muscles
3. Ringing in ears	30. Back pains
4. Temporary deafness or hard of hearing	31. Sensitive or tender skin
5. Lump in throat	32. Face flushes
6. Choking sensations	33. Tightness in chest
7. Sneezing spells	34. Skin breaks out in rash
8. Running nose	35. Acne or pimples on face
9. Congested nose	36. Acne/pimples other than face
10. Bleeding nose	37. Boils
11. Asthma or wheezing	38. Sweat even in cold weather
12. Coughing	39. Strong reactions to insect bites
13. Out of breath	40. Headaches
14. Swollen ankles	41. Feeling pressure in head
15. Chest pains	42. Hot flashes

16. Racing heart	43. Chills
17. Cold hands or feet even in hot weather	44. Dizziness
18. Leg cramps	45. Feel faint
19. Insomnia or difficulty sleeping	46. Numbness or tingling in any part of body
20. Toothaches	47. Twitching of eyelid
21. Upset stomach	48. Twitching other than eyelid
22. Indigestion	49. Hands tremble or shake
23. Heartburn or gas	50. Stiff joints
24. Abdominal pain	51. Sore muscles
25. Diarrhea	52. Sore throat
26. Constipation	53. Sunburn
27. Hemorrhoids	54. Nausea

Since the beginning of the semester, how many:

_____ Visits have you made to the health center or private physician for illness

- _____ Days have you been sick
- _____ Days your activity has been restricted due to illness

Center for Epidemiologic Studies Depression Scale (CES-D)

Below is a list of the ways you might have felt or behaved. Please circle the number for each statement which best describes how often you felt or behaved this way during THE PAST WEEK.

- 0 = Rarely or None of the Time (Less than 1 Day)
- 1 = Some or a Little of the Time (1-2 Days)
- 2 = Occasionally or a Moderate Amount of Time (3-4 Days)
- 3 = Most or All of the Time (5-7 Days)

	During the past week:	Less than 1 Day	-2 Days	-4 Days	-7 Days
1.	I was bothered by things that usually don't bother me.				
2.	I did not feel like eating; my appetite was poor.				
3.	I felt that I could not shake off the blues even with help from my family or friends.				
4.	I felt that I was just as good as other people.				
5.	I had trouble keeping my mind on what I was doing.				
6.	I felt depressed.				
7.	I felt that everything I did was an effort.				
8.	I felt hopeful about the future.				
9.	I thought my life had been a failure.				
10.	I felt fearful.				
11.	My sleep was restless.				
12.	I was happy.				

- 13. I talked less than usual.
- 14. I felt lonely.
- 15. People were unfriendly.
- 16. I enjoyed life.
- 17. I had crying spells.
- 18. I felt sad.
- 19. I felt that people disliked me.
- 20. I could not get "going."

APPENDIX B: WRITING INSTRUCTIONS

Experimental group

This study is a project about writing and well-being. You are being asked to participate in this study because you are a family member of a person with Alzheimer's disease or a related disorder. If you choose to participate in this study over the next week, you will be asked to write about one of several different topics for 20 minutes every other day for a total of three 20 minute writing sessions. Please arrange for a convenient time when you can write for 20 minutes without interruption. Your timer will start off as soon as you click on the "Start Composition" button at the end of this page. The timer will display the time about at the time left for you to complete the composition.

The only rule we have about your writing is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write. Because this is a research study, we will tell you the topic you are to write about at the time that you are writing.

Sometimes people feel a variety of emotions after writing. If that happens, it is completely normal. Most people say that these feelings go away in an hour or so. If at any time over the course of the experiment you feel upset or distressed because of what you are writing, please contact me immediately.

Also, your writing is completely confidential. The only people who will have access to what you write are study personnel. Your writing will not be linked personally. The one exception is that if your writing indicates that you would harm yourself or others, we are legally bound to match your ID with your name and we will inform you about this and offer a referral to support services.

Click on "Read Specific instruction" to read instructions specific to the composition you are about to write.

Writing Instructions, First Day

What I would like you to write about today, and for two more times after today, for 20 minutes each time, are your deepest emotional thoughts and feelings about caring for your loved one, family member or friend who has Alzheimer's disease. In your writing, we would like you to explore your very deepest thoughts and feelings about your experience as a family caregiver of a loved one with Alzheimer's disease. I realize that caregivers of person's with Alzheimer's disease experience a full range of emotions, and I want you to focus on any and all of them. Because Alzheimer's disease can touch every part of our lives, you might explore how this experience is linked to issues in your childhood, relationships with parents, old friends, and others you have cared about. You might tie your thoughts and feeling of being a caregiver to other family issues, finances, or even traumatic experiences you have suffered. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You may think about all the various feeling and changes that you experienced since you first became a caregiver to your loved one, family member or friend who has Alzheimer's disease, and whatever you are feeling now. You can write about the problems or conflicts that you have experienced or are experiencing now. How your caregiving experience is related to your childhood, your parents, children, the people you love, who you are, or who you want to be. Ideally, I would like you to focus on those experiences, changes, thoughts, and feelings that you have not discussed in great detail with others. Remember, you will have three separate occasions for writing. You can write about the same experiences each day or about different experiences each day. Again, the most important part of your writing is that you really focus on your deepest emotions and thoughts. The only rule we have is that you write for the entire 20 minutes. Don't worry about grammar, spelling, or sentence structure. If you run out of things to say, just repeat what you have already written. Just write your story.

Second day

How did the writing go the other day? Today is the second to last day of writing and I want you to continue writing about your deepest thoughts and feelings about caring for your loved one, family member or friend who has Alzheimer's disease. You may want to write about experiences you did not cover on the first day or you may want to go into even more depth about things you have already written about. I realize that caregivers of persons with Alzheimer's disease experience a full range of emotions, and I want you to focus on any and all of them. Because Alzheimer's disease can touch every part of our lives, you might explore how this experience is linked to issues in your childhood, relationships with parents, old friends, and others you have cared about. You might tie your thoughts and feeling of being a caregiver to other family issues, finances, or even traumatic experiences you have suffered. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You may think about all the various feeling and changes that you experienced since you first became a caregiver to your loved one, family member or friend who has Alzheimer's disease, and what ever you are feeling now. You can write about the problems or conflicts that you have experienced or are experiencing now. How your caregiving experience is related to your childhood, your parents, children, the people you love, who you are, or who you want to be. Ideally, I would like you to focus on those experiences, changes, thoughts, and feelings that you have not discussed in great detail with others. Again, the most important part of your writing is that you really focus on your deepest emotions and thoughts. The only rule we have is that you write as continuously as *possible* for the entire 20 minutes. Don't worry about grammar, spelling, or sentence structure. If you run out of things to say, just repeat what you have already written. Just continue to explore your deepest thoughts and feelings by writing your story.

Third day

You have completed the first two days of writing, and today is the last one. In your writing today, I again would like you to explore your deepest thoughts and feelings about caring

for your loved one, family member or friend who has Alzheimer's disease. Because Alzheimer's disease can touch every part of our lives, you might explore how this experience is linked to issues in your childhood, relationships with parents, old friends, and others you have cared about. You might tie your thoughts and feelings of being a caregiver to other family issues, finances, or even traumatic experiences you have suffered. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You may think about all the various feeling and changes that you have experienced since you first became a caregiver to your loved one, family member or friend who has Alzheimer's disease, and whatever you are feeling now. You can write about the problems or conflicts that you have experienced or are experiencing now. How your caregiving experience is related to your childhood, your parents, children, the people you love, who you are, or who you want to be. The only rule we have is that you write continuously for the entire 20 minutes. Don't worry about grammar, spelling, or sentence structure. Remember that this is the last day and so you might want to wrap everything up. For example, how has being a caregiver changed your life and your future? But feel free to go in any direction you feel most comfortable with and delve into your deepest emotions and thoughts.

Control group

This study is a project about writing and well-being. You are being asked to participate in this study because you are a family member of a person with Alzheimer's disease or a related disorder. If you choose to participate in this study over the next week, you will be asked to write about one of several different topics for 20 minutes every other day for a total of three 20 minute writing sessions. Please arrange for a convenient time when you can write for 20 minutes without interruption. Your timer will start off as soon as you click on the "Start Composition" button at the end of this page. The timer will display the time about at the time left for you to complete the composition.

The only rule we have about your writing is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write. Because this is a research study, we will tell you the topic you are to write about at the time that you are writing.

Sometimes people feel a variety of emotions after writing. If that happens, it is completely normal. Most people say that these feelings go away in an hour or so. If at any time over the course of the experiment you feel upset or distressed because of what you are writing, please contact me immediately.

Also, your writing is completely confidential. The only people who will have access to what you write are study personnel. Your writing will not be linked personally. The one exception is that if your writing indicates that you would harm yourself or others, we are legally bound to match your ID with your name and we will inform you about this and offer a referral to support services.

Writing Instructions, First Day

Today we are interested in learning about your nutrition. What I would like you to write about today are the preparations you make in preparing food for yourself and family. In your writing, I want you to be as objective as possible. I am not interested in your emotions or opinions. Rather I want you to try to be completely objective. Feel free to be as detailed as possible. In today's writing, I want to write in detail what preparations you have made for meals yesterday and today. I am interested in the specifics, therefore, be extremely detailed in describing all the facts and details involved in where you shop, how you get there, how you decide on the menu, why you selected the particular foods you prepared, how the foods fit with food groups, how you prepared it, how you cooked the food, what you think about the size of the portions. If you went out to eat or ate at a senior center, describe in deal what you ate, how you selected portions. Describe all the foods for each meal. No fact or detail is too big or too small. The only rule we have is that you write continuously for the entire 20 minutes. Don't worry about grammar, spelling, or sentence structure. If you run out of things to say, just repeat what you have already written. Just continue to describe all the details that was involved in preparing each meal yesterday and today.

Second Day

How did the writing go the other day? Today, I would like you to describe in detail information related to any medications or vitamins **you** are taking. In your writing, I want you to be as objective as possible. Feel free to be as detailed as possible. You can describe each medication, explain everything you know about the medication. What each pill looks like, what it is for, if you know how it works, and whether it helps. How often you take it, when you take it. Explain as much as you know about *your* medications. Also, write about what kind of strategies you use to remember to take your medications, when you take them, how you know which medication to take, how long you have been taking each one. If you run out of current medications to write about, then you can write about any or all medications you have taken in the past. What is important is that you write continuously for the entire 20 minutes. Don't worry about grammar, spelling, or sentence structure. If you run out of things to say, just repeat what you have already written. Just continue to describe all the details that have to do with your medications.

Third Day

You have completed the first two days of writing, and today is the last one. Today, I would like you to describe in detail everything associated with leisure and physical activities. Feel free to be as detailed as possible. What kind of physical exercise do you get? How do you exercise? How often? Do you go for walks, or go out shopping? You can describe in detail any physical activity. Where do you shop? If it is going out and doing things, describe what it is you do. What activities are involved? Where do you go? How do you get there and back? Describe any activities in as much detail as you can. How do you think the activity helps you? If you feel you are not getting enough physical activities, what kind of exercise did you once do, or what would you like to do more of? Also, write about leisure activities. Do you read any newspapers, magazines, or books? Which newspapers, magazines, and/or books are you reading? You can write about the types of books or about your favorite sections of the paper. Do you watch TV? What shows do you enjoy watching? Are there particular kinds of shows you like to watch? You can describe in detail particular TV shows or stories you have read. If you run out of activities to write about, just repeat what you have already written. What is important is that you write continuously for the entire 20 minutes. Don't worry about grammar, spelling, or sentence structure. Just continue to describe all the details that have to do with physical and leisure activities.

APPENDIX C: SWEE WEBSITE

Nursing Family Caregiver Writing Study THE UNIVERSITY OF IOWA DOES Writing promote health?

Informed Consent Form

Signup

Are you the caregiver for a loved one who has Alzheimer's Disease or other type of dementia?

Eligibility Criteria

If so, you are invited to participate in a University of Iowa research study that will learn about your caregiving and your health.

- You will be asked to write about your thoughts and feelings regarding caring for a family member or regarding activites related to caring for one's self. The writing will take place online and requires that you have a computer and internet access for participation.
- Three days must be allocated in your schedule for the writing sessions. Each writing experience will require approximately 20 minutes.
- After you complete the writing sessions, you will be asked to complete online survey forms on two more occasions. There is no pain or discomfort associated with any activities in this study.
- Total time commitment for participants over a one-month period should not be more than 6 hours.

Please call Dr. Howard Butcher (319-335-7039) if you would like more information and/or are interested in participating.

Informed Consent Form (It is highly recommended that you read through the previous sections before printing out and signing this form)

Sign up for this project

(First time users that do NOT have a UserID and password must go through this one-time process. This process requires an access code provided by Dr. Howard Butcher. If you do not have one, please contact Dr. Butcher)

Participants will be offered compensation.

Introduction

FAQs

Investigator: Howard Butcher, PhD, RN, APRN, BC Principal Investigator College of Nursing University of Iowa Iowa City, Iowa 319-335-7039 howard-butcher@uiowa.edu Visit <u>Dr Howard Butcher's Home Page</u> A project sponsered by Iowa Informatics Initiative at the University of Iowa.

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Trising Family Caregiver Writing Study THE UNIVERSITY OF IOWA Does writing promote health?

Family Caregivers Web-Based Writing Study Invites Participants

Anyone taking care of someone with memory loss knows how stressful this can be. Dr. Howard Butcher is trying to learn whether people who write about their caregiving experiences are less stressed than those who do not.

Eligibility Criteria

Other researchers have studied persons who have had stressful experiences such as job loss, illness, abuse, natural disasters and loss of a spouse. People in those groups wrote about their thoughts and feelings for a short time, usually only three 20-minute sessions. Overall, the writers had psychological and physiological health benefits that could last for six to twelve months after taking part in the studies.

To join Dr. Butcher's study, you need to be a caregiver for a family member or a friend who has Alzheimer's disease or some other condition that causes memory loss. Since data are collected on a secure website, you would need to have access to a computer. You do not have to be a "good writer" -Dr. Butcher is studying the effect of writing, so you don't have to worry about whether or not you are a good writer. So, you don't even need to pay attention to spelling or grammar. Also, all information is kept strictly private: no one will even know that you are in the study unless you tell them about it.

If you would like to learn more about the study, click here to see "Common Questions" and Answers."

Howard Butcher, RN, PhD, APRN, BC, is an Associate Professor of Nursing at the University of Iowa. He is the principal investigator of the Iowa Informatics Initiative funded study. If you would like more information than you can find on the website, he can be contacted at 319-335-7039 or at howard-butcher@uiowa.edu.

The second s	
Home Intro	duction FAQs Eligibility Criteria Informed Consent Form Signup Login
	Common Questions and Answers
Why are you d	oing this study?
Other studies have has reduc patients.Since it about caregiving caregivers.	ave found that writing for 20 minutes three times during only one ed stress for many people, such as college students and hospital t has been helpful to them, we are trying to learn whether writing g experiences will lessen the physical and emotional stress of the
How can I join	the study?
 First, read the Then, if you of form and ema Sign the cons it to the addre 	e eligibility criteria (<u>here</u>) and the consent form (<u>here</u>). decide you want to be part of the study, print a copy of the consent ail the research team (<u>here</u>) to let them know that you plan to sign up sent form (be sure to have someone witness your signature) and ma ess given on the form.
What happens	after I sign up?
 Someone from any questions If you wish to can fill out que secure. 	n the research team will contact you by email or telephone to answe s you may have and to make sure that you are eligible for the study continue, we will give you a Log-on ID and a password so that you estionnaires online, keeping your information confidential and
What do I do d	luring the study?
Use your ID a information of Complete 4 s during the stu	Ind password to log onto the study website and fill in the background n the form provided. hort questionnaires (you will be asked to do this again twice more udy).
other day for • 4 days after y	20 minutes about the topic we give you for that day. /ou finish writing, you will
 Log on to t user accept 	ne computer and complete your second set of questionnaires, plus stance survey.
 30 days after Log on to t 	be computer and complete your third set of questionnaires
How much tim	e will all this take?

What if I'm not a good writer?

That doesn't matter. We aren't judging your writing, spelling, or punctuation. We only want to know if writing has an effect on your stress level. So, it's best not to worry about trying to write well. We want you to spend your 20 minutes writing freely about the day's topic, not thinking about whether an English teacher would give you a good grade!

Will it cost me any money?

No, not at all. We are asking only for your time.

What if I change my mind?

You can leave the study at any time, and you do not have to give a reason.

How will I keep track of everything?

- The website will guide you through the schedule for the month
- . The research team will send you email reminders
- You will have contact names that you can email or telephone if you have questions or concerns

Howard Butcher, RN, PhD, APRN, BC Principal Investigator College of Nursing Univeristy of Iowa Iowa City, Iowa 319-335-7039 howard-butcher@uiowa.edu



HOW LONG WILL I BE IN THIS STUDY?

If you agree to take part in this study, your involvement will last for about 5 weeks. The total time required for the entire study should be less than 6 hours over course of the five weeks.

WHAT ARE THE RISKS OF THIS STUDY?

You may experience one or more of the risks indicated below from being in this study. In addition to these, there may be other unknown risks, or risks that we did not anticipate, associated with being in this study.

You may be uncomfortable writing about caring for your family member and the writing may make you recall difficult times or situations. If you are concerned about your feelings or your responses to the questions, please contact the researchers. If needed, the researcher will make a referral to counseling services to assist any participant who may experience emotional upset. You may withdraw from the study at any time.

There is a risk that information sent through the internet may be viewed by others who have access to your computer.

WHAT ARE THE BENEFITS OF THIS STUDY?

There may be no personal benefit for participating in this study. However, we hope that, in the future, other people might benefit from this study by demonstrating how a web based writing intervention can reduce stress and promote health for caregivers caring for a family member with memory loss.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will be responsible for the cost of access to the Internet. You should not have any additional costs for participating in this research project.

WILL I BE PAID FOR PARTICIPATING?

You will be paid for your participation in this study. You will receive in the mail a \$20.00 Wal-Mart gift certificate. If there is no Wal-Mart store in your area, or if you do not shop there, contact Ji Woon Ko and she will make an alternative arrangement. If you withdraw from the study at anytime, you will receive an \$8.00 gift certificate.

WHO IS FUNDING THIS STUDY?

The University and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

WHAT ABOUT CONFIDENTIALITY?

We will keep your participation in this research project confidential to the extent permitted by law. However, it is possible that other people such as those indicated below may become aware of your participation in this study and may inspect and copy records pertaining to this research. Some of these records could contain information that personally identifies you.

- · federal government regulatory agencies,
- auditing departments of the University of Iowa, and
- the University of Iowa Institutional Review Board (a committee that reviews and approves research

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To help protect your confidentiality, we will assure that the web site on which questionnaires, your answers to the questions, and writing samples are stored is secure. All of the data collected in the study is stored at the University of Iowa's Information Technology Services computer server. This server is also housed in a secure server room with very limited access. This server is maintained to have incredibly high availability and low downtime. There is also ITS staff constantly monitoring these servers to watch for security breaches of any kind. This server is setup with a RC4 128 bit SSL certificate to allow for encrypted connections with the users. All communication between the web server and the users is encrypted to prevent eavesdropping.

We will use an assigned ID number and not your name to identify all study data. You will use you're assigned ID number to sign into the study web site. The list linking you're assigned study ID numbers will be stored in a secure location that is accessible only to the investigators. If we write a report or article about this study or share the study data set with others, we will do so in such a way that you cannot be directly identified.

IS BEING IN THIS STUDY VOLUNTARY?

Taking part in this research study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop participating at any time. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

What if I Decide to Drop Out of the Study?

If you decide to leave the study early, we ask you to notify us using the email.

Will I Receive New Information About the Study while Participating?

If we obtain any new information during this study that might affect your willingness to continue participating in the study, we'll promptly provide you with that information.

Can Someone Else End my Participation in this Study?

Under certain circumstances, the researchers might decide to end your participation in this research study earlier than planned. This might happen because if we encounter the unlikely possibility of a problem with the website that prevents you from completing the questionnaires at the scheduled times or because in our judgment it would not be best for you to continue.

WUATIE I UAVE OTTESTIONS?

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Under certain circumstances, the researchers might decide to end your participation in this research study earlier than planned. This might happen because if we encounter the unlikely possibility of a problem with the website that prevents you from completing the questionnaires at the scheduled times or because in our judgment it would not be best for you to continue.

WHAT IF I HAVE QUESTIONS?

We encourage you to ask questions. If you have any questions about the research study itself, please contact: Ji Woon Ko at 👜 - 319-594-0502 🚱 if you experience a research-related injury, please contact: Ji Woon Ko at 👜 - 319-594-0502 🚱 .

If you have questions, concerns, or complaints about your rights as a research subject or about research related injury, please contact the Human Subjects Office, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564 , or e-mail irb@uiowa.edu. General information about being a research subject can be found by clicking "Info for Public" on the Human Subjects Office web site, http://research.uiowa.edu/hso. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

This Informed Consent is not a contract. It is a written explanation of what will happen during the study if you decide to participate. You are not waiving any legal rights by agreeing to this electronic Informed Consent. Your agreement indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study.

Contact information

Ji Woon Ko, RN, MSN

422 College of Nursing The University of Iowa Iowa City, Iowa, 52242

E-mail: jiwoon-ko@uiowa.edu Tel: 💷 🗸 319-594-0502 📀

Name:	
Email:	
Agree:	
	Submit Consent Form

Nursing Family Caregiver Writing Study

Scheduler

Logout

Does writing promote health?

2

Welcome to the University of Iowa - College of Nursing Family Caregiver Writing Project, joo

Progress Report

Shown below is your progress in the project. Please click on the appropriate link, if available, to continue working on the project:

Available Forms

Demographics	Incomplete
PILL 1	Incomplete
FMTCS 1	Incomplete
<u>BI 1</u>	Incomplete
CESD 1	Incomplete
Does writing promote health?

Return to Progress Report

Project Schedule Planner

The table shown below describes the stages involved in the project and time intervals between them. The schedule for all the phases in the project are displayed upon choosing a date for Item number 1. While the dates for Item numbers 2 and 3 are strictly dependent upon the chosen date for Item number 1, the schedule for all the other stages in the project can be subsequently modified by changing the date for Item number 4.

This tool will only assist you in working up a schedule and will NOT record any schedule you choose. You are responsible for following a schedule that best suits you. Furthermore, you are not bound to the schedule you choose, although it is preferred that you follow the chosen schedule.

Instructions for using this tool

- 1. Choose a date for Item number 1 using the drop-down menu
- 2. Click on the "Display Schedule" button to view the schedule for the project
- 3. Once the schedule is displayed, you may choose to do one of the following:
- If you are satisfied with the schedule, click on the "Return to Progress Report" link in the top left corner of this page to return to the previous page
- ii. If you are satisified with the schedule for the first three items in the list, but would like to change the schedule for the rest of the project, enter appropriate values in the text-boxes for Item 4 and click on "Display Schedule" again. A modified schedule for Items 5 through 10, based on the date entered for Item 4, is displayed.
- iii. If you wish to change the date for Item number 1 to a FUTURE date, please do so and click on the "Display Schedule" button to get an entirely new schedule
- iv. If you wish to push back the date for Item number 1 to an EARLIER date, you can do so and click on the "Display Schedule" button. Please note that this will NOT change the date for Item numbers 4 through 10 in the new schedule. However, you can enter a date convenient to you in Item number 4 and click on "Display Schedule" to view a modified schedule for Items 5 through 10.

			(c	Display S	Schedu
1. Use Login ID and Password to read instructions for saliva collection; complete web-based questionnaires		ember 💌 Day	/ 28 🗙 Year 20	109	
12/28/2009					
2. First Writing Session - scheduled no less	s than one day	20 minutes	December 😽	29	2009
after the previous item.			Update		
3. Second Writing Session.		20 minutes	12/31/2009		
4. Third Writing Session.		20 minutes	1/2/2010		
5. Fourth Day After Writing - Questionnaires.		45 min to 1 hr	1 1/6/2010		
6. Thirtieth Day After Writing - Questionnaires.		45 min to 1 hr	2/1/2	2010	

Demo	graphics
1. State of data collection 2. Country	
3 Date	
4. Your name	
5. Your phone number	
6. Have you ever received any caregiver training?	○ Yes ○ No
7. How many average hours weekly do	
you provide care to the care recipient?	
List actual hours) (must be more than 4)	
8. How many hours is professional or	
nired support in the house every week?	
9. What is your relationship to the care recipient?	O Spouse O Offspring
	O Sibling (brother or sister)
	O Other Relation
	O Filend
10. What is your birth date? (MM-DD-YY)	
11. What is your gender?	OMale
	© Female
12. What is your ethnicity?	⊖ Caucasian
	 African American
	 American Indian / Native American Hispanic
	O Asian
	O Other, specify:
13 What is your highest educational	
level? (list actual number of years of	1 <u></u> J
schooling completed)	

	ort Scheduler Logout
Demogr	aphics - Page 2
14. Do you live:	o Alone O With care recipient only O With more than one family member (one of whome is th care recipient) O With one or more family members (none of whom are th care recipient) O Other, describe:
15. Do you attend a support group?	⊙ Yes ⊙ No
16. If yes to above, how many times a month?	
17. How often do you use respite care? (list actual number of hours per week)	
18. What is your working status?	 Working at a paying job full-time Working at a paying job part-time Retired Laid-off or unemployed, but looking for work A full-time homemaker Other
19. Average annual income available for you to provide care:	 ○ Less than \$10,000 ○ \$10,000 - \$30,000 ○ \$30,000 - \$50,000 ○ Over \$50,000
20. Does the care giving role result in a financial burden for you?	O No O Yes
21. Length of time being a caregiver: (list in actual months)	
22. Medications you are taking (please list)	
23. Number of serious health problems you have (please list)	



Thinking about your friends and family, other than the person you care for , please indicate the extent to which you agree or disagree with the following statements:

O Every day

	Strongly Agree (4)	Agree (3)	Disagree (2)	Strongly Disagree (1)
27. There is really no one who understands what you are going through.	0	o	0	0
28. The people close to you let you know that they care about you.	0	o	0	0
29. You have a friend or relative in whose opinions you have confidence.	0	o	0	0
30. You have someone whom you feel you can trust.	0	0	0	0
31. You have people around you who help you to keep your spirits up.	o	o	0	0
32. There are people in your life who make you feel good about yourself.	o	o	0	0
33. You have at least one friend or relative you can really confide in.	0	o	0	0
34. You have at least one friend or relative you want to be with when you are feeling down.	0	0	0	0

Save Demographics

Bad

Does writing promote health?

Progress Report Scheduler Logout

PILL

Several common symptoms or bodily sensations are listed below. Most people have experienced most of them at one time or another. We are currently interested in finding out how prevalent each symptom is among various groups of people. On the page below, choose the letter that expresses how frequently you experience each symptom. For example, if your eyes tend to water once every week or two, you would choose "D" for item 1.

		Rarely or never experience the symptom (A)	Every month or so (B)	Every week or so (C)	At least 2 or 3 times per week (D)	Every day (E)
1	Eyes water	0	0	0	0	0
2	Itchy eyes or skin	Ø	0	0	0	0
3	Ringing in ears	0	0	0	0	0
4	Temporary deafness or hard of hearing	0	0	0	0	0
5	Lump in throat	Ø	0	0	0	0
6	Choking sensations	0	0	0	0	0
7	Sneezing spells	0	0	0	0	0
8	Running nose	0	0	0	0	0
9	Congested nose	0	0	0	0	0
10	Bleeding nose	0	0	0	0	0
11	Asthma or wheezing	Ø	0	0	0	0
12	Coughing	0	0	0	0	0
13	Out of breath	0	0	0	0	0
14	Swollen ankles	0	0	0	0	0
15	Chest pains	O	0	0	0	0
16	Racing heart	0	0	0	0	0
17	Cold hands or feet even in hot weather	0	0	0	0	0
18	Leg cramps	0	0	0	0	0
19	Insomnia or difficulty sleeping	0	0	0	0	0
20	Toothaches	0	0	0	0	0
21	Upset stomach	0	0	0	0	0
22	Indigestion	0	0	0	0	0
23	Heartburn or gas	0	0	0	0	0
24	Abdominal pain	0	0	0	0	0
25	Diarrhea	0	0	0	0	0

Continue

Nursing Family Caregiver Writing Study THE LINIVERSITY OF YOWA Does writing promote health?

Progress Report

PILL -	Page 2
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Scheduler

Locout

	Rarely or never experience the symptom (A)	Every month or so (B)	Every week or so (C)	At least 2 or 3 times per week (D)	Every day (E)
26 Constipation	0	0	0	0	0
27 Hemorrhoids	0	0	0	0	0
28 Swollen joints	0	0	0	0	0
29 Stiff or sore muscles	0	0	0	0	0
30 Back pains	0	0	0	0	0
31 Sensitive or tender skin	0	0	0	0	0
32 Face flushes	0	0	0	0	0
33 Tightness in chest	0	0	0	0	0
34 Skin breaks out in rash	0	0	0	0	0
35 Acne or pimples on face	Ō	0	0	0	0
36 Acne/pimples other than face	0	0	0	0	0
37 Boils	0	0	0	0	0
38 Sweat even in cold weather	0	0	0	0	0
39 Strong reactions to insect bites	O	0	0	0	0
40 Headaches	0	0	0	0	0
41 Feeling pressure in head	0	0	0	0	0
42 Hot flashes	0	0	0	0	0
43 Chills	0	0	0	O	0
44 Dizziness	0	0	0	0	0
45 Feel faint	0	0	0	0	0
46 Numbness or tingling in any part of body	0	0	0	0	0
47 Twitching of eyelid	0	0	0	0	0
48 Twitching other than eyelid	0	0	0	0	0
49 Hands tremble or shake	0	0	0	O	0
50 Stiff joints	0	0	0	0	0
51 Sore muscles	0	0	Ø	0	0
52 Sore throat	0	0	0	0	0
53 Sunburn	0	0	0	0	0
54 Nausea	0	0	0	0	0

Since the begining of the study, how many:

Visits have you made to the doctor's office or hospital for illness

Days have you been sick

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Progress Report Scheduler

Logout

BI

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After each statement, please choose the one that corresponds to how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

		Never (1)	Rarely (2)	Sometimes (3)	Quite Often (4)	Nearly Always (5)
1	Do you feel that your relative asks for more help than he/she needs?	0	0	0	0	0
2	Do you feel that because of the time you spend with your relative you don't have enough time for yourself?	0	0	o	0	0
3	Do you feel stressed between caring for your relative and trying to handle other responsibilities for your family or work?	0	0	0	0	0
4	Do you feel embarrassed over your relative's behavior?	0	0	0	0	0
5	Do you feel angry when you are around your relative?	0	0	0	0	0
6	Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	0	0	0	0
7	Are you afraid of what the future holds for your relative?	0	0	0	0	0
8	Do you feel your relative is dependent upon you?	0	0	0	0	0
9	Do you feel strained when you are around your relative?	0	0	0	0	0
10	Do you feel your health has suffered because of your involvement with your relative?	0	0	0	0	0
11	Do you feel you don't have as much privacy as you would like, because of your relative?	0	0	0	0	0

Continue

Does writing promote health?

Progress Report Scheduler Logout

BI - Page 2

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After each statement, please choose the one that corresponds to how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

		Never (1)	Rarely (2)	Sometimes (3)	Quite Often (4)	Nearly Always (5)
12	Do you feel that your social life has suffered because you are caring for your relative?	0	0	0	0	0
13	Do you feel uncomfortable about having friends over, because of your relative?	0	0	0	0	0
14	Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?	0	0	0	0	0
15	Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?	0	0	0	0	0
16	Do you feel that you will be unable to take care of your relative much longer?	0	0	0	0	0
17	Do you feel you have lost control of your life since your relative's illness?	O	0	0	0	0
18	Do you wish you could just leave the care of your relative to someone else?	0	0	0	0	0
19	Do you feel uncertain about what to do about your relative?	0	0	Ő	Ö	Ö
20	Do you feel you should be doing more for your relative?	0	0	0	0	0
21	Do you feel you could do a better job in caring for your relative?	0	0	0	0	0

		Not at all	A little	Moderately	Quite a bit	Extremely
22	Overall, how burdened do you feel in caring for your relative?	0	0	0	0	0

Save BI

Bad

Nut Sing Family Caregiver Writing Study THE UNIVERSITY OF IOWA Does writing promote health?

Progress Report Scheduler Logout

FMTCS

This questionnaire contains a number of statements related to opinions and feelings about yourself, your impaired relative and your caregiving experience. Read each statement carefully, then indicate the extent to which you agree or disagree with the statement. Choose one of the alternative categories.

		Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
1	I miss the communication and companionship that my family member and I had in the past.	0	0	0	0	0
2	I miss my family member's ability to love me as he/she did in the past.	0	0	0	0	0
3	I am sad about the mental and physical changes I see in my relative.	0	0	0	0	0
4	I miss the little things my relative and I did together in the past.	0	0	0	0	0
5	I am sad about losing the person I once knew.	0	0	0	0	0
6	I miss not being able to be spontaneous in my life because of caring for my relative.	0	0	0	o	0
7	My situation feels endless.	0	0	0	0	0
8	l enjoy having my relative with me; l would miss it if he/she were gone.	0	0	0	0	0
9	I count my blessings.	0	0	0	0	0
10	Caring for my relative gives my life a purpose and sense of meaning.	0	0	0	0	0
11	The Lord won't give you more than you can handle.	0	0	0	0	0
12	I miss not having more time for other family members and/or friends.	0	0	0	0	0
13	have no hope, I am clutching at straws.	0	0	0	0	0
14	I cherish the past memories and experiences that my relative and I have had.	0	0	o	o	0
15	am a strong person.	0	0	0	0	Ø

Continue

Progress

Does writing promote health?

FMTCS - Page 2

Scheduler

Logout

This questionnaire contains a number of statements related to opinions and feelings about yourself, your impaired relative and your caregiving experience. Read each statement carefully, then indicate the extent to which you agree or disagree with the statement. Choose one of the alternative categories.

100		Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
16	Caregiving makes me feel good that I am helping.	0	0	0	0	0
17	I believe in the power of prayer; without it I couldn't do this.	0	0	0	0	0
18	I miss our previous social life.	0	0	0	0	0
19	have no sense of joy.	0	0	0	0	0
20	The hugs and "I love you" from my relative make it worth it all.	0	0	0	0	0
21	I'm a fighter.	0	0	0	0	0
22	I am glad I am here to care for my relative.	0	0	0	0	0
23	believe that the Lord will provide.	0	0	0	0	0
24	I miss not being able to travel.	0	0	0	0	0
25	l wish I were free to lead a life of my own.	0	0	0	0	0
26	Talking with others who are close to me restores my faith in my abilities.	0	0	0	0	0
27	Even though there are difficult things in my life, I look forward to the future.	0	0	0	0	0
28	Caregiving has helped me learn new things about myself.	0	0	0	0	0
29	I have faith that the good Lord has reasons for this.	0	0	0	0	O ×
30	I miss having given up my job or other personal interests to take care of my family member.	0	0	0	0	0

Continue

Back

Does writing promote health?

FMTCS - Page 3

cheduler

Logout

This questionnaire contains a number of statements related to opinions and feelings about yourself, your impaired relative and your caregiving experience. Read each statement carefully, then indicate the extent to which you agree or disagree with the statement. Choose one of the alternative categories.

		Strongly Agree (1)	Agree (2)	Undecided (3)	Disagree (4)	Strongly Disagree (5)
31	I feel trapped by my relative's illness.	0	0	0	0	0
32	Each year, regardless of the quality, is a blessing.	0	0	0	0	0
33	I would not have chosen the situation I'm in, but I get satisfaction out of providing care.	0	0	0	0	0
34	We had goals for the future but they just folded up because of my relative's dementia.	0	0	0	0	0
35	God is good.	0	0	0	0	0
36	miss my relative's sense of humor.	0	0	0	0	0
37	l wish I could run away.	0	0	0	0	0
38	Every day is a blessing.	0	0	0	0	0
39	This is my place; I have to make the best out of it.	0	0	0	0	0
40	I am much stronger than I think.	O	0	0	Ø	0
41	I feel that the quality of my life has decreased.	0	0	0	0	0
42	l start each day knowing we will have a beautiful day together.	0	0	0	Ö	0
43	Caregiving has made me a stronger and better person.	0	0	0	0	0

Save FMTCS

Back

Does writing promote health?

CESD

Progress Report

eduler

Logout

Below is a list of the ways you might have felt or behaved. Please choose the number for each statement that best describes how often you felt or behaved this way during THE PAST WEEK. 0 = Rarely or None of the Time (Less Than 1 Day); 1 = Some or a Little of the Time (1-2 Days); 2 = Occasionally or a Moderate Amount of Time (3-4 Days); 3 = Most or All of the Time (5-7 Days)

(† 1		Less Than 1 Day (0)	1-2 Days (1)	3-4 Days (2)	5-7 Days (3)
1	I was bothered by things that usually don't bother me.	0	0	0	0
2	I did not feel like eating; my appetite was poor.	0	0	0	0
3	I felt that I could not shake off the blues even with help from my family or friends.	0	0	0	0
4	I felt that I was just as good as other people.	0	0	0	0
5	I had trouble keeping my mind on what I was doing.	0	0	0	0
6	I felt depressed.	0	0	0	0
7	I felt that everything I did was an effort.	Ø	0	0	0
8	I felt hopeful about the future.	0	0	0	0
9	I thought my life had been a failure.	0	0	0	0
10	I felt fearful.	0	0	0	0

Continue

Does writing promote health?

cheduler Progress R Locout

CESD - Page 2

Below is a list of the ways you might have felt or behaved. Please choose the number for each statement that best describes how often you felt or behaved this way during THE PAST WEEK. 0 = Rarely or None of the Time (Less Than 1 Day); 1 = Some or a Little of the Time (1-2 Days); 2 = Occasionally or a Moderate Amount of Time (3-4 Days); 3 = Most or All of the Time (5-7 Days)

	Less Than 1 Day (0)	1-2 Days (1)	3-4 Days (2)	5-7 Days (3)
11 My sleep was restless.	0	0	0	0
12 I was happy.	Ø	0	0	0
13 I talked less than usual.	0	0	0	0
14 I felt lonely.	0	0	0	0
15 People were unfriendly.	Ø	0	0	0
16 I enjoyed life.	O	0	0	0
17 I had crying spells.	0	0	0	0
18 felt sad.	Ő	0	0	0
19 I felt that people disliked me.	0	0	0	0
20 could not get "going"	0	0	0	0

Save CESD

Bade

Nursing Family Caregiver Writing Study THE UNIVERSITY OF IOWA Does writing promote health?

Progress Report Collection Instructions Scheduler Logout

User Acceptance of a Web-based Written System for ADRD Caregivers

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I found the web-based writing system useful for managing my stress related to caregiving	0	0	0	0
2. Using the web-based writing system made it easier to deal with my stress related to caregiving	0	0	0	0
 Using the web-based writing system helped me express my issues related to caregiving at any time. 	0	0	0	0
4. Learning to use the web-based writing system was easy for me.	O	Ø	0	0
5. I found the web-based writing system easy to use.	0	0	0	0
6. Using the web-based writing system took too much time.	0	0	0	0
 Using the web-based writing system is a good idea for caregivers with Alzheimer's disease and related disorders. 	0	0	0	0
8. The web-based writing system was interesting to me.	0	0	0	ø
9. I liked working with this web-based writing system to manage my stress related to caregiving .	0	0	0	0
10. I had the resources I needed to use the web- based writing system.	0	0	0	0
 The web-based writing system was not compatible with other ways I manage my caregiving related stress. 	0	0	0	0
12. I could control how I used the web-based writing system.	0	0	0	0
13. I could use the web-based writing system even if no one was around to tell me what to do.	0	0	0	0
14. I felt nervous about using the web-based writing system.	0	0	0	0
15. It scared me to think that I might make a mistake when using the web-based writing system.	0	0	0	0
16. I was worried about using the web-based writing system.	Ø	ø	0	0
17. I would use the system again for managing my stress related to caregiving.	0	0	0	0

We are interested in your opinion of the web-based writing system for managing stress related to caregiving . Please tell me what you liked about using the system.

Were there things that you didn't like about the system or that didn't work well for you?

Do you have any suggestions for how to make the system more useful to you?

Save User Acceptance

N.

1

4

	Availa	ole Writings	
	Writing 1	Available	
-	Writing 2	Not Available	
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Nursing Family Caregiver Writing Study THE UNIVERSITY OF IOWA Does writing promote health?

Scheduler

Lonout

General Instructions

Progress Report

This study is a project about writing and well-being. You are being asked to participate in this study because you are a family member of a person with Alzheimer's disease or a related disorder. If you choose to participate in this study over the next week, you will be asked to write about one of several different topics for 20 minutes every other day for a total of three 20 minute writing sessions. Please arrange a convenient time of the day when you can write for 20 minutes without interruption. Your timer will start off as soon as you click on the "Start Composition" button at the end of this page. The timer will display the time left for you to complete the composition.

The only rule we have about your writing is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write. Because this is a research study, we will tell you the topic you are to write about at the time that you are writing.

Sometimes people feel a variety of emotions after writing. If that happens, it is completely normal. Most people say that these feelings go away in an hour or so. If at any time over the course of the experiment you feel upset or distressed because of what you are writing, please contact me immediately.

Also, your writing is completely confidential. The only people who will have access to what you write are study personnel. Your writing will not be linked to you personally. The one exception is that if your writing indicates that you would harm yourself or others, we are legally bound to match your ID with your name and we will inform you about this and offer a referral to support services.

Click on "Read Specific Instructions" to read instructions specific to the composition you are about to write.

Return to Main Page Read Specific Instructions

Does writing promote health?

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Specific Instructions for Composition 1

Progress Report

Following are some instructions and guidelines specific to this composition. Please read them to better understand the objective of writing this composition. For your convenience, the specific instructions will also be available to you on the composition page, in case you need to look them up while writing.

What I would like you to write about today, and for two more times after today, for 20 minutes each time, are your deepest emotional thoughts and feelings about caring for your loved one, family member or friend who has Alzheimer's disease. In your writing, we would like you to explore your very deepest thoughts and feelings about your experience as a family caregiver of a loved one with Alzheimer's disease. I realize that caregivers of person's with Alzheimer's disease experience a full range of emotions, and I want you to focus on any and all of them. Because Alzheimer's disease can touch every part of our lives, you might explore how this experience is linked to issues in your childhood, relationships with parents, old friends, and others you have cared about. You might tie your thoughts and feeling of being a caregiver to other family issues, finances, or even traumatic experiences you have suffered. In your writing, I want you to really let go and explore your very deepest emotions and thoughts. You may think about all the various feeling and changes that you experienced since you first became a caregiver to your loved one, family member or friend who has Alzheimer's disease, and whatever you are feeling now. You can write about the problems or conflicts that you have experienced or are experiencing now. How your caregiving experience is related to your childhood, your parents, children, the people you love, who you are, or who you want to be. Ideally, I would like you to focus on those experiences, changes, thoughts, and feelings that you have not discussed in great detail with others. Remember, you will have three separate occasions for writing. You can write about the same experiences each day or about different experiences each day. Again, the most important part of your writing is that you really focus on your deepest emotions and thoughts. The only rule we have is that you write for the entire 20 minutes. Don't worry about grammar, spelling, or sentence structure. If you run out of things to say, just repeat what you have already written. Just write your story.

Click on "Write Composition" to begin writing the composition.

Once this button is chosen, you will be redirected to the composition page. When you are ready to start writing click the start button to start the timer and make the writing area active. You will NOT have an option of returning to the Main Page till the composition is submitted.

Write Composition

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APPENDIX D: RECRUITMENT MATERIALS

News release form

FOR IRB USE ONLY APPROVED BY: IRB-01 IRB ID #: 201005755 APPROVAL DATE: 09/13/10 EXPIRATION DATE: 07/21/11

University of Iowa News Item 09xx10 Writing Study CFP

THIS IS TO RECRUIT SUBJECTS FOR THE WRITING STUDY

IRB Reviewers: In addition to the news release, this text may also be used in other UI publications (online and print)

At-a-Glance

Caregiver writing study invites participants

Adults age 18 and older who provide care for a person living in the home with Alzheimer's disease or other conditions involving memory-loss are invited to participate in a University of Iowa research study investigating whether expressing thoughts and feelings in writing can help manage stress associated with the caregiving experience.

Study participants will use an Internet-based approach to write about their experiences related to their caregiving role for 20 minutes three times during one week. Participants also will complete two additional online survey forms. Participants need not be experienced writers as the study focuses on the effect of writing rather than the written content itself.

Ji Woon Ko, a doctoral student at the UI College of Nursing, and Howard Butcher, Ph.D., associate professor of nursing, will lead the study, which also will test the acceptance of the Web-based writing intervention to manage stress related to caregiving experiences. Compensation is provided.

For more information, visit http://swee.its.uiowa.edu/swee/ or contact Ji Woon Ko at 319-594-0502 or jiwoon-ko@uiowa.edu.

SUBMITTED BY: Jennifer Brown, 319-356-7124, jennifer-lbrown@uiowa.edu

SHOULD RUN ON: DAY, DATE, 2010

Family Caregiver Writing Study

 Researchers of the College of Nursing are seeking volunteers to take part in a study of Web-based Structured Written Emotional Expression for Alzheimer's caregivers. This research will test the acceptance of the Web-based writing intervention to manage stress related to caregiving experiences.



- Volunteers must be:
 - Care for someone who is living at home and who has memory loss due to any form of dementia like Alzheimer's disease, Parkinson's, or Huntington's disease
 - 18 years of age or older
 - Not paid for the care you provide
 - The person who spends on average at least 4 hours a day helping your relatives or friend. This includes any time that you spend watching, monitoring, assisting, or simply being available in case help is needed (even during hours that you are sleeping)
 - Able to read and write in English
 - Have access to a computer

Compensation is provided.

For details e-mail: jiwoon-ko@uiowa.edu or call: 319-594-0502

> The University of Iowa college of NURSING

APPENDIX E: QUALITATIVE DATA

The questions and descriptive opinions are as follows (spelling, grammar and

punctuation are reported exactly in the format submitted by participants):

- We are interested in your opinion of the web-based writing system for managing stress related to caregiving. Please tell me what you liked about the using the system.
- I don't think I really understood just what you mean by the "web-based writing system". To me it seemed to be just a free-association method of writing about your thoughts about Alzheimer's and care-giving.
- I liked the ease of use.
- I couldn't really find much to like. It was easy to use and it did help focus on elements of caregiving and my daily life.
- Thank you for the opportunity to try this "system". I found it very helpful. Especially since it is coming at a time when my relative is rapidly deteriorating both physically and mentally as well as approaching his 104th birthday with family visits all planned!
- I believe this web-based system is a good tool for some situation because half the time they are functioning like robots. And I can understand that sometimes answering questions allows the caregiver to think more relevantly about his/her expressing oneself is good since there are not too many people who want to hear about the caregiver's woes.
- The writing topics were not relative to my care-giving situation at all. If I had written about those topics it may have been more helpful.
- It was very easy to use and interesting.
- I was able to speak emotions and feelings to get them out without anyone hearing.
- Time. I could do it at a time which was convenient form
- It made me think more about my feelings that I had taken for granted. It has been a blessing taking care of my mom and really realized how good I felt after I started taking the survey.
- The writing did not afford me the opportunity to express how I feel about topics related to the care of my husband. I was surprised at the assigned topics.
- Brought up interesting thoughts
- I think that writing/journaling is extremely helpful and revealing. Writing constantly for 20 minutes was a little stressful but in the end it was well worth it.
- It could help the user identify if one was unaware of slipping into depression or becoming resentful of being a care giver.
- It was simple to use and understand. Once I got started the words poured out of me. This made me realize that I need to unload my feelings and thoughts. I think this system would be very helpful to many caregivers.
- I enjoyed having a place to express my feelings. It felt like a safe place where the words would not personally affect the one reading this.

- I liked that I had something to do and take my mind off my problems for a few minutes.
- It was impersonal no one was reading it to grade me or belittle me. I felt like I could write whatever I wanted even if that was the same sentence over and over and that would have been ok. A daily topic was given to get you started. It made me think about myself for a change it was easy to use and it was helpful to see things written down as a way to identify feelings.
- The timeframe to complete it.
- It made me feel better to talk about my problems.
- I liked that a topic was given so I didn't have to think about what to write. Since I was supposed to write for a specific period of time
- It's helpful to get your feelings out in the open even online in this sort of journal.
- I liked the writing better than the questionnaires. The 20 minute sessions went by very quickly. I always felt I could write more.
- Once I started writing my feelings just flowed it felt good to let it out and not feel I was being judge.
- I don't feel I got anything out of it....not sure what I expected but this was mainly just a waste for me...I hope your research group got something from it.
- System was relatively easy to access and very easy to use. Did not take much time from my day in relation to the amount of stress relief it provided.
- good to write everything and anything without regard for who is reading it
- Any time I write, I learn more about what I am thinking and how I am feeling. The questionnaires led me to think more about how I really felt about a lot of issues that I don't normally sit and think about.
- You have many typing errors in this paragraph. Please fix. it was fun but i daily to see how it would help a caregiver. Perhaps it puts someone's thoughts in order to a certain extent. Please elaborate/ incorporate more in your system for burnt out caregivers such as ways to manage the stress or signs to get oneself to counseling before one drops dead
- I liked writing about me thought and feelings but needed more than 20 minutes. Or more than 3 sessions. it helped me to put the overall picture into perspective but needed more of it.
- Setting aside time for a specific activity for me.
- It was simple- I did not have to correct spelling- write in complete sentences
- I liked having the different emotions listed so that I could acknowledge my degree of how I was feeling.
- It's easy to use. In theory I think it could help if a person is actually writing about their stress and caregiving issues but I was not in that group. It contains Christian statements about "the Lord" and "the good Lord" and I am not a Christian although I do believe in spiritual powers and entities. That wording needs to be changed. I had to answer "No" to those statements even though that response does not reflect my spiritual beliefs.
- I sometimes felt worse after using it. I was fearful my husband would question what I was doing.

- Confirmed what my husband says about me. I tend to give to much information before answering the question or getting to the point. Doing better with that thanks to this assignment. sticking to the schedule. Finding 20 interrupted minutes was challenging but taught me that I need to schedule time to do things that are important to me
- I like expressing myself and getting at the heart of a problem. The questionaires especially made me know there are others who have some of the same feelings I have.
- The system is easy to master on line....the writing is very focused on just me which I liked and I could choose a convenient time to write so there was no stress involved in scheduling my writing time. The writing system is a writing activity I can do for myself!!
- It made me feel better to talk about my problems.
- Obviously I was in the control group but just writing was helpful
- The questions led me to examine how I really felt about my life; my mother is not as difficult as some elderly dementia patients but the continuing forgetfulness does try my patience. I liked being able to express myself anonymously and non-judgmentally. I believe that being able to express my frustrations even when they are irrational or contradictory is helpful to my mental and emotional state.
- Was very easy to use.
- the topics and questions validated my own thoughts & feelings which i have found to be so important in dealing [or coping] with the loneliness of being a caregiver for a loved one with dementia / alzheimers.
- I think it helped me see a little clearer once I wrote it down. I also liked having the time to myself while I was writing
- It was easy to understand. It did not take too much time. Very useful for me to reflect on what I really feel about being the caregiver. I liked the email prompts.
- It was easy and made me write which I would not do on my own.
- well. before this....I thought I had not time to do it.....it looked like to much time for me to take away from caring.
- I would like to know how my thoughts compare to other caregivers.
 - 2) Were there things that you didn't like about the system or that didn't work well

for you?

- To me it was totally unstructured and there wasn't much of a "method" to it. I think you should (1) define just what you mean by that term and (2) ask these questions much closer to the time we did the writing.
- The PILL exercises required numerical values which I found impossible to enter.
- Having specific topics versus addressing a general concern or something that happened that day. I would use a writing system if I felt I was writing to someone that would actually be listening and commenting/counseling on my writing. Otherwise I'm basically talking to myself.

- It worked well.
- I deal with all sorts of emotions on a daily basis. To write about them or answer any kind of questions once in a while is okay, but it would not serve me well as I'd only have to see in print or remind myself how miserable I might be feeling. Sometimes just accepting one's duty and doing the best they can is sufficient.
- The system was very user-friendly
- A few of the questions were hard for me to answer. My mother has always been a very difficult person and her illness has brought out the worst in her. It is sad to say that she was never a loving, caring person so I was not able to say that I missed those things about her I couldn't miss it because I never had it. One time the time frame did not match my schedule.
- It was writen well and easy to follow. At times it felt that I was re-doing questions which I understand that I was. The reason for this is unknown.
- Just the limitations of the topics. Perhaps I am too clinical to use the topics as a stimulus to express myself about other care issues and frustrations. Perhaps the topics were eading and I stuck too much to the assigned topics.
- Some of the questions did not apply to me general assumptions may have been made regarding the past relationships.
- The time constraints were often hard to stick with because of busy schedule with my grandmother.
- Some questions didn't apply to me. I have no family (except for my Mom Dad [who has advanced Dementia] and my Dog) no friends and no job and some questions were related to that.
- No it was all easy
- I was glad the web took care of timing me.
- I didn't like the time limit...sometimes I wanted to write more...often I wanted to stop around 15 min.
- Some of the questions were repetitive or didn't really apply to my situation.
- I had problems several times signing on.
- Fine...hate the whole ratings 1-5 how much?
- Set up this system needs to be aware that there are many people out there who either do not believe in "God" Whomever who call their deity by a name other than "God"...continually using references to "God" can be insulting to those folks...
- Also might want to have more spaces for notes on the parts of the selection. it brought out a lot of feeling that may have otherwise been buried for some time periods. I felt very frustrated at times and would like to have had a therapist at those times.
- Some of the questions were a bit difficult for me to answer; I felt like my thoughts and feelings didn't exactly fit.
- Didn't like the topics I had to write about.
- I thought the 20-minute writing sessions were a little too long.
- It was good to express my feelings but I knew I would not get help from anyone so it seemed senseless. Somewhat like a blabk hole. felt instructions for writing assignments were too long. had to go back to read several times.

- I was a bit confused with the scheduler. I found it hard to stay on schedule for a while because I was so busy.
- I did not like the topics I was asked to write about the topics were personal and related to my health and life such as my diet, medications writing about these topics felt more like a task than a pleasure...However I did enjoy writing about my leisure activities more than my meds and diet because the topic addressed my interests and helped me think about the activities I enjoy. Give me more and different topics to write about....I would like more challenging topics that encourage me to write and think beyond my health and boring medications...
- The computer system was too picky for someone like me who doesn't use computers well. It was simple but I would have liked it better if there were more than 3 writings. ie. if 3 random writings about my life helped then presumably more would have helped more.
- i didn't like the timer cutting my writing off in mid-sentence/in the midst of a deep feeling a strong emotion a complex or overwhelming thought that i was trying to caregivers express. it seems counter-productive.
- Cant think of anything
- I lost my password but other than that it was just fine.
- time.....
- It did not go deep into the real problems of care giving

3) Do you have any suggestions for how to make the system more useful for you?

- More written essays with more varied topics.
- Nothing really. It's probably a generally good idea for some people. It's just not for me. As I sit here and type my wife is standing in the hallway needing something. Another strike against the wed-based writing system.
- It would be nice to continue this system.
- I think that allowing the caregiver to set some goals or have visions for herself/himself might be useful. This study stresses the difficult and sad part of caregiving.
- no complaints. Just the topics I didn't like to write about. None related to the system.
- It might be good to have an "other" answer with a field for writing a brief description. There were a few answers that were hard to fit into the choices provided.
- I would do it again since I had to think about how I felt daily and weekly and monthly. My health is good even with the stress. Well we get some type a data results?
- to write feeling was wonderful
- I think there are two groups of care givers... one where they live together and one where they do not. Some are family and some are not related to the person needing care. I am a niece by marriage and had very little communication with my aunt before I became her care giver.

- A lenient time constraint.
- List more topics of discussion
- A little less time writing maybe only 15 minutes
- No, I was happy with everything.
- Remove the time limit.
- Skip the questions and have writing sessions. Perhaps tips on managing stress n caring for a loved one etc.
- It would be great if resources could be listed somewhere. I live in rural Iowa and there are no support groups for me. Most caregiver books I've have read the writer in my opinion doesn't share their resentment and most have money and a staff to help them. They are free to take off on get always ect.
- How about real life people and real life problems we face?
- If there were some way to get some feedback on the written portion--a two-way support system by e-mail where questions could be fielded on my feelings that would be even more helpful.
- Write more about feelings and emotions
- I felt it helped me and also it was simple to use- since I did not grow up with computetrs
- I would shorten the writing sessions to perhaps 10 minutes but maybe more often.
- put me in the group that actually writes about their feelings and problems. And again replace the Christian terms with non sectarian terms
- Not really.
- A little less time writing maybe only 15 minutes
- I think that health conditions can vary so much that the answers don't always match the questions. For example I've had a few minor health problems but recently developed diverticulitis partly as a result of the stress. I haven't had a recurrence and I am watching my diet more carefully. The only thing I can think of is the advance notice but I think there was advance notice during the testing period. Occasional input would be helpful like receiving information that it is normal to feel angry or frustrated and love the person at the same time much as we do our children as we are raising them. I'm glad I took advantage of this opportunity.
- Could there be a way to access it when stressed rather than just the 3 random and closely timed writings? It would be interesting to track people writing when unhappy and see if there is a corresponding relief within 1-2 weeks. rather than just the 3 random and closely timed writings? It would be interesting to track people writing when unhappy and see if there is a corresponding relief within 1-2
- no, except maybe for a continuation of the opportunity to keep writing answering questions related to the overwhelming stress & guilt associated with being the caregiver. i do find the 'blog' feedback format helpful i.e. on the alzheimers association website forums the national caregivers association e-newsletters. reading the comments of others who feel & experience what i do is so tremendously valuable & validating; it is like the "knot" at the end of the rope that one can hold on to "one day at a time" - thank you for this opportunity.sometimes one hour or one minute at a time :-/

- Revisit my answers in a few months. Be able to see the overall results of your research.
- The login button should be bigger and in the middle of the screen so it is easily seen. I didn't notice it the first time.
- I would like to know what you get out of this....LOL
- The ideals that I had to write about were not the real problems in my life and did nothing to relieve me of any stress. I would query the person as to what his real worries were and then base a study around them

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