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Who Is Caring for the Caregiver? The Role of Cybercoping for Dementia Caregivers

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Who Is Caring for the Caregiver? The Role of Cybercoping for Dementia Caregivers

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Abstract: The purpose of this study is to investigate the relationship between dementia caregivers' communication behaviors (information seeking and forwarding) and their outcomes (coping outcomes: e.g., dealing better with negative feelings or improved medical outcomes). A survey data set of dementia patients' caregivers substantiates the effects of communication behaviors about dementia illness on coping outcomes, as well as the mediating role of emotion-focused and problem-focused coping processes. Using structural equation modeling (SEM), this study found positive effects of communication behaviors on outcomes through coping processes. Further, the results indicate that communication behaviors in cyberspace are crucial for caregivers to cope with dementia, both affectively (improvement of caregivers' emotional control) and physically (health improvement of patients). The implications for the improvement of public health through online health communication behaviors are discussed.

Dementia is a common, chronic disease that involves a wide range of symptoms associated with deterioration in cognition, behavior, and the ability to perform everyday activities (Alzheimer's Association, [2016](#)). The causes of dementia are not fully known, and it is incurable using currently available treatments. The World Health Organization (WHO, [2012](#)) reported that 35.6 million people have dementia worldwide, and Alzheimer's disease accounts for 60–70% of this total. The number of people with dementia is projected to double by 2030 and to more than triple to almost 100 million by 2050 (WHO, [2012](#)).

At the country level, the Alzheimer's Association ([2016](#)) reports that more than 5 million Americans are living with the disease and "15.5 million [caregivers] provided 17.7 billion hours of unpaid care" valued at more than \$220 billion (p. 1). Furthermore, the Korean Ministry of Health and Welfare ([2012](#)) reported that the number of elderly patients with dementia increased by 26.4% over the last 4 years, despite the elderly population increasing by only 17.4%. The socioeconomic cost caused by dementia in South Korea was estimated to be \$8 billion in 2010 and is projected to double every 10 years to \$35.9 billion (Korean Ministry of Health and Welfare, [2011](#)).

Because dementia primarily involves cognitive disorders that affect learning and memory, it is particularly difficult for patients to cope with it by themselves; caregivers' help and support for the patients are necessary. Unfortunately, caring for a person with dementia becomes more challenging physically and psychologically as the disease progresses (Simpson & Carter, [2013](#)). Family members caring for someone with dementia can become hidden patients or second victims facing various difficulties, which can be exacerbated as the disease advances without recovery and feelings of fear and hopelessness increase (Eisdorfer et al., [2003](#)).

Previous research found that family members caring for dementia patients show physical and psychological difficulties, such as depression, anxiety, and eating disorders (Sørensen, Duberstein, Gill, & Pinquart, [2006](#)). Family members caring for dementia patients are twice as likely to have a mental disorder more than family caregivers for nondementia patients (Blom, Bosmans, Cuijpers, Zarit, & Pot,

[2013](#)); Bruce et al.). Further, caregivers ages 65 year and older are likely to encounter serious physical problems (Bruce et al., [2005](#)).

Due to these findings, researchers have studied intervention plans that improve caregivers' working life, as well as providing psychological and physical support for caregivers who suffer from difficulties in caring for patients (Karlawish et al., [2003](#); Morimoto, Schreiner, & Asano, [2003](#); Vellone, Piras, Talucci, & Cohen, [2008](#)). However, there is a lack of research examining how caregivers cope with this situation in their daily life. The existing studies have focused on descriptive reports or results of intervention programs. Caregivers report difficulties in caring for dementia patients, including psychological turmoil due to the lack of clear treatment options for their patients. In this limited environment, caregivers cope with difficulties by using various communication channels and by consulting with medical teams online. In this regard, cyberspace can play a critical role in providing and sharing available medical information among caregivers. Due to the limitations of current treatments, collecting formal information through information seeking (i.e., obtaining updated factual information and accounts of others' experiences with dementia) and exchanging informal information online through information sharing (i.e., connecting with others who have had firsthand experiences) can influence the ways in which caregivers cope with the challenges caused by caring for dementia patients.

Therefore, this study investigates the active communication behaviors of these caregivers and their effects on coping outcomes, in light of the rapidly growing concerns about dementia rates in South Korea. Furthermore, this study aims to extend health communication research to the examination of caregivers' communication behaviors and their effects on health disease situations (e.g., dementia) in which patients cannot cope without others' help and support.

The uniqueness of dementia caregivers

As the total number of people with dementia has increased worldwide, the number of dementia caregivers and the amount of time spent caring for dementia patients have also increased.¹ A major difference compared to other diseases is that caregivers for dementia

patients are usually nonprofessional caretakers such as family members.

Nonprofessional caregivers may face many challenges because caring for dementia patients entails consideration of the whole situation surrounding the patient, including unique personal characteristics, progression of dementia, and a caring environment, and not satisfying the patient's specific needs (Goldsmith, [2002](#); Montgomery & Williams, [2001](#); Wilkinson, [2002](#)). In addition, nonprofessional caregivers experience uncertainty about caring for patients appropriately and understanding dementia because they have not experienced the disease (Darcy, Brunsden, & Hill, [2011](#)). Although new communication technology and the media environment have provided information that has helped improve the quality of patients' and caregivers' lives, nonprofessional caregivers have limited access to health information as dementia advances. In other words, accessing more information about dementia is still required for nonprofessional caregivers (Elliott, Burgio, & DeCoster, [2010](#)). Accordingly, cyberspace can play a vital role in helping caregivers find more information because online communities have become a critical resource as a function of providing communication spaces for health consumers (Chung & Kim, [2008](#)). Cyberspace can be used to effectively address individuals' diseases due to several advantages, such as easy-to-access details and fewer time and space constraints. Thirty-six percent of individuals recognized the important role of online information for health decision making, and 58% of the same group perceived online information as a more important source than offline sources (Fox, [2006](#)).

It is reasonable to assume that caregivers' information behaviors in cyberspace can be understood in terms of obtaining general health information. Previous research explicates that caregivers usually begin caring for dementia patients without proper preparation, due to the uncertain timing of the illness. As the illness advances, caring for the patients can be improved, and experiences can be shared with others who do not yet have firsthand caregiving experience (Kim, [2007](#)). Chiu and Eysenbach ([2011](#)) classified ways to approach information for caregivers through information systems or through mediators. They stated that health care experiences of the caregivers determine which approach they prefer. While caregivers

who have experience prefer reflective learning through interaction with websites that provide health information, caregivers who have little experience prefer interactive learning with health professionals. This process demonstrates that caregivers can become health information seekers as well as providers, as they seek dementia information and offer the information they have found to other people. Kim and Lee (2014) classify patients' information behavior into two dimensions: information seeking (i.e., behavior focused on accessing information for uncertainty reduction) and information forwarding (i.e., behavior focused on action in a social context, such as sharing and expressing information and experiences in cyberspace).

Individuals' information seeking and forwarding behaviors may be influenced by age and duration of care since these factors have been shown to influence accessibility. For this reason, this study assesses caregivers' information seeking and information forwarding separately, and examines how these information behaviors vary based on patients' duration of care and caregivers' age. Furthermore, information behaviors affect caregivers' subsequent behaviors related to caring for patients. Thus, the following research questions are proposed:

RQ1: Are dementia caregivers' seeking and forwarding communication behaviors and subsequent behaviors related to duration of care and caregivers' age?

RQ2: Do caregivers' seeking and forwarding communication behaviors affect their subsequent behaviors?

Coping and online health information behaviors in health problems

Coping is a typical action in caring for patients. Coping refers to the set of available conscious strategies that serve to decrease negative elements of life during a period of adversity (Endler & Parker, 1990). In general, the preceding research identifies three types of coping styles: task focused, emotion focused, and avoidance focused (Endler & Parker, 1990; Wilks, Little, Gough, & Spurlock, 2011). While task-focused coping aims to remove and revise problems, emotion-focused coping is associated with controlling unpleasant emotions and

involves strategies such as emotional expression. By contrast, avoidance-focused coping involves avoiding adverse circumstances (Bauman, Haaga, & Dutton, [2008](#); Wilks et al., [2011](#)).

For caregivers of dementia patients, task-focused coping provides physical care based on collected care information and previous experiences. This task-focused coping not only enhances caregivers' mental health, but also prolongs time for the patients (Wilks et al., [2011](#)). With respect to emotion-focused coping, despite weak ties among people in cyberspace, health blogging enables effective coping with health problems through social support (Rains & Keating, [2011](#)). Thus, information-forwarding behavior is an important antecedent of emotion-focused coping because individuals in cyberspace share official information as well as private information about health.

This study assumes that emotion-focused and problem-focused coping are influenced by both information seeking and information forwarding as communication behaviors. Communication behaviors in cyberspace have been studied mainly in terms of patients' individual behaviors and their outcomes. Morris and Royle ([1988](#)) found that the more patients are involved in the process of treatment decisions, the better are their physical and psychological outcomes. Kim and Lee ([2014](#)) elucidated that the personal efforts in cyberspace of those who are facing health difficulties bring corresponding changes according to time and situational context, and this process inevitably results in outcomes. Through this finding, they suggested that information-seeking and -forwarding behaviors in cyberspace go through emotion- and problem-focused coping, and in turn positively affect physical and affective coping outcomes among patients with chronic disease.

Both process and outcome efforts of health problem solving appear at the same time among dementia patients who have difficulty performing cognitive activities, and successful coping strategies of caregivers not only become critical factors in reducing suffering but may also be important factors for physical and mental health (Ross, Holliman, & Dixon, [2003](#)). Chung and Kim ([2008](#)) illuminated that a blog is useful for both patients and their companions by offering outlets for people to communicate with others. Our dementia research does not allow us to study patients as in the cancer study by Chung

and Kim (2008) because, unlike cancer patients, dementia patients cannot report on the variables of interest due to diminished cognitive functioning. By taking caregivers into consideration, our study brings another dimension to the study of health communication. Therefore, we focus on the communication behavior of caregivers who do not directly suffer from the illness and how they express and share their experiences, particularly fatigue and exhaustion, on cyberspaces such as blogs. The existing research states that cyberspace plays a pivotal role in mediating role by offering knowledge and understanding to patients and their family members (Wright & Bell, 2003).

Sabir, Pillemer, Suitor, and Patterson (2003) reported that active communication behaviors such as sharing caregivers' prior experiences related to caring for patients brings effective support. Winkler, Bedford, Northcott, and Hilari (2014) also found that using blogs in cyberspace positively influences caregivers of stroke and aphasia patients when they have to adapt to new roles and states of well-being. Thus, information activities in cyberspace affect both patients and caregivers. For example, such activities lead to maintaining progress or improving the illness of dementia patients. As a result, active communication behaviors such as information seeking and information forwarding in cyberspace can affect emotional coping outcomes and physical coping outcomes through emotion- and problem-focused processes. Specifically, communication behavior impacts affective coping outcomes through emotion-focused coping for caregivers, and affects physical-coping outcomes through problem-focused coping for patients.

Consequently, this study addresses the following research questions and hypotheses, which are summarized in [Figure 1](#):

RQ2a: What are the differential effects, if any, of information-seeking and information-forwarding behavior on affective and physical coping outcomes?

H1: (a) Information-seeking and (b) information-forwarding behaviors are positively associated with increases in perceived affective coping outcomes.

H2: (a) Information-seeking and (b) information-forwarding behaviors are positively associated with increases in perceived physical coping outcomes.

H3: (a) Information-seeking and (b) information-forwarding behaviors are positively associated with enhancement in the emotion-focused coping process in health problem solving.

H4: (a) Information-seeking and (b) information-forwarding behaviors are positively associated with enhancement in the problem-focused coping process in health problem solving.

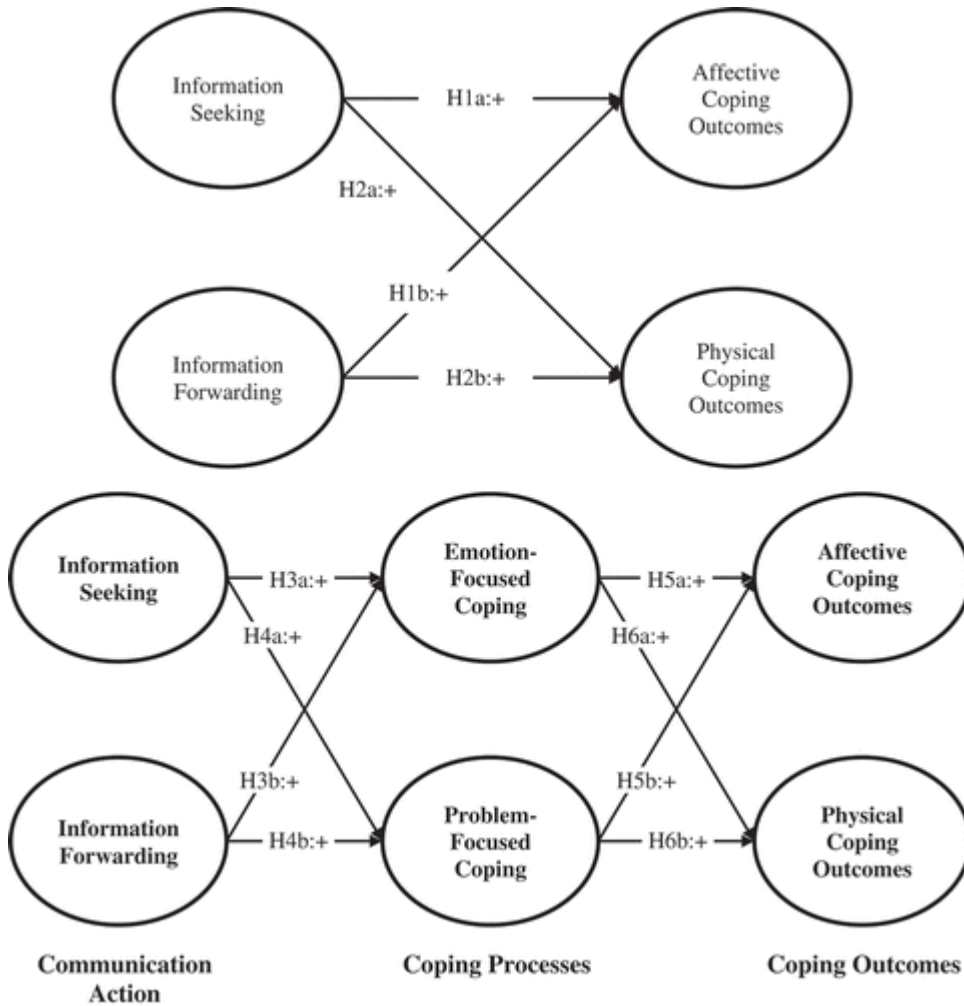
H5: Enhancement of (a) emotion-focused coping and (b) problem-focused coping in health problem solving is positively associated with improvement of affective coping outcomes.

H6: Enhancement of (a) emotion-focused coping and (b) problem-focused coping in health problem solving is positively associated with improvement of physical coping outcomes.

RQ2b: What are the differential effects, if any, of information seeking and information forwarding on emotion-focused coping and problem-focused coping?

RQ2c: What are the differential effects, if any, of emotion-focused coping and problem-focused coping on physical and affective coping outcomes?

Figure 1. Hypothesized model 1 regarding the effects of communication behaviors on coping outcomes and hypothesized model 2 of coping processes mediating the effects of communication behaviors on coping outcomes.



Method

Participants

One hundred fifty-four residents in Seoul, South Korea, agreed to participate in the current study. After removing surveys with missing or unusable data, the final sample contained data from 104 participants. All questionnaires of survey were approved by the institutional review board (IRB) of the Ministry of Health and Welfare (IRB number POL-201407-SB-02).

The average age of participants was 44.21 years ($SD = 11.61$), and 33.7% ($n = 35$) of respondents were male ($n = 69$ female). The average length of duration of care was 19.57 months ($SD = 18.92$). In

order to test research question 1, the length of caring time was categorized into 18 months or less or more than 18 months²; age was categorized into 45 years or less or more than 45 years.

Analysis

First, we found the best measurement items through a confirmatory factor analysis (CFA) and a reliability test. Cronbach's alpha reliabilities were acceptable for all items and are shown in Table 1. In addition, we performed independent-sample *t*-tests to examine mean differences between the two different age and care-time groups. Finally, we evaluated our six hypotheses using structural equation modeling (SEM) in AMOS 19 and tested a mediation model.

Table 1. Reliability for dependent and independent variables (*N* = 104).

Latent variable and measurement item	Factor loading
Information seeking (regarding patient cared for)	
I look for information on dementia from others' blogs and websites.	.860***
I have a collection of Internet sources that I check regularly for new dementia information.	.925***
I regularly check Internet sites and others' blogs to see if there is any new information about dementia.	.884***
Information forwarding (regarding patient cared for)	
I often post comments to help other people with patients.	.854***
I have posted my opinion and experience on my experiences regarding dementia.	.928***
I volunteer for informing others about dementia.	.887***
Enhancement of emotion-focused coping	
After using the online community, I found several friends who share concerns similar to mine.	.574***
The online community has helped me solidify existing relationships with friends and family.	.653***
I have online friends I turn to whenever I feel down.	.871***
Through the online community, I meet people to whom I can vent my emotional stress because of dementia.	.839***
Enhancement of problem-focused coping	
The online community has helped me find alternative treatment methods.	.907***

Latent variable and measurement item	Factor loading
The online community has helped me change current healthcare options.	.880***
The online community has helped me decrease the cost of treatment-related healthcare.	.850***
Affective coping outcome	
I am more confident in facing negative feelings associated with dementia since using the online community.	.895***
I became more optimistic regarding my health status since I interacted with other people in the online community.	.895***
Physical coping outcome	
The online community has helped me decrease the length of hospital stays.	.860***
The online community has helped prevent the development of dementia.	.689***
I heard that a recent medical evaluation indicates dementia patients' state does not worsen.	.785***
I heard that a recent medical evaluation indicates improvement of a patient.	.805***

*** $p < .001$.

To assess model fit, we used the following cutoff criteria based on recommendations by Kline (2005): standardized root mean square residual (SRMR) $< .10$, comparative fit index (CFI) $> .90$, goodness of fit index (GFI) $> .90$, incremental fit index (IFI) $> .90$, root mean square error of approximation (RMSEA) $< .08$. The structural model achieved good model fit, as indicated by RMSEA $< .08$, SRMR $< .10$, and GFI $> .90$ (see Figure 1). Lastly, the Sobel test was used to calculate whether the indirect effect, via the potential mediator variable, is significantly different from zero.

Measures

In this study, communication behaviors were classified by information seeking and information forwarding. Information seeking refers to gathering information in cyberspace regarding dementia. Conversely, information forwarding refers to more active behaviors, such as sharing information about caregiving experiences. Information seeking was measured by four items ($\alpha = .869$), and information forwarding was measured by three items ($\alpha = .865$). The coping

processes were categorized as emotion focused and problem focused. Emotion-focused coping refers to processes aimed at managing the emotion generated by the stressful situation; problem-focused coping refers to problem-oriented processes for addressing dementia effectively. Emotion-focused coping was measured by four items ($\alpha = .695$), and problem-focused coping was measured by three items ($\alpha = .853$). Coping outcomes were classified as affective coping outcomes and physical coping outcomes. Affective coping outcomes are applicable to caregivers, and refer to the extent to which caregivers control negative emotions; physical coping outcomes refer to patients' physical state after care. Affective coping outcomes were measured by four items ($\alpha = .695$), and physical coping outcomes were measured by three items ($\alpha = .853$). A 5-point Likert-type scale was used for all of the items in this study, with response options ranging from one (not at all) to five (very much). Items for all measures and their factor loadings are shown in Table 1.

Results

Descriptive statistics and correlations among study variables are shown in Table 2. We applied the confirmatory models to test the proposed structural model (Table 1). Results indicated modest fit indices for the measurement model [$\chi^2/df (137) = 262.363$, CFI = .930, TLI = .903, RMSEA = .070] were good. Factor loadings for each observation variables exceeded the cut-off value of .50.

Table 2. Correlation matrices, means, and standard deviations.

	ISK	IFW	EC	PC	AO	PO
ISK	—					
IFW	.426**	—				
EC	.434**	.670**	—			
PC	.633**	.462**	.540**	—		
AO	.504**	.391**	.499**	.546**	—	
PO	.415**	.393**	.553**	.668**	.512**	—
Mean	2.85	1.75	2.20	2.62	2.85	2.84
SD	.945	.652	.609	.748	.763	.707

Note. All items were on a 7-point Likert scale. ISK = information seeking. IFW = information forwarding. EC = enhancement of emotion-focused coping.

PC = enhancement of problem-focused coping. AO = affective coping outcome. PO = physical coping outcome.

** $p < .01$.

The estimated group difference (RQ1) indicated that there were no significant differences in age or duration of care. However, group differences in three variables were marginally significant: information seeking, affective coping, and information forwarding. As the significance level of information seeking was near .05 ($t = 1.975$, $p = .051$), information-seeking behaviors are likely to have a group difference by age. Affective coping outcome was also higher in the younger age group ($t = 1.784$, $p = .077$). In other words, people who are 45 years or younger are more likely to be more actively information seeking and with affective coping outcome than those who are over 45 years old. In addition, information forwarding is more likely to differ by duration of care ($t = 1.938$, $p = .055$). These results show that people who have cared for dementia patients 18 months or less are more likely to be actively information forwarding than those who have been caregivers for more than 18 months.

The results of the mediation model (Figure 2) showed that information seeking and information forwarding were positively mediated with emotion- and problem-focused coping. They were positively associated with affective coping outcomes and physical coping outcomes, especially information seeking, which was directly associated with affective coping outcomes.

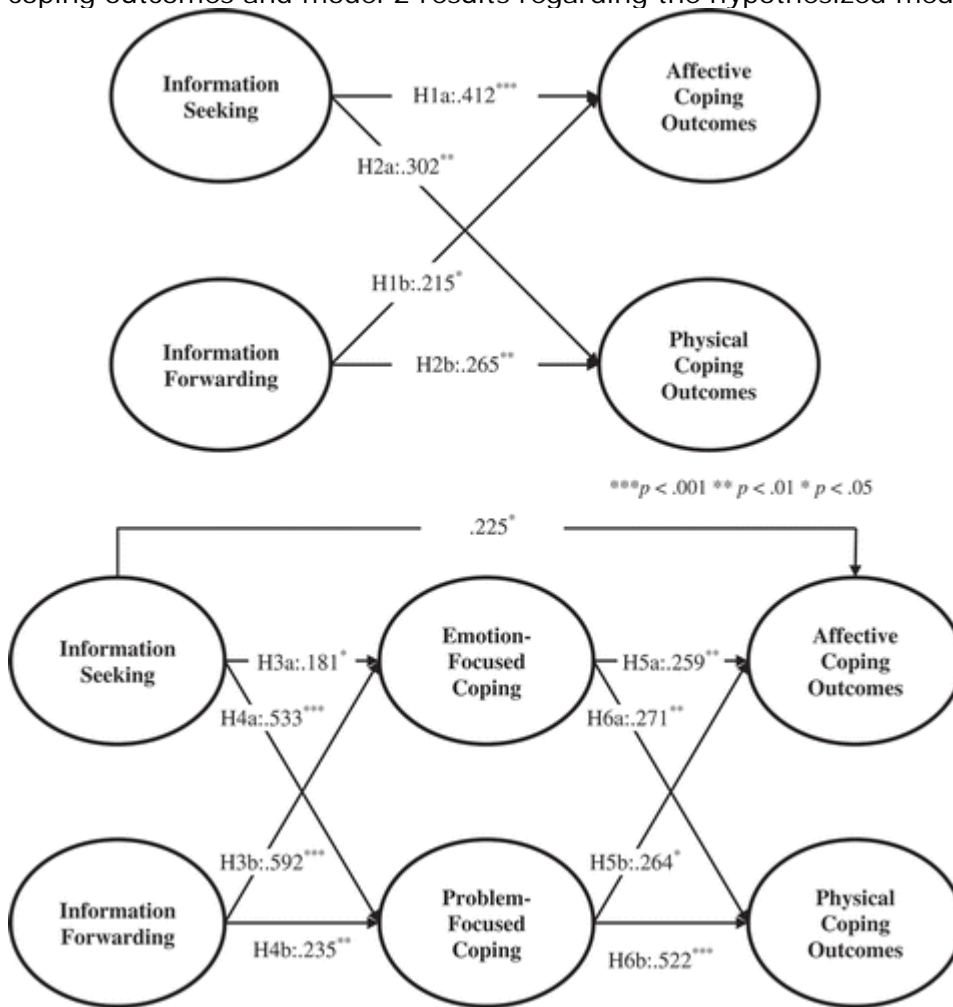
Table 3. Means and mean differences of communication behaviors, coping processes, and outcomes segmented by age (years) and duration of care.

Variable	Age			Duration of Care		
	Mean (SD)	Mean (SD)	t Statistic (p value)	Mean (SD)	Mean (SD)	t Statistic (p value)
	45 or less	Over 45		18 or less	Over 18	
Information seeking	3.00 (.890)	2.63 (.990)	1.975 (.051)	2.83 (1.023)	2.89 (.821)	-.348 (.728)
Information forwarding	1.82 (.724)	1.65 (.520)	1.323 (.189)	1.85 (.636)	1.60 (.655)	1.938 (.055)
Emotion-focused coping	2.20 (.626)	2.21 (.591)	-.120 (.904)	2.24 (.641)	2.14 (.559)	.854 (.395)
Problem-focused coping	2.70 (.707)	2.49 (.799)	1.376 (.172)	2.61 (.790)	2.63 (.688)	-.152 (.879)

Variable	Age			Duration of Care		
	Mean (SD)		t Statistic (p value)	Mean (SD)		t Statistic (p value)
	45 or less	Over 45		18 or less	Over 18	
Affective coping outcome	2.96 (.743)	2.69 (.773)	1.784 (.077)	2.89 (.780)	2.79 (.741)	.627 (.532)
Physical coping outcome	2.91 (.702)	2.75 (.711)	1.124 (.264)	2.81 (.737)	2.90 (.664)	-.672 (.503)

As shown in [Figure 2](#), model 1 results regarding effects of communication behaviors on coping outcomes indicate that information seeking was positively associated with affective coping outcomes ($\beta = .412, p < .001$; H1a), and information forwarding ($\beta = .215, p < .05$; H1b) was also positively significant with affective coping outcomes. Both information seeking ($\beta = .302, p < .01$; H2a) and information forwarding ($\beta = .265, p < .01$; H2b) were positively associated with physical coping outcomes. The comparison of the parameters estimates shows the different effects of information seeking and information forwarding on affective coping and physical coping outcomes (RQ2a). Information seeking is more strongly associated with affective coping and physical coping than information forwarding.

Figure 2. Model 1 results regarding effects of communication behaviors on coping outcomes and model 2 results regarding the hypothesized mediation.



Hypotheses 3 through 6 tested the mediated effects of communicative action on coping outcomes through two types of coping processes (Figure 2). Information seeking ($\beta = .181$, $p < .05$; H3a) and information forwarding ($\beta = .592$, $p < .001$; H3b) were each positively associated with the emotion-focused coping process. The result of hypothesis 4 also indicates that information seeking ($\beta = .533$, $p < .001$; H4a) and information forwarding ($\beta = .235$, $p < .01$; H4b) were positively associated with the problem-focused coping process. The comparison of estimated parameters shows that information seeking and information forwarding are differentially associated with emotion-focused coping and problem-focused coping (RQ2b). Based on the findings, information seeking is more strongly

associated with problem-focused coping, whereas information forwarding is more strongly associated with emotion-focused coping.

This study found that emotion-focused coping ($\beta = .259$, $p < .01$; H5a) and problem-focused coping ($\beta = .264$, $p < .05$; H5b) were each positively associated with affective coping outcomes. In addition, emotion-focused coping ($\beta = .271$, $p < .01$; H6a) and problem-focused coping ($\beta = .522$, $p < .001$; H6b) were each positively associated with physical coping outcomes. The comparison of estimated parameters shows that emotion-focused coping and problem-focused coping are differentially associated with affective coping outcomes and physical coping outcomes (RQ2c). For RQ2c, emotion-focused and problem-focused coping influenced physical coping outcomes more than affective coping outcomes. In particular, problem-focused coping showed a greater association with physical coping outcomes ($.522$, $p < .001$) than with affective coping outcomes ($.264$, $p < .001$). Therefore, caregivers' communication behaviors, information seeking, and information forwarding affect subsequent behaviors: coping process and coping outcomes (RQ2). The Sobel test showed that information seeking affected both physical coping outcomes through emotion- and problem-focused coping ($Z = 2.19$, $p < .05$; $Z = 4.71$, $p < .001$) and affective coping outcomes through emotion- and problem-focused coping ($Z = 2.02$, $p < .05$; $Z = 2.27$, $p < .05$). Information forwarding also affected both physical coping outcomes through emotion- and problem-focused coping ($Z = 1.97$, $p < .05$; $Z = 2.31$, $p < .05$) and affective coping outcome through emotion- and problem-focused coping ($Z = 2.61$, $p < .01$; $Z = 1.97$, $p < .05$).

Discussion

This study investigated the effects of caregiver online behavior on both caregiver and patient outcomes. Specifically, we sought to examine (a) whether caregivers' communication behaviors (i.e., information seeking and forwarding) were related to coping outcomes and (b) whether this relationship was mediated by coping processes.

This study contributes to prior research on online communication and cybercoping in several ways. First, it demonstrates how caregivers' communication behaviors positively affect coping

processes and outcomes psychologically for themselves, as well as physically for patients.

In addition, existing studies reveal that coping outcomes are mainly based on self-report studies with a population of both patients and informal caregivers (e.g., Boots, Vugt, Knippenberg, Kempen, & Verhey, 2014; Kim & Lee, 2014). Our study examined third-party caregivers, who tend to deal with problems related to the patients' disease rather than to deal with negative emotions such as stress and fatigue for themselves. Boots et al. (2014) report a lack of methodological quality in the literature provided. By fitting a model to the communication behaviors reported, this study affords greater insight into the effectiveness of cybercoping based on correlational data.

Communication behaviors affect their subsequent behaviors such as coping process and outcomes with dementia. Specifically, two communication behaviors are differentially associated with coping outcomes in the effectiveness. Information seeking is more associated with affective coping and physical coping outcomes than information forwarding. This is especially important given the current lack of understanding regarding the causes of and treatments for dementia. This result is critical because the usefulness of information seeking and health information in cyberspace significantly influences the ability of individuals to cope. Furthermore, information seeking was strongly associated with problem-focused coping, and information forwarding was strongly associated with emotion-focused coping. This indicates that caregivers' active information-seeking behavior in cyberspace is essential for the process of dealing with their patients' health problems, and information forwarding is also essential for the process of managing emotional and psychological issues of caregivers through online social support. In the particular case of dementia, this information forwarding is very important, as is information seeking. Caregivers need effective self-care because these individuals are more likely to be exposed to frequent fatigue, stress, and subsequent physical problems.

Furthermore, communication behaviors and coping outcomes were mediated by coping processes, yet had different mediating effects. In particular, problem-focused coping was found to have the

largest contribution to physical coping outcomes, while emotional-focused coping was found to have a smaller contribution to affective and physical coping outcomes. This stands in contrast to existing studies of patients, which found that emotion-focused coping leads to better physical and emotional coping outcomes than problem-focused coping (e.g., Kim & Lee, [2014](#)). The results of this study also revealed that caregivers, as the third person, tend to cope with problems related to patients rather than to cope with problems related to themselves. This result is in line with research that found that patients and caregivers both manage their emotions and share information through the use of blogs (Chung & Kim, [2008](#)). However, patients who rely on online information have been found to more effectively cope with their emotions and health problems because patients are more likely to participate in their own health problem than caregivers.

In addition, communication and coping behaviors of caregivers are likely to differ by duration of care and caregiver's age. Information forwarding was more likely to differ by duration of care. This result supports the idea that caregivers feel the highest pressure in the early stages of dementia. These caregivers rely more on interactive learning through interactions with health professionals. However, as the duration of care increases, they rely more on reflective and passive learning by seeking information from websites (Chiu & Eysenbach, [2011](#)). At the beginning of dementia, caregivers receive social and psychological support, and seek and share health information and subjective experiences, but these communication behaviors decrease over time. This is because the uncertain nature of dementia gives caregivers challenges such as disease burden and increased long-term stress, and these factors make interactive communication behaviors such as information forwarding more effortful. It was also found that people who are 45 years or younger are more likely to be actively involved in information seeking and affective coping outcomes than those who are older than 45 years. This difference perhaps arises out of the accessibility and familiarity to computer-mediated communication of younger individuals, which could potentially lead to better comprehension and coping with dementia caregiving.

In summary, this study on caregivers' communication behaviors suggests that caregivers use practical and rational coping methods for patients as well as emotional coping for themselves by using

information-seeking and information-forwarding behaviors. These activities provide caregivers with social support, the subjective perception of caregivers about potential material and psychological resources provided through online interactions between other caregivers and people in general (Norbeck, Lindsey, & Carrieri, [1981](#)). Consequently, cyberspace plays an important role in relieving caregivers' negative emotions and physical symptoms of patients.

This finding has important practical implications for clinical and health policy. When considering the current medical environment that does not provide medical solutions for dementia (i.e., no current cure for dementia), the results of this study show that caregivers rely on information seeking and forwarding to cope with the physical diseases of patients and for their own psychological health. In fact, people rarely cope with dementia independently, and caregivers tend to be stressed due to the extensive duration of care. Moreover, it seems that cyberspace does not play a large enough role in providing affective and psychological support for caregivers of dementia patients. However, the emergence of cyberspace may provide alternative spaces to cope with diseases like dementia because both patients and caregivers can easily participate without limitation of time and space. In order to make cyberspace a proper forum for rational and emotional coping, professionals' participation and governmental support is necessary.

In the particular case of dementia, which does not have clear treatments or cures, sharing information regarding the processing and coping methods is very important. Family caregivers need effective self-care because these individuals are more likely to be exposed to fatigue, burden, stress, and subsequent physical problems. Furthermore, family caregivers face more difficulties if they have a dementia patient because they have to function as family members and caregivers simultaneously. As nonprofessional caregivers, they not only need knowledge and understanding about patients, but they are also required to take additional responsibilities, such as financial concerns. Accordingly, systematic and social supports for nonprofessional caregivers are needed. It is critical that they be supported with (a) credible sources, (b) educational information, and (c) psychological support. Cyberspace can provide these supportive functions that will help patients with dementia and caregivers cope

with difficulties more effectively. Nevertheless, due to the overwhelming amount of health information available online, it is hard for nonexperts such as patients and family caregivers to differentiate reliable and useful information from unreliable and false information. A possible solution is a formal policy in which medical experts evaluate the available health information online, thereby improving health literacy.

This study has several important limitations. First, caregivers' ages were high because dementia occurs among elderly men as a chronic disease. For this reason, future research should have a greater sample size across various ages in order to assess the effects of online and offline communication behaviors. In addition, information seeking and forwarding in cyberspace are necessary to carry out research on coping actions more generally, because elderly people comparatively tend to share health information.

Second, as noted, dementia is a long-term disease in which the affective coping process of caregivers varies over time. Therefore, subsequent research will need to investigate the dynamic effects of caregiver coping and the long-term consequences of stress and external support over time. Third, the participants of this study were family members of dementia patients whose communication behaviors and coping processes may differ from those of professional caregivers. Future research should focus on the relationship between these factors and the extent of one's professional ability to care for patients.

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Notes

¹In the United States, 15.9 million caregivers are family members and other unpaid caregivers who spend 21.9 hours per week on average in caregiving, a contribution valued at more than \$221.3 billion in 2015 (Alzheimer's Association, [2016](#)). United Kingdom censuses reported that the number of nonprofessional caregivers has steadily increased from 2001 to 2011, and 16.8% of caregivers provide at least 50 hours per week caring for dementia patients (Department of Health, [2010](#)).

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²Our cutoff point of 18 months was chosen because prior studies that follow up patients' conditions or behavior changes about illness used 18 months as a cutoff (e.g., Unverzagt et al., [2001](#)).

References

- Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 12, 459–509.
doi: <https://doi.org/10.1016/j.jalz.2016.03.001>
- Bauman, E. M., Haaga, D. A., & Dutton, M. A. (2008). Coping with intimate partner violence: Battered women's use and perceived helpfulness of emotion-focused coping strategies. *Journal of Aggression, Maltreatment & Trauma*, 17, 23–41. doi: 10.1080/10926770802250942
- Blom, M. M., Bosmans, J. E., Cuijpers, P., Zarit, S. H., & Pot, A. M. (2013). Effectiveness and cost-effectiveness of an Internet intervention for family caregivers of people with dementia: Design of a randomized controlled trial. *BMC Psychiatry*, 13, 17. doi: 10.1186/1471-244X-13-17
- Boots, L. M. M., Vugt, M. E., Knippenberg, R. J. M., Kempen, G. I. J. M., & Verhey, F. R. J. (2014). A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *International Journal of Geriatric Psychiatry*, 29, 331–344.
doi: 10.1002/gps.4016
- Bruce, D. G., Paley, G. A., Nichols, P., Roberts, D., Underwood, P. J., & Schaper, F. (2005). Physical disability contributes to caregiver stress in dementia caregivers. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 60, 345–349.
doi: 10.1093/gerona/60.3.345
- Chiu, T. M., & Eysenbach, G. (2011). Theorizing the health service usage behavior of family caregivers: A qualitative study of an Internet-based intervention. *International Journal of Medical Informatics*, 80, 754–764. doi: 10.1016/j.ijmedinf.2011.08.010
- Chung, D. S., & Kim, S. (2008). Blogging activity among cancer patients and their companions: Uses, gratifications, and predictors of outcomes. *Journal of the American Society for Information Science and Technology*, 59, 297–306. doi: 10.1002/asi.20751
- Darcy, J., Brunsdon, V., & Hill, R. (2011). Exploring online support: Informal caregivers' usage of a mental health discussion board. *Journal of Cyber Therapy & Rehabilitation*, 4, 477–482.
- Department of Health. (2010). *Recognised, valued and supported: Next steps for the carers strategy*. Retrieved from <https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-forthe-carers-strategy>

- Eisdorfer, C., Czaja, S. J., Loewenstein, D. A., Rubert, M. P., Argüelles, S., Mitrani, V. B., & Szapocznik, J. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *The Gerontologist*, 43, 521–531. doi: 10.1093/geront/43.4.521
- Elliott, A. F., Burgio, L. D., & DeCoster, J. (2010). Enhancing caregiver health: Findings from the resources for enhancing Alzheimer's caregiver health II intervention. *Journal of the American Geriatrics Society*, 58, 30–37. doi: 10.1111/j.1532-5415.2009.02631.x
- Endler, N. S., & Parker, J. D. (1990). Multidimensional assessment of coping: A critical evaluation. *Journal of Personality and Social Psychology*, 58, 844–854. doi: 10.1037/0022-3514.58.5.844
- Fox, S. (2006, October 29). *Online health search 2006*. Retrieved from <http://www.pewinternet.org/2006/10/29/online-health-search-2006/>
- Goldsmith, M. (2002). *Hearing the voice of people with dementia: Opportunities and obstacles*. London, UK: Jessica Kingsley Publishers.
- Karlawish, J. H., Casarett, D. J., James, B. D., Tenhave, T., Clark, C. M., & Asch, D. A. (2003). Why would caregivers not want to treat their relative's Alzheimer's disease? *Journal of the American Geriatrics Society*, 51, 1391–1397. doi: 10.1046/j.1532-5415.2003.51456.x
- Kim, J.-N., & Lee, S. (2014). Communication and cybercoping: Coping with chronic illness through communicative action in online support networks. *Journal of Health Communication*, 19, 775–794. doi: 10.1080/10810730.2013.864724
- Kim, Y. J. (2007). Understanding family caregivers' experiences of living with dementia: A transcendental phenomenological inquiry. *Journal of the Korean Gerontological Society*, 27, 963–986.
- Kline, R. B. (2005). *Principles and practice of structural equation modeling* (2nd ed.). New York, NY: Guilford Press.
- Korean Ministry of Health & Welfare. (2011). *Status of older people with dementia in Korea*. Seoul, Korea. Retrieved from <http://www.mohw.go.kr/eng/index.jsp>
- Korean Ministry of Health & Welfare. (2012). *2nd Dementia management master plan*. Seoul, Korea. Retrieved from <http://www.mohw.go.kr/eng/index.jsp>
- Montgomery, R. J. V., & Williams, K. N. (2001). Implications of differential impacts of care-giving for future research on Alzheimer care. *Aging & Mental Health*, 5, 23–34. doi: 10.1080/713650007
- Morimoto, T., Schreiner, A. S., & Asano, H. (2003). Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Ageing*, 32, 218–223. doi: 10.1093/ageing/32.2.218
- Morris, J., & Royle, G. T. (1988). Offering patients a choice of surgery for early breast cancer: A reduction in anxiety and depression in patients

- and their husbands. *Social Science & Medicine*, 26, 583–585.
doi:10.1016/0277-9536(88)90021-4
- Norbeck, J. S., Lindsey, A. M., & Carrieri, V. L. (1981). The development of an instrument to measure social support. *Nursing Research*, 30, 264–269.
doi:10.1097/00006199-198109000-00003
- Rains, S. A., & Keating, D. M. (2011). The social dimension of blogging about health: Health blogging, social support, and well-being. *Communication Monographs*, 78, 511–534.
doi:10.1080/03637751.2011.618142
- Ross, L., Holliman, D., & Dixon, D. R. (2003). Resiliency in family caregivers: Implications for social work practice. *Journal of Gerontological Social Work*, 40, 81–96. doi:10.1300/J083v40n03_07
- Sabir, M., Pillemer, K., Suito, J., & Patterson, M. (2003). Predictors of successful relationships in a peer support program for Alzheimer's caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 18, 115–122. doi:10.1177/153331750301800211
- Simpson, C., & Carter, P. (2013). Short-term changes in sleep, mastery and stress: Impacts on depression and health in dementia caregivers. *Geriatric Nursing*, 34, 509–516. doi:10.1016/j.gerinurse.2013.07.002
- Sörensen, S., Duberstein, P., Gill, D., & Pinquart, M. (2006). Dementia care: Mental health effects, intervention strategies, and clinical implications. *The Lancet Neurology*, 5, 961–973. doi:10.1016/S1474-4422(06)70599-3
- Unverzagt, F. W., Gao, S., Baiyewu, O., Ogunniyi, A. O., Gureje, O., Perkins, A., ... Hendrie, H. C. (2001). Prevalence of cognitive impairment data from the Indianapolis study of health and aging. *Neurology*, 57, 1655–1662. doi:10.1212/WNL.57.9.1655
- Vellone, E., Piras, G., Talucci, C., & Cohen, M. Z. (2008). Quality of life for caregivers of people with Alzheimer's disease. *Journal of Advanced Nursing*, 61, 222–231. doi:10.1111/j.1365-2648.2007.04494.x
- Wilkinson, H. (2002). *The perspectives of people with dementia: Research methods and motivations*. Philadelphia, PA: Jessica Kingsley Publishers.
- Wilks, S. E., Little, K. G., Gough, H. R., & Spurlock, W. J. (2011). Alzheimer's aggression: Influences on caregiver coping and resilience. *Journal of Gerontological Social Work*, 54, 260–275.
doi:10.1080/01634372.2010.544531
- Winkler, M., Bedford, V., Northcott, S., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect the career and their relationship with the person with aphasia? *Aphasiology*, 1–19.
doi:10.1080/02687038.2014.928665
- World Health Organization. (2012). *10 facts on dementia*. Retrieved from <http://www.who.int/features/factfiles/dementia/en/>

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Wright, K. B., & Bell, S. B. (2003). Health-related support groups on the Internet: Linking empirical findings to social support and computer-mediated communication theory. *Journal of Health Psychology, 8*, 39–54. doi: 10.1177/1359105303008001429

Additional information

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