

Friendsourcing Peer Support for Alzheimer's Caregivers

Using Facebook Social Media

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## Abstract

This research piloted an e-health intervention that used social media to friendsource peer support for Alzheimer's disease (AD) caregivers. Friendsourcing is a variant of crowdsourcing. Crowdsourcing recruits online participants who share a *characteristic* that makes their volunteerism meaningful when they join to achieve an outcome. Friendsourcing recruits online participants who share *membership in a social network* that makes their volunteerism meaningful when they join to achieve an outcome. This paper introduces our friendsourcing intervention research and examines the effects on the psychological well-being of AD caregivers. After a six-week intervention, caregivers were found to have significantly decreased burden ( $Z=-2.01$ ,  $p<.05$ ) and perceived stress ( $Z=-2.95$ ,  $p<.01$ ). Emotional and informational support scores were significantly increased ( $Z= -2.32$ ,  $p<.05$ ). Qualitative data analysis of the intervention identified positive effects in new caregiving knowledge acquisition and application and reduced stress in the acceptance of the caregiving role. Joining social networks in support groups through friendsourcing was feasible for AD caregivers who were familiar with social media, and can provide another means of guiding the development of their personal support networks.

*Keywords: Alzheimer's caregivers, friendsourcing, online support groups, social media, social networking*

# FRIENDSOURCING PEER SUPPORT

## Friendsourcing Peer Support for Alzheimer's Caregivers

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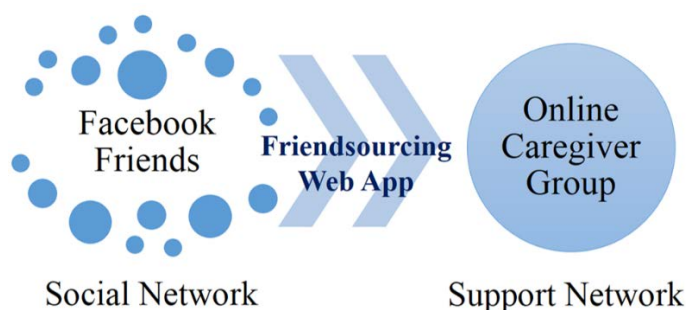
Emotional and informational support are important needs of Alzheimer's disease (AD) caregivers. This is due to the complexity of the disease, the encompassing nature of caregiving tasks, the biopsychosocial risks of informal caregiving, the financial demands, and the potentially lengthy timespan of the illness (Alzheimer's Association & others, 2016; Capistrant, Moon, Berkman, & Glymour, 2012; Lu & Wykle, 2007; Wennberg, Dye, Streetman-Loy, & Hiep Pham, 2015). Caregiving also confers protective benefits to the person with AD, including postponement of institutionalization (Toot, Swinson, Devine, Challis, & Orrell, 2017) and slowing of disease progression (Gaugler & Kane, 2015). Development of a support network is an early coping strategy of informal caregivers (Egdell, 2012). Social media has increasingly become a means through which individuals can expand their social and support networks (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Social media can overcome logistical barriers that limit caregivers' use of services, although evidence of its effectiveness remains to be demonstrated (Hamm et al., 2013).

This research project investigated a friendsourcing peer support (FPS) group intervention that used a web-based application (app) to join Facebook social network members with AD caregivers' Facebook support groups (Figure 1). Friendsourcing is a variant of crowdsourcing. Crowdsourcing recruits online participants who share a *characteristic* that makes their volunteerism meaningful when they join to achieve an outcome. Friendsourcing recruits online participants who share *membership in a social network* that makes their volunteerism meaningful when they join to achieve an outcome. This paper introduces our FPS intervention research and examines the effects on the psychological well-being of AD caregivers. For this research, AD

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caregivers met in small, private Facebook groups and discussed emotional and informational support questions that they wanted to push to their Facebook friends' social networks using the FPS web app. Data collection involved administering pre- and post-intervention survey-based clinical scales on the outcomes of caregiver burden, perceived stress, and transformative changes to the caregiver role.

Figure 1. Friendsourcing peer support group intervention



### Literature Review

#### Caregiver Burden

One metric for the importance of informal, unpaid caregiving to persons with AD is its economic value, which was estimated at \$230.1 billion in 2016 (Alzheimer's Association, 2017). These numbers only reflect the direct hours of unpaid caregiving. They do not account for the economic losses from days of missed work or lost wages. Clearly, persons with AD benefit from caregiving, as it enables them to live in the community setting longer and may contribute to less rapid disease progression (Gitlin & Hodgson, 2015).

Caregiving risks are subsumed under the construct *caregiver burden*. Caregiver burden has been defined as a stress response elicited by negative self-appraisal of coping capacity and/or resources needed to meet the demands of caregiving (Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008). The onset of caregiver burden occurs prior to a diagnosis of dementia when a

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mild cognitive impairment or behavioral changes are first observed. Thirty percent of a heterogeneous caregiver population was found to experience significant caregiver burden irrespective of gender, spousal or adult-child relationship, demographics, or living arrangement (Bruce et al., 2008).

Caregiver burden has also been described as an outcome of the interaction between patient and caregiver characteristics, both of which can act as determinants of caregiver burden. A systematic literature review of caregiver burden determinants found support to be a caregiver determinant in 22 of 32 studies where caregiver burden was a study outcome variable, and in 16 of 24 studies where mental health was an outcome variable (van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). Findings from the systematic review could not identify the predictive value for either caregiver burden or mental health outcomes due to the variation in conceptualizations and variables of support and functioning used in the studies. Many individual studies have found subjective and objective experiences of social support to be strongly associated with reduced caregiver burden and improved caregiver well-being.

### **Caregiver Support**

The numerous conceptualizations of support in the literature contribute to difficulties in analyzing the effectiveness of support interventions (Eysenbach et al., 2004; Hogan, Linden, & Najarian, 2002). Conceptualizations may include the elements of structure and function or subjective elements like perceptions of support. Forms of support have been categorized as informational (advice-giving and education), emotional (messages of concern and caring), and instrumental (provision of tangible resources like respite caregiving or other in-person assistance) (Wang, Zhao, & Street, 2017). In their analysis of online health communities (OHC), (Wang et al., 2017) included companionship as a fourth form of support. Examples of

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companionship included sharing off-topic content like birthdays or holiday celebrations. Four decades of caregiver intervention research show support to be effective when included in multicomponent interventions (Wennberg et al., 2015). When support was joined with a problem-focused coping intervention, it was found to contribute to caregiver well-being as well as slowed cognitive and functional decline of AD patients (Tschanz et al., 2013).

Support has been studied outside of multicomponent interventions through the ways in which caregivers seek and receive professional and peer support (Brodaty, Thomson, Thompson, & Fine, 2005). Seeking and receiving support has been conceptualized to follow three routes: organic, chance, and guided (Egdell, 2012). The organic route develops when caregivers receive support through formal and informal sources that address the diagnosis and symptoms of the disease. The chance route develops when caregivers receive support in response to a crisis. The guided route develops when caregivers determine that the quality or quantity of support is unavailable through the other routes.

### **Social Media Support**

Social media and online forums have been extensively studied as resources for support and self-care among patient populations (Hamm et al., 2013b). Patients use social media to learn more about their health conditions and to seek informational and emotional support (Vlahovic, Wang, Kraut, & Levine, 2014). Informal caregivers, who may not have immediate access to clinicians or other professional sources of health-related information, also use these resources. Overall, patients, caregivers, and other stakeholders form complex online “neotribes” to overcome the limitations of traditional healthcare resources (Johnson & Ambrose, 2006).

Informal caregivers are increasingly using the internet and social media to cope and obtain support. In 2012 (Fox, Duggan, & Purcell, 2013), a national survey of 3,014 adults—

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1,171 (39%) of whom were informal caregivers—was conducted. Of the informal caregivers who used online resources, 84% reported using the internet to obtain healthcare information compared with 64% of non-caregivers. Furthermore, 50% of the informal caregivers' searches for healthcare information were on the behalf of someone else. About one-third (31%) of informal caregivers who used online resources used the internet to track a loved one's health indicators. In addition to their searches for professional sources of information, 28% reported that they sought support online and offline from family and friends, and 11% posted healthcare questions online or contributed information about their health concerns.

The use of social media by caregivers to obtain support can be conceptualized as a new tool for development of a guided route to enhance a support network. Social media support can be sought through dedicated online health communities, as well as through general-use sites like Facebook and Twitter. These technologies provide inexpensive and readily available platforms through which support seekers can connect and interact. For informal caregivers, social media's logistical advantages of accessibility, overcoming barriers of time and travel, and ease of use can be important factors in participation. Synthesized findings from a systematic literature review of the meaningfulness of support group participation by dementia caregivers described caregivers' positive feelings about their use of online social support groups based on their logistical advantages (Lauritzen, Pedersen, Sørensen, & Bjerrum, 2015). Davison, Pennebaker, and Dickerson (2000) also found that overcoming logistical barriers to accessibility and availability of support was associated with participation in receiving support online.

Caregivers may also use these social media platforms to seek out new connections with other caregivers who are in similar roles as themselves. Caregivers may join special-topic Facebook groups to find information, relieve their own anxiety, and engage in advocacy for the

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condition of their care recipient, resulting in a powerful form of *networked empowerment* among the caregiver community (Ammari & Schoenebeck, 2015). Asynchronous discussion forums are among the most common and readily available types of peer-to-peer online support technologies available through social media. Caregivers and patients can use these discussion forums to share information, experiences, and companionship.

### **Limitations of Social Media Use**

Unstructured peer support in online health communities is generally open-ended and often does not require membership. These forums may pose drawbacks, including a design that encourages lurking [name deleted to maintain the integrity of the review process], a lack of contributor content (Mierlo, 2014), the inequality of content (Nielsen, 2006), and an unreliability of health information (Cole, Watkins, & Kleine, 2016). The lack of contributor content is an important factor because it can threaten the sustainability of an online health community.

McKechnie, Barker, and Stott (2014) researched an online peer-to-peer social support site for dementia caregivers that illustrated the advantages and limitations of social media use. Participants were new users of their asynchronous discussion forum. They were only able to recruit a low percentage of participants (3.6%), and the new users' forum usage demonstrated low levels of content contributions. There were no changes in new users' anxiety or depression ratings, although their relationships with the AD care recipients improved. The qualitative analysis described the forum as important for social comparison, and descriptions suggested the presence of a mutual aid experience of "all-in-the-same-boat" (Garvin, Gutiérrez, & Galinsky, 2004) or the related therapeutic factor of "universality" (Yalom, 1995). The analysis also found that informational support provided value to participants and was thought to explain improvement in the caregiving relationship. Wang et al.'s (2017) study of an online health



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community for breast cancer survivors supplements these findings regarding informational support and its effects on forum usage and user retention. Whereas informational support was the highest ranked form of participation, seeking and receiving informational support was associated with low retention to the online health community.

Although the specialized focus of an online health community provides anonymity for participants, caregivers also publically seek support from their existing social networks on social media programs or apps such as Facebook or Twitter. Caregivers of people with health concerns seek out social support from their existing networks for motivation, reinforcement, and advice (Liu et al., 2011). They also maintain a presence on social media sites to share updates about their care recipients. Caregivers can receive positive reinforcement and support on these platforms (Piper, Cornejo, Hurwitz, & Unumb, 2016). However, complex concerns exist regarding the privacy of health information that is shared online and/or about the self-presentation on general-purpose platforms (Newman, Lauterbach, Munson, Resnick, & Morris, 2011). It is unknown whether caregiver concerns about self-presentation are similar to or different from patient concerns.

### **Designing for Support**

Schorch, Wan, Randall, and Wulf (2016) provided further insight into the experience of the AD caregiving role and its implications for designing online support. Their qualitative analysis described an evolutionary process through which the struggle to cope and adapt leads to a new role-identity of “care expert” (Schorch et al., p.792). The often unaided and difficult process of learning to perform this role is accompanied by a shrinking social network and isolation. Campbell et al.’s (2008) conceptualization of “role captivity” and Lewis’ (2014) conceptualization of “role entrapment” provide analogous models to the role of care expert for

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understanding the effects of social isolation. Role captivity was associated with resentment, whereas role entrapment was associated with the experience of becoming an irreplaceable care expert. Schorch et al. (2016) recommended that online platforms be designed to provide a range of peer-to-peer and professional support opportunities to manage the effects of isolation on caregivers. Based on caregivers' current use of online health communities and general-purpose sites like Facebook, designs may also be useful if they empower caregivers to exercise guidance in developing or enhancing routes of support. In contrast to Newman et al.'s (2011) findings regarding social media use, online designs that join caregiver social and support networks may empower caregivers to develop guided routes to support.

### **The Friendsourced Peer Support Network**

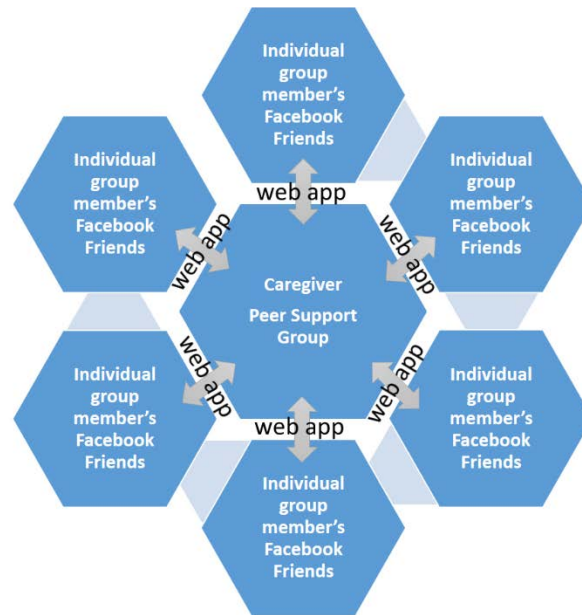
The rationale for joining social and support networks with FPS was based on the challenges that caregivers experience in meeting their needs for support. Their in-person social networks provide a foundation for the initial development of a support network. Enlisting social network members into a support network, however, can be problematic. For instance, members of a caregiver's informal social network may not recognize their need for support, or the caregiver may be reluctant to ask for support (Egdell, 2012). Seeking and receiving support was also seen to be limited by psychosocial risks like role entrapment (Lewis, 2014), the demands associated with becoming a care expert (Schorch et al., 2016), and the difficulties of maintaining in-person social networks based on logistical factors like time, distance, and the care demands of the AD patient.

The FPS intervention designed for this research sought to clarify the feasibility of joining a Facebook social network with a support network for use as a coping strategy to guide support development. When the peer support group's emotional and informational support questions

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were pushed to each participant's Facebook friends social networks with the study's web app, Facebook friends had the opportunity to enlist as support network members by answering caregiver group questions (Figure 2). In addition, the FPS intervention provided AD caregivers with a new group identity as a peer support member for social comparison and mutual support.

Figure 2. Web app friendsourcing communications



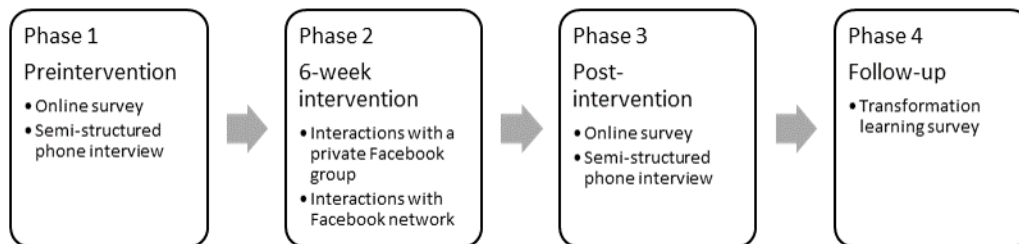
This research assumes that FPS can be used to recruit caregiver Facebook social network members (Facebook friends) to become support network members by volunteering to answer caregiving questions about informational or emotional support. In addition, it was assumed that when informational or emotional support questions were answered, caregivers would experience increased support. Following these assumptions, it was hypothesized that participation in FPS would decrease caregiver burden and perceived stress. The psychosocial dimensions of caregiving were further explored through the framework of role transformation to discover the impact of the intervention on cognitive and behavioral coping strategies for caregiving when caregivers worked together to decide upon and push their support-based questions to their Facebook friends social network members.

## METHODS

### Design

This study used a pre-test-post-test design with mixed methods. Participants included informal, non-paid family caregivers of people with AD. Participants were sequentially allotted to two private Facebook groups to receive the intervention over the course of six weeks. The study was composed of four parts (Figure 3): (1) the pre-intervention phase, during which participants completed informed consent, an online survey, a semi-structured interview, and the installation of the study Facebook app; (2) the six-week intervention phase, during which participants (a) interacted with peer caregivers within a closed Facebook group via a web app, and (b) reacted to feedback about anonymous caregiving questions that the research team posted to each participant's Facebook News Feed; (3) the post-intervention phase, during which participants completed a post-intervention survey, semi-structured interview, and optional online reflection group; and (4) the follow-up phase, during which participants completed a transformation learning survey six weeks after completion of the intervention.

Figure 3. Research composition



### Data Collection

#### Recruitment

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All aspects of this research were approved by the Indiana University Institutional Review Board through expedited review. Informal caregivers of AD patients were recruited as potential participants across the U.S. using online media, including the local Alzheimer's Association web page and newsletter, the Alzheimer's Reading Room newsletter, the Indiana University Newsletter, radio interviews at National Public Radio (NPR), and Joy's House in Indiana and using social media, including Twitter, Facebook, and an Indiana University alumni listserv. Recruitment was conducted in July 2016 for Group 1 and in November 2016 for Group 2. Potential participants accessed the study website, which provided study information, inclusion/exclusion criteria, links to the online survey, and a pdf of the informed consent form. To be included in the study, potential participants had to self-identify as non-paid, informal caregivers of patients with AD; be 18 years of age or older; live in the United States; provide at least eight hours of caregiving per week to the person with AD; have a Facebook account with at least 40 friends in their social network; and have an average pattern of posting at least twice per week for the past month. Additionally, participants had to have ready access to the internet; be able to read, comprehend, and write in the English language; and provide informed consent to participate in this research.

Upon meeting the screening criteria, participants completed an online informed consent and initiated the online survey. Twenty-three of the 60 caregivers who accessed the online survey completed it. After completing the survey, participants were contacted by the research team to arrange an interview. Twelve participants, four for Group 1 and eight for Group 2, completed the pre-intervention interview and installed the study application (Table 1).

Participants received compensation in the form of electronic gift cards for their time and effort.

Table 1. Recruitment and completion process (number and %)

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Group	Recruitment and Intervention Periods	Accessed online survey (n)	Completed survey (n)	Completed phone interview (n)	Participated in a group (n)
1	Jul. 2016	12	6 (50%)	6 (50%)	4 (33.3%)
2	Aug. 29 <sup>th</sup> -Oct. 10 <sup>th</sup> , 2016	48	17	9 (18.8%)	8 (16.7%)
	Dec. 19 <sup>th</sup> , 2016 – Feb. 6 <sup>th</sup> , 2017		(35.4%)		
Total		60	23 (38.3%)	15 (25%)	12 (20%)

### Measurement

SPSS24 was used for quantitative data analysis. Dedoose was used for qualitative data analysis. Due to the limited sample size, this study used nonparametric statistics that did not assume a normal distribution. Quantitative and qualitative data were collected at multiple points during the study. Data collection consisted of pre- and post-survey data; audio-recorded interviews; posts and comments in a Facebook group; and from participants' Facebook social networks, audio-recorded follow-up reflection groups, and transformational learning surveys. The pre- and post-intervention online surveys included standardized self-reported caregiving-related instruments, including the Zarit Burden Interview Short Form (ZBI-12), the Perceived Stress Scale-14 (PSS-14), the Revised Scale for Caregiving Self-Efficacy, and the Medical Outcomes Study (MOS) Social Support Survey. A transformative learning survey was conducted for the follow-up.

The ZBI-12 (Bédard et al., 2001) was developed to measure perceived caregiving burden and consists of 12 questions that ask about the frequency of certain types of caregiving difficulties (5-point Likert-type scale; 0 never - 4 nearly always). Perceived Stress Scale –14 (PSS-14) (Cohen, Kamarck & Mermelstein, 1983) is composed of 14 items that ask about frequencies of emotional problems during the last month (5-point Likert-type scale; 0 never - 4

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very often). The MOS Social Support Survey (Sherbourne & Stewart, 1991), which measures the availability and frequency of emotional, informational, tangible, and affectionate supports, is composed of 19 items (5-point Likert scale; 1 none of the time - 5 all the time). The transformative learning survey was developed by our research team based on King's (2009) Learning Activities Survey, which was designed to identify whether learning activities contribute to perspective changes in one's values, beliefs, opinions, or expectations. The survey questionnaire used in this study included three sections: (1) 13 binary questions that asked about the transformative learning experience during the research project (yes/no); (2) four questions that asked about a critical point of changing caregiving values and causes of these changes (yes/no and qualitative descriptions); and (3) one binary question that asked about the willingness to reflect learnings gained from the research project (yes/no).

### **Group Moderation**

During the six-week intervention phase, participants were asked to interact with a closed Facebook online support group by posting caregiving questions and responding to each other's comments. The research team observed, and a moderator engaged participants in group processes and guided them in activities associated with the use of our friendsourcing app for connecting Facebook social network members with the peer support group.

Engagement activities included welcoming members, providing directions for making introductions, and emailing individual members with reminders to participate or to inform them of recent group posting activities. Scripts were developed for some of these activities, as in the following example of directions for making introductions:

*"Hi, I'm Patrick, I'm caring for my mom and have been for 3 years. One of my challenges is she gets confused and thinks that I'm her husband and she gets upset when I change the*

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*topic. What I like to do the most is go golfing, and my goals for this group are to get some answers for how to manage it when my mom gets upset."*

The moderator facilitated group participation through weekly prompts and individual emails, which asked caregivers to discuss emotional or informational support questions that they wanted to share with their Facebook friends social network. The moderator aggregated questions posted by the group members into a poll so that members would vote on a single question. This question would then be pushed to the group members' Facebook friends social networks via the study's friendsourcing app.

### **Friendsourcing Web App**

Friendsourcing was accomplished through a Facebook login interface that captured the peer support group users' credentials, which allowed the web application to post questions to their peer Facebook News Feed. The web app collected the comments made in response to questions in a database. The database displayed the question that was pushed, and peer support group members aggregated the comments.

## **RESULTS**

The study's peer group participants were diverse across many of the demographic categories summarized in Table 2. They were evenly distributed for the caregiver's relationship with the AD patient, with 50 percent caring for a parent and 50 percent caring for a wife, husband, or partner.

Table 2. Demographics of the research participants



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	(n = 12)
Variables	Mean (SD) /N (%)
Age	55.7 (12.5)
Gender (1=Female)	7 (58.3)
Ethnicity	
Caucasian	9 (75.0)
African American	3 (25.0)
Marital status	
Married	7 (58.3)
Single	3 (25.0)
Living together	2 (16.7)
Place to live	
Suburban	6 (50.0)
Metropolitan	4 (33.3)
Urban	1 (8.3)
Rural	1 (8.3)
Education	
Master's or higher degree	5 (41.6)
Bachelor degree	3 (25.0)
2-year college	2 (16.7)
High school	2 (16.7)
Income Level	
70K and higher	7 (58.3)
Below 70K	3 (24.9)
Unemployed/Retired	2 (16.7)
Working status	
Retired	5 (41.7)
Full-time	4 (33.3)
Part-time	2 (16.7)
Unemployed	1 (8.3)
Subjective health status	
Good or Very good	10 (83.3)
Fair and below	2 (16.6)
Relationship w/ care recipients	
Wife/Husband/Partner	6 (50.0)
Parents (mother/father)	6 (50.0)

### Survey Outcomes

Table 3 presents the changes in caregivers' caregiving burden, perceived stress, and emotional and informational support between pre- and post-intervention. A Wilcoxon Signed-Ranks Test indicated that, after the intervention, the participants' median score of the caregiver

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burden significantly decreased from 30.5 to 24 ( $Z=-2.01$ ,  $p<.05$ ). Perceived stress level was also significantly reduced from 29.5 to 20 ( $Z=-2.95$ ,  $p<.01$ ). The median score for emotional and informational supports significantly increased from 22.5 to 29 ( $Z= -2.32$ ,  $p<.05$ ). The effect sizes, calculated by Fritz, Morris, and Richler's (2011) method, were moderate, which locate between .3 and .5.

Table 3. Pre- and post-outcome comparison: Caregiving burden, perceived stress, emotional and informational support

	Pre-test (Median/Mean)	Post-test (Median/Mean)	Z-score	Effect size (r)
Caregiving burden (ZBI)	30.50 (31.50)	24.00 (25.55)	-2.01*	-.42
Perceived stress (PSS-14)	29.5 (28.33)	20.00 (22.64)	-2.95**	-.62
Emotional/informational support (MOS Social Support Survey)	22.5 (21.92)	29.00 (25.73)	-2.32*	-.48

\*\*  $p<.01$ , \* $p<.05$

### Friendsourcing Questions and Responses

The comments from group members' Facebook friends were shared with peer support group members after they were edited for ease of reading, and any irrelevant comments were eliminated. Peer support group members were then invited to discuss which answers they found helpful to leverage their impact on peer social support. Below is an example of a question that was pushed from Group 1:

*I find it impossible to maintain a positive attitude all of the time. When that happens, I get depressed, which doesn't help me or my wife. I finally pull myself up, but sometimes it's hard. I am sure this happens to you also. What do you do to get yourself up and going again?*

Below is an example of a friendsourced answer to that question:

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*It is important for the caregiver to arrange for respite through an agency or a family member to step in for an hour or two. Then go out and do something you enjoy doing.*

*Sometimes it is difficult for caregivers to remember to take care of themselves.*

### **Post-interview Outcomes**

In the post-group interviews, participants discussed their experiences with the intervention, including the use of the friendsourcing app and the private Facebook peer support group. Qualitative data analysis identified those caregivers with fewer social supports, less caregiving experience, and a greater number of responses from their Facebook friends social network to be more likely to describe the friendsourced peer support group as helpful for reducing burden and perceived stress. Participation outcomes for reducing burden included (a) discovering caregivers in their social network and (b) engaging in more active help-seeking behaviors. Participation outcomes for reducing perceived stress included (a) increasing objective self-reflection and (b) experiencing greater self-acceptance of their caregiving (Textbox 1).

Textbox 1. Post-intervention interview summary of friendsourcing effects on caregiver burden and perceived stress

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### Caregiver burden

- *I had some people that I hadn't been in touch with and I didn't know that they had a personal experience with dementia, and they wouldn't know that I was a caregiver, so in a way, it opens up more of a support system within your actual network of people.*
- *I've had a discussion with my son and my daughter and asked them for help and of course, they both work, but they can do things on the weekend.*
- *It prompted me to get into some chat organizations on the internet through the Alzheimer's website.*
- *It affected more a little bit [of my] planning of next steps I might have to do with my mom.*

### Perceived stress

- *I think [friendsourcing] has been really helpful because...because I can actually evaluate my feelings and understand what she needs from me, and I don't portray any of my feelings onto her, you know?*
- *One of the... [Facebook friends]...suggests to keep a journal. I started one last week and I haven't hit it every night, but at the end of the day, I sit down and try to write my thoughts in there and think about what's happened, think about what I could have done better or something I could have responded to better, so that's the other thing I started – why I didn't ever think about that myself, but that's very helpful.*
- *I found that people were providing feedback that was specific, but not judging or telling you what you should do or what you ought to be doing.*
- *It did help me feel like I wasn't doing anything wrong, that I wasn't the only one, you know, coming in with the same kind of questions, you know? I'm experiencing the same thing all Alzheimer's caregivers do.*

## **Transformative Learning Outcomes**

Of the 12 participants in the two intervention groups, ten completed the transformative learning experience survey six weeks post-intervention. The survey included seven questions about cognitive transformation and five questions about behavioral transformation. On average, participants reported 2.08 cognitive changes (SD=0.90) and 2.22 behavioral changes (SD=1.09) in their caregiving roles. Specifically, participants reported that they experienced changes in their

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beliefs of caregiving role expectations (70%) and were aware that other participants also questioned their caregiving beliefs (60%). They also answered that they attempted new behaviors that they learned through the intervention, such as seeking new ways of caregiving, trying new caregiving roles that were more comfortable for them, and taking action to apply the newly gained caregiving roles (50%, respectively) (Table 4).

Table 4. Transformative learning experience following the intervention

		(n=10)
Transformation in:	Statements	n (%)
Beliefs	“As I questioned my ideas, I realized I still agreed with my beliefs or role expectations.” (reversely coded)	7(70)
	“I realized that other people also questioned their beliefs.”	6(60)
Behavior	“I tried to figure out a way to adopt these new ways of acting.”	5(50)
	“I tried out new roles so that I would become comfortable or confident in them.”	5(50)
	“I took action and adopted these new ways of acting.”	5(50)

Seven out of ten (70%) replied that they had experienced a critical point of realization that their caregiving values, beliefs, opinions, or expectations had changed since beginning the intervention. Experiences included: realizing the importance of self-care, having confidence and positive attitudes in their caregiving roles, obtaining new caregiving information and techniques, creating more family conversations, and requesting support (Textbox 2).

Textbox 2. Critical point of changing caregiving beliefs, behaviors, and causes of the changes

Changes in caregiver role beliefs

[Realizing problem] *“I was having trouble dealing with how my partner did not believe things that were happening around her.”*

[Confidence] *“I was having a hard time being the "young adult" child caring for my mother with early-onset Alzheimer's. After the study, I realized that my age and her age aren't the main factors and that the main factors are that I can provide a rich and fulfilling end-of-life experience for her.”*

[Confidence] *“Perhaps just an overall sense of relief talking to others going through the same thing as I am.”*

[Positive attitude] *“In parallel to this experience I started focusing more on helping [the person with Alzheimer's] enjoy each day.,,less focus on me, more on them.”*

Changing caregiving behaviors

[New approach] *“As a new care partner as my wife was diagnosed just a year ago with the slow progress of ALZ; I was sorting out and finding my way to be the care partner that I want to be and that she needs. As my beliefs and care matured, the discussions within the study with other caregivers enlightened, supported or altered my approach to care. Example: when to take the car keys away; understanding that the disease is our adversary, not my wife; some of the behaviors demonstrated by my wife were not abnormal with AL patients.”*

[New approach] *“Seeing other ways of caregiving gave me new ideas.”*

[Family conversations] *“I became more concerned about my health and well-being. Started talking more to immediate family about my caregiver experiences and asking for support so I could get some free time occasionally.”*

**Moderation Outcomes**

Post-interviews indicated that participants found it helpful to receive moderator-delivered individual reminder emails to participate in discussions. Participants indicated that caregiving demands or other activities could prevent their timely participation, making these emails particularly helpful. Some participants, however, would have liked greater moderation of group

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activities inside the private Facebook group. A few participants stated that they were confused about when to contribute their informational or emotional support questions for discussion, and others wanted more group encouragement and direction from the moderator regarding ongoing caregiver discussions.

### DISCUSSION

This study investigated the effects of friendsourcing on the psychological well-being of AD caregivers for reducing burden and perceived stress. To our knowledge, this is the first study of the use of friendsourcing with social media for the delivery of online support to AD caregivers. The rationale for joining social and support groups within Facebook was to determine whether they would be useful to AD caregivers as a guided route for obtaining support. Friendsourcing was accomplished through a web app that allowed small Facebook peer support groups of AD caregivers to communicate informational or emotional support questions in a single voice to members in their individual Facebook social networks.

After the six-week intervention, caregivers were found to have significantly decreased burden ( $Z=-2.01$ ,  $p<.05$ ) and perceived stress ( $Z=-2.95$ ,  $p<.01$ ). Emotional and informational support scores were significantly increased ( $Z= -2.32$ ,  $p<.05$ ). Interview data indicated that participants discovered members of their social network also shared caregiver experiences. Friendsourced responses to emotional and informational support questions were primarily accepting, non-judgmental, and encouraged caregiver role self-acceptance.

At six-weeks post-intervention, a transformative learning survey found that 70 percent of respondents experienced a critical point during the intervention that resulted in changes to their caregiver role beliefs, and 50 percent experienced a critical point that resulted in changes to their caregiver behaviors. Changes in caregiving beliefs and behaviors can be associated with

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reductions in caregiver burden and perceived stress. These findings are consistent with previous studies in the AD caregiver literature, which indicates social support can reduce caregiver burden and enhance psychological well-being (Gitlin, Marx, Stanley, & Hodgson, 2015).

Whereas more AD caregivers are using social media to obtain support, in part because of its easy accessibility and ability to remove logistical barriers (Lauritzen et al., 2015), friendsourcing interventions—like the one developed for this study—still pose concerns about caregiver participation. For instance, although 60 individuals accessed the study’s pre-intervention survey, only 23 (38.3%) completed the survey and only 12 (20%) participated in the intervention. Two participants indicated privacy concerns for the persons for whom they provided care. These included whether personal information would be shared outside of Facebook and whether Facebook was collecting personal data to share with third parties. Three participants indicated mild concerns regarding the use of the friendsourcing app to push informational and emotional support questions to their Facebook News Feed, although their concerns did not prevent their participation in the intervention. Concerns primarily centered on apprehension about negative social comparison by their social network members. Based on these concerns, we recommend that future friendsourcing interventions include continuous monitoring of participants’ acceptance and consent of the content that is being pushed to their social network members.

### **Limitations**

Our exclusion criteria limited participation of caregivers with fewer than 40 members in their social network and with fewer than two postings to their social network the month prior to participation in the study. These factors limited recruitment. Several individuals contacted our team to indicate disappointment about their ineligibility due to these criteria. This limitation is



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particularly noteworthy because qualitative data analysis found caregivers with fewer social supports experienced friendsourcing as more helpful. Removing the criterion of a specific number of social network members could increase inclusivity and the number of participants. Adding social network members could then be explored through collaborations with other Facebook groups of AD caregivers. This could, in effect, increase the social network of Facebook users with few members.

There were also cultural limitations to our study. One participant identified a lack of cultural diversity in discussions and stated that he/she wished his/her group included more African-American participants. The lack of cultural diversity is an important limitation to consider, especially since African-Americans have a greater incidence and a younger onset of AD (Griffith & Lopez, 2009). In addition, the numbers of African-American caregivers are proportionally greater than Caucasian caregivers (Alzheimer's Association, n.d.). African-American caregivers' use of informal support may vary culturally from Caucasian caregivers; therefore, it would be important to gain further understanding of the cultural uses of friendsourcing to join social and support networks with social media. Future friendsourcing studies that intervene with African-American caregivers could consider the importance and meaningfulness of spiritual support, as well as collaboration with Facebook groups managed by African-American churches.

In addition, because this study piloted a friendsourcing peer support innovation for social media delivery, its acceptability had not been previously tested, and our recruitment sample was small. Our design was not experimental, so our findings cannot be generalized to other AD caregiver populations.

### **Future Direction**

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This study showed that an online friendsourcing intervention for AD caregivers was feasible and potentially effective at increasing caregiver support and reducing caregiver-perceived stress and burden. These findings suggest that there is a significant opportunity to help improve caregiver stress, burden, and support through online peer support interventions. Feedback from our study indicates that participants want increased moderation to facilitate peer dialogue. Our work, and that of other studies, suggest that the experience of each AD caregiver is unique and that caregivers prefer interventions tailored to their individual needs (Cristancho-Lacroix et al., 2015). In summary, larger studies with more culturally diverse caregiver populations are needed to test the effectiveness of web-based peer support interventions for AD caregivers.

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