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An Investigation of Information Sought by Caregivers of Alzheimer's Patients on Online Peer-Support Groups

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ABSTRACT

Caregivers of Alzheimer's patients find respite in online communities for solutions and emotional support. This study aims to understand the characteristics of information caregivers of Alzheimer's patients are searching for and the kind of support they receive through internet-based peer-support communities. Using a web crawler written in Python web programming language, we retrieved publicly available 2500 random posts and their respective solutions from April 2012 to October 2016 on the solutions category of the Caregiver's Forum on ALZConnected.org. A content analysis was conducted on these randomly selected posts and 4,219 responses to those posts based on a classification system derived from initial analyses of 750 posts and related responses. The results showed most posts (26%) related to queries about Alzheimer's symptoms, and the highest percentage of responses (45.56%) pertained to caregiver well-being. The LIWC analyses generated an average tone rating of 27.27 for the posts, implying a negative tone and 65.17 for their responses, implying a slightly positive tone. The ALZConnected.org website has the potential of being an emotionally supportive tool for caregivers; however, a more user-friendly interface is required to accommodate the needs of most caregivers and their technological skills. Solutions offered on the peer support groups are often subjective opinions of other caregivers and should not be considered professional or comprehensive; further research on educating caregivers using online forums is necessary.

Keywords: Online peer-support groups, caregiver needs analysis, Alzheimer's disease, dementia, content analysis

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INTRODUCTION

1
2
3 The term *caregiver* refers to an individual committed to caring for the health needs of
4 another, often aiding with one or more tasks of daily living¹. Caring for Alzheimer's patients is an
5 undertaking that often places burden on caregivers, many of whom sacrifice their own quality of
6 life to care for patients^{2,3}. Caregiving often is a responsibility undertaken by the patient's close
7 family who have little to no knowledge or experience in the professional care of Alzheimer's
8 patients. Most are unpaid and receive little recognition for their work⁴. More than 15 million people
9 in the United States care for Alzheimer's patients and people with other forms of dementia¹. The
10 economic value in the U.S. of this unpaid service was estimated to as much as \$470 billion in
11 2013^{5,6}.

12 Approximately four million people in the United States are living with Alzheimer's⁷, and every
13 year millions of people in this country die from complications of the disease¹. It has been predicted
14 the number of people living with Alzheimer's in the United States is likely to rise by 10 million by
15 2050⁸. The health of this rising population of Alzheimer's patients is dependent on the health and
16 capacity of its caregivers. Without these voluntary care providers, all healthcare institutions across
17 the country combined would be insufficient to care for the rising numbers of Alzheimer's
18 patients^{9,10}.

19 Caregivers are an invaluable, irreplaceable component of the public health system¹¹. The
20 work conditions of caregivers have a direct impact on the quality of care delivered to patients
21 therefore; attending to the needs of the caregiver should be an integral to the overall care for the
22 patient¹².

Impact/problems of Alzheimer's disease on patients and caregivers

24 Alzheimer's disease has the potential of wreaking havoc on the psychological, physical,
25 social, and economic well-being of the patient and caregiver¹³. The impact of Alzheimer's on public
26 health is especially significant due to the prolonged duration of the illness and the degree of

1 dependency and disability it imposes¹. The higher level of advancement of the disease and the
2 longer the period of care, the greater the emotional and physical stress experienced by the
3 caregiver³. Physical stress for caregivers is associated with a higher level of dependency of the
4 patient coupled with cognitive failure, the lack, or total absence, of social support, and emotional
5 stress^{14,15}. The level of stress, frustration and depression faced by caregivers surpasses levels
6 considered normal for their respective ages¹⁶. Caregiving is physically and emotionally draining,
7 and people come to ALZConnected.org to seek or offer support^{17,18}.

8 With Alzheimer's disease, caregiving implies a commitment for an extensive period that can
9 prove mentally and physically draining and often restricts the caregiver's social life and career
10 choices¹⁹. A caregiver's social life may be disrupted and, in extreme cases, completely cutoff²⁰.
11 Personal relationships become strained²¹. Marital relationships, especially between a caregiver
12 and patient, get tenuous^{22,23}. Those with little or no support system face the challenge of managing
13 caregiving, family, career, and social life. Inability to cope with this challenge can lead to break
14 down in one or more of these areas²⁴.

15 Alzheimer's disease ranks third in the United States with respect to costs (roughly \$100
16 billion annually)⁷. Expenses like the costs of diagnosis, treatment, medicines and long-term care
17 are often shared between the patients and caregivers wherein caregivers contribute, but patients
18 endure the most of the expenses²⁵. Decrease in productivity of the patient and the caregiver has
19 an indirect impact on the cost of care⁷.

20 *Internet use among caregivers and the role of social support*

21 Many institutions and programs cater to the needs of caregivers of Alzheimer's patients²⁶.
22 Caregivers need solutions tailored to their specific needs, which many formal organizations cannot
23 provide²⁷. Many caregivers of Alzheimer's patients have found respite in support groups for
24 information, solutions, and social support²⁸. The caregivers cannot always participate in traditional
25 face-to-face support groups due to logistics, time, cost and other constraints; therefore, online
26 communities, such as ALZConnected.org, offer a convenient way to receive support^{29-31,44}.

1 Participation in online communities has been associated with reducing the burden experienced
2 by caregivers^{32,44}. Past studies have determined that anecdotal information can have an undue
3 influence on the health consumer in understanding a health condition, subsequently impacting the
4 decisions made^{45,46,47}. One of the most persuasive features of anecdotal information on peer
5 support groups is that it shows the sequence of events and the consequences of making a specific
6 healthcare decision.

7 Informal caregivers of those with dementia face several issues requiring different types of
8 social support including emotional, informational, tangible, positive social interaction, and
9 affectionate support³³. These types of support can be offered on-line with the benefit of anonymity;
10 a need revealed in our pilot study as well as in work by Colvin et al.³⁴ who studied views about
11 internet-based support of 63 caregivers of adults (half of whom had Alzheimer's disease). Colvin
12 et al.³⁴ found that anonymity fosters a non-judgmental atmosphere that enables online participants
13 to feel freer to express their frailties and emotionally sensitive issues³⁴. This type of atmosphere
14 also provides the opportunity to vent, a need also expressed by our pilot study participants. Colvin
15 et al. (2004) also found that online support participants benefited from the feeling of connectivity
16 to others in similar situations; in fact, they concluded connectivity was the central concept
17 integrating all themes related to online social support. Han et al.³³ found from their analysis of the
18 National Survey of Dementia Care in South Korea data (n=731), that positive social interaction
19 and affectionate support directly and indirectly reduced psychological burden which is an
20 important health concern for caregivers. The study participants most frequently cited emotional
21 support as a need, but they also indicated caregivers needed informational support such as advice
22 about care facilities, health care providers, and disease management strategies.

23 *Research questions*

24 There has been substantial progress around caregiving²⁶; however, there is room for
25 improvement in the quality of caregiving and the experience of the caregivers. Previous research
26 has examined the problems voiced by Alzheimer's caregivers in traditional peer-support

1 groups^{28,35}; however, no research has systematically investigated and outlined the various kinds
2 of questions posed by the caregivers of Alzheimer's patients on online peer support groups. This
3 study aims to facilitate the improvement of caregiving of Alzheimer's patients by highlighting the
4 issues faced by caregivers and the kind of support they receive through internet-based peer-
5 support communities. This research analyzes the content of messages exchanged on a web portal
6 for Alzheimer's caregivers—ALZConnected.org, part of the official website of the Alzheimer's
7 Association, a leading voluntary health organization in Alzheimer's care, support and research.
8 We used content analysis, a research technique that provides useful and pertinent information
9 about conversations, to better understand the types of information searched by caregivers and
10 the content of the responses received to answer the following research questions:

11 *RQ1: What are the major themes and corresponding frequencies of information sought*
12 *on ALZConnected.org?*

13 *RQ2: What are the types and levels of emotion experienced by caregivers of Alzheimer's*
14 *patients?*

15 *RQ3: What is the content of the responses received to queries on ALZConnected.org?*

16
17

METHOD

Study sample

19 Data was obtained through the Caregiver's forum on ALZConnected.org. This site has two
20 target groups with different forums for each: Patient's Forum and Caregiver's Forum. Only the
21 Caregiver's Forum was used in our research as the main objectives were to categorize the types
22 of support given to caregivers and the amount of corresponding support from one caregiver to
23 another. The Alzheimer's Association had already created categories for the common post
24 questions. However, these categories were not specific enough to categorize the entire data
25 corpus, producing the need for an overall content analysis to specify the appropriate
26 subcategories.

1 *Step 1: Category generation*

2 Initially, 500 posts were analyzed, creating unique categories to organize the types of
3 problems caregivers face and the solutions given. These 500 posts were taken from activity on
4 the site between April 2015 and January 2016. All identifiers were removed except for the date
5 and time of the post, which were used for filing purposes. The corresponding solutions for each
6 of the posts were recorded with all identifiers removed. Each of the 500 posts and corresponding
7 responses were interpreted based on emotions and needs present. Two observers read every
8 post to negate any bias in interpretation. For some posts, the needs and/or emotions were clearly
9 stated. In other posts, the needs and emotions had to be interpreted based on detailed
10 examination of the content of the post. The responses given to each post were summarized to
11 analyze the emotions and content. The problems and solutions were then put into major
12 categories observed in all 500 posts. The subset categories created were based on repetitive
13 questions or solutions seen within each major category.

14 *Step 2: Pilot analysis of 250 posts*

15 Scarpy, a Python-based web crawler program developed to collect openly available data, was
16 used to collect data from the peer support group. The program included a random data generator
17 to sort over one million posts on the “Solutions” tab of the Caregiver’s Forum and randomly select
18 250 posts and their respective solutions. This pilot study was done to ensure the original
19 categories sufficiently summarized the data. For posts that did not fall into a specific category, an
20 “Other” category was created to ensure this data was not lost or discarded, and could be further
21 analyzed for trends. Three observers analyzed each of the 250 posts to reduce bias in
22 categorization. When at least two of the observers disagreed, the post or solution was set aside
23 and later reanalyzed for consensus.

24 *Step 3: Analysis of 2,500 posts*

25 Once the categories were finalized, a sample of 2,500 random publically available posts
26 with corresponding solutions was obtained for analysis using the Web Crawler. This included the

1 posts from April 2012 to October 2016. Three raters individually categorized each post and
2 solution, ensuring individual opinions without collaboration between raters to negate bias. The
3 rater's responses compared and for every problem or solution where at least two of the three
4 raters did not agree, the problems or solutions were re-categorized by two of the raters
5 collaboratively.

6 To analyze the emotional levels, the Linguistic Inquiry and Word Count System (LIWC)³⁶⁻³⁸
7 was used. This system analyzed every word in a post and returned an emotional rating. These
8 numbers ranged from zero to 100, zero being an extremely negative emotion and 100 being an
9 extremely positive emotion. If this level was between forty to sixty, the post had little to no
10 emotion³⁶⁻³⁸. Any level greater than sixty or less than forty was considered an emotional post.
11 This ranking allowed the team to analyze an entire database of data for the magnitude and type
12 of emotions present.

13 *Statistical Analysis*

14 To calculate interrater reliability, Fleiss' Kappa Statistic, an adaptation of Cohen's kappa
15 for 3 or more raters was used^{39,40}. This calculation determined consistency amount the three
16 raters⁴¹. Fleiss' Kappa analysis was performed for the categorization of the 2500 posts as well
17 as the 4219 responses to these posts.

18 **RESULTS**

19 *Pilot results*

20

21 The pilot categorization of the first 250 posts are summarized in Appendix 1 and 2.

22

23 *Analysis results of 2,500 posts*

24 The LIWC system generated an average tone rating for the posts of 27.27 and the average
25 tone for the responses of 65.17. These results indicate, for the 2,500 posts analyzed, the average
26 of all problems contained very negative emotions and the average of all responses contained only
27 slightly positive emotions. An interrater reliability analysis using the Fleiss' Kappa statistic^{39,40} was

1 performed to determine consistency among raters for the problem set⁴¹. The interrater reliability
2 for the raters for the problem-related posts was found to be substantial, Fleiss' Kappa = 0.628 (p
3 <.0.001), 95% CI (0.622, 0.634). The interrater reliability for the raters for the solutions-related
4 post was found to be moderate, Fleiss' Kappa = 0.533 (p <.0.001), 95% CI (0.527, 0.539). The
5 categorization of the 2,500 posts is summarized in Tables 1 and 2.

6 INSERT TABLE 1 HERE

7
8 INSERT TABLE 2 HERE

9
10 The research questions in this study focused on what types of needs are being presented
11 and how often caregivers visiting this forum present them. The study also focused on what types
12 and levels of emotion caregivers of Alzheimer's patients express. The content analysis method
13 was useful as it allowed for differentiating themes in user's needs, common emotions seen in
14 posts, and varying ways solutions to posts were communicated. The major trends identified, along
15 with the major trends in emotional levels of the posts, are explained further below. These posts
16 and excerpts are quotes from the portal, www.ALZConnected.org, without any spelling or
17 grammatical corrections to preserve the emotional tone of the original posts.

18 *Problem-related posts*

19 A highlight of the key findings of the 2500 problem-related posts using the categories in
20 Table 1 are presented in Table 3. See Appendix 3 for a complete list of all key findings of the 2500
21 problem-related posts.

22 INSERT TABLE 3 HERE

23 *Responses given to Problem-related posts*

24 Users, including caregivers and patients who visited ALZConnected.org, responded to the
25 original 2,500 posts. These responses were analyzed and classified using the criteria presented
26 in Table 2. Highlights of the key findings of the 4219 responses to the problem-related posts are
27 presented in Table 4. See Appendix 4 for a complete list of all key findings of the 4219 responses.

1 INSERT TABLE 4 HERE

2 **DISCUSSION**

3 Through the analysis of the Caregiver's Forum for Alzheimer's patients, posts on the forum
4 most frequently conveyed some form of emotion ranging from heartbreak to intense anger. The
5 results showed most posts (26%) related to queries about Alzheimer's symptoms, and the highest
6 percentage of responses (45.56%) pertained to caregiver well-being. The LIWC
7 analyses generated an average tone rating of 27.27 for the posts, implying a negative tone and
8 65.17 for their responses, implying a slightly positive tone. In general, most responses were
9 informative and directly answered the problem in the original post. Due to the variety of
10 experiences and opinions, the solutions varied greatly.

11 *Emotional and common content*

12 Our content analysis found that many users come to the site solely to express their emotions
13 and seek affirmation from fellow caregivers. This need for emotional support appeared in 191 of
14 the 2,500 posts analyzed. Many of the caregivers feel fatigue from the constant burden of the
15 patient especially near the end stages of the disease^{17,18}. These emotional posts were met with
16 either no emotion or specific encouragement from other caregivers on the forum as reflected in
17 the LIWC score of 65.17 showing the responses contained only slight positive emotions. The
18 reason this number is lower than expected is unknown. One possibility could be the reiteration of
19 the originally stated problem, which would have created a more negative overall tone, lowering
20 the LIWC score.

21 *Symptoms advice*

22 The largest percentage of inquiries (26% of all posts analyzed) were seeking information on
23 symptoms. Whether seeking medical advice, social support, or diagnosis of their own conditions.
24 Often, responses to inquiries about specific symptoms urged the caregiver to consult the patient's
25 doctor or shared a similar experience. These solutions were typically encouraging and affirmative.
26 Affirmation is sometimes all caregivers need to make the necessary decisions for the patient⁴³.

1 *Financial and legal advice*

2 Another type of information frequently sought by caregivers was cost effective solutions for
3 different expenses, including medical devices, treatments, safety equipment, assisted care
4 facilities, in-home assistance, and other costs of caregiving. Since this website is free and open
5 to anyone, it is a no-cost tool for people around the world to find low cost solutions²⁹. Instead of
6 caregivers leaving home to find a local support group or discussing their needs with an expert,
7 they can simply login to the site for instant feedback⁴³. Questions related to financials often
8 included questions about legal advice, elder law attorneys and acquiring a power of attorney.

9 *Limitations*

10 The community member had the option to send each other private messages. These
11 information exchanges were also not included in this study. This study only looked at posts from
12 the past four years. The posts had to be generalized into broad categories for organizational and
13 analysis purposes. These categories were created from interpretation of the posts having no
14 background information on the patients or caregivers.

15 *Future Work and Conclusion*

16 An unforeseen limitation on the forum was the issue of confronting a coworker or employee
17 with Alzheimer's disease. When caregivers post on the forum, they understand Alzheimer's and
18 symptoms of the disease²⁹. However, caregivers are not the only people with whom patients
19 associate. Acquaintances and strangers may not understand a patient's abnormal behavior.
20 These acquaintances and strangers may not feel it is appropriate to ask questions on this forum.
21 Future research should consider the possibility of an inclusive forum for questions regarding
22 Alzheimer's disease.

23 A common problem voiced in the 2,500 posts were questions about the website itself. Adults
24 over the age of 65 are at a disadvantage when using technology due to age-related cognitive
25 issues, vision impairments, and dexterity issues^{43, 48-50}. Not only are the people with Alzheimer's
26 disease primarily over the age of 65 but also the people caring for them are nearing this age^{8,49}.

1 Due to the lack of knowledge and experience, questions regarding the use of the Caregiver's
2 Forum were common. Future research should be cognizant of this issue and the need to improve
3 the usability of online user forms to accommodate an elderly audience.

4 The Alzheimer Caregivers' Forum is a useful place for caregivers to give and receive
5 information and emotional support. Through this content analysis, we gained a better
6 understanding of the overall emotional and physical needs of caregivers of Alzheimer's patients,
7 thereby providing us with specific future improvements for online user support.

8

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10

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13

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