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
INTRODUCTION

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

Approximately four million people in the United States are living with Alzheimer’s\(^7\), and every year millions of people in this country die from complications of the disease\(^1\). It has been predicted the number of people living with Alzheimer’s in the United States is likely to rise by 10 million by 2050\(^8\). The health of this rising population of Alzheimer’s patients is dependent on the health and capacity of its caregivers. Without these voluntary care providers, all healthcare institutions across the country combined would be insufficient to care for the rising numbers of Alzheimer’s patients\(^9,10\).

Caregivers are an invaluable, irreplaceable component of the public health system\(^11\). The work conditions of caregivers have a direct impact on the quality of care delivered to patients therefore; attending to the needs of the caregiver should be an integral to the overall care for the patient\(^12\).

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

Alzheimer’s disease has the potential of wreaking havoc on the psychological, physical, social, and economic well-being of the patient and caregiver\(^13\). The impact of Alzheimer’s on public health is especially significant due to the prolonged duration of the illness and the degree of
dependency and disability it imposes. The higher level of advancement of the disease and the longer the period of care, the greater the emotional and physical stress experienced by the caregiver. Physical stress for caregivers is associated with a higher level of dependency of the patient coupled with cognitive failure, the lack, or total absence, of social support, and emotional stress. The level of stress, frustration and depression faced by caregivers surpasses levels considered normal for their respective ages. Caregiving is physically and emotionally draining, and people come to ALZConnected.org to seek or offer support.

With Alzheimer's disease, caregiving implies a commitment for an extensive period that can prove mentally and physically draining and often restricts the caregiver’s social life and career choices. A caregiver’s social life may be disrupted and, in extreme cases, completely cut off. Personal relationships become strained. Marital relationships, especially between a caregiver and patient, get tenuous. Those with little or no support system face the challenge of managing caregiving, family, career, and social life. Inability to cope with this challenge can lead to breakdown in one or more of these areas.

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

Internet use among caregivers and the role of social support

Many institutions and programs cater to the needs of caregivers of Alzheimer's patients. Caregivers need solutions tailored to their specific needs, which many formal organizations cannot provide. Many caregivers of Alzheimer's patients have found respite in support groups for information, solutions, and social support. The caregivers cannot always participate in traditional face-to-face support groups due to logistics, time, cost and other constraints; therefore, online communities, such as ALZConnected.org, offer a convenient way to receive support.
Participation in online communities has been associated with reducing the burden experienced by caregivers\textsuperscript{32,44}. Past studies have determined that anecdotal information can have an undue influence on the health consumer in understanding a health condition, subsequently impacting the decisions made \textsuperscript{45,46,47}. One of the most persuasive features of anecdotal information on peer support groups is that it shows the sequence of events and the consequences of making a specific healthcare decision.

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

\textit{Research questions}

There has been substantial progress around caregiving\textsuperscript{26}; however, there is room for improvement in the quality of caregiving and the experience of the caregivers. Previous research has examined the problems voiced by Alzheimer’s caregivers in traditional peer-support
groups\textsuperscript{28,35}; however, no research has systematically investigated and outlined the various kinds of questions posed by the caregivers of Alzheimer’s patients on online peer support groups. This study aims to facilitate the improvement of caregiving of Alzheimer’s patients by highlighting the issues faced by caregivers and the kind of support they receive through internet-based peer-support communities. This research analyzes the content of messages exchanged on a web portal for Alzheimer’s caregivers—ALZConnected.org, part of the official website of the Alzheimer’s Association, a leading voluntary health organization in Alzheimer’s care, support and research. We used content analysis, a research technique that provides useful and pertinent information about conversations, to better understand the types of information searched by caregivers and the content of the responses received to answer the following research questions:

\textit{RQ1:} What are the major themes and corresponding frequencies of information sought on ALZConnected.org?

\textit{RQ2:} What are the types and levels of emotion experienced by caregivers of Alzheimer’s patients?

\textit{RQ3:} What is the content of the responses received to queries on ALZConnected.org?

\textbf{METHOD}

\textit{Study sample}

Data was obtained through the Caregiver’s forum on ALZConnected.org. This site has two target groups with different forums for each: Patient’s Forum and Caregiver’s Forum. Only the Caregiver’s Forum was used in our research as the main objectives were to categorize the types of support given to caregivers and the amount of corresponding support from one caregiver to another. The Alzheimer’s Association had already created categories for the common post questions. However, these categories were not specific enough to categorize the entire data corpus, producing the need for an overall content analysis to specify the appropriate subcategories.
Step 1: Category generation

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

Step 2: Pilot analysis of 250 posts

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

Step 3: Analysis of 2,500 posts

Once the categories were finalized, a sample of 2,500 random publically available posts with corresponding solutions was obtained for analysis using the Web Crawler. This included the
posts from April 2012 to October 2016. Three raters individually categorized each post and solution, ensuring individual opinions without collaboration between raters to negate bias. The rater’s responses compared and for every problem or solution where at least two of the three raters did not agree, the problems or solutions were re-categorized by two of the raters collaboratively.

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

\textit{Statistical Analysis}

To calculate interrater reliability, Fleiss’ Kappa Statistic, an adaptation of Cohen’s kappa for 3 or more raters was used\(^{39,40}\). This calculation determined consistency amount the three raters\(^{41}\). Fleiss’ Kappa analysis was performed for the categorization of the 2500 posts as well as the 4219 responses to these posts.

\textbf{RESULTS}

\textit{Pilot results}

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

\textit{Analysis results of 2,500 posts}

The LIWC system generated an average tone rating for the posts of 27.27 and the average tone for the responses of 65.17. These results indicate, for the 2,500 posts analyzed, the average of all problems contained very negative emotions and the average of all responses contained only slightly positive emotions. An interrater reliability analysis using the Fleiss’ Kappa statistic\(^{39,40}\) was
performed to determine consistency among raters for the problem set\textsuperscript{41}. The interrater reliability for the raters for the problem-related posts was found to be substantial, Fleiss' Kappa = 0.628 (p <0.001), 95% CI (0.622, 0.634). The interrater reliability for the raters for the solutions-related post was found to be moderate, Fleiss' Kappa = 0.533 (p <0.001), 95% CI (0.527, 0.539). The categorization of the 2,500 posts is summarized in Tables 1 and 2.

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

Problem-related posts

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

Responses given to Problem-related posts

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

Through the analysis of the Caregiver’s Forum for Alzheimer’s patients, posts on the forum most frequently conveyed some form of emotion ranging from heartbreak to intense anger. 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. In general, most responses were informative and directly answered the problem in the original post. Due to the variety of experiences and opinions, the solutions varied greatly.

Emotional and common content

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

Symptoms advice

The largest percentage of inquiries (26% of all posts analyzed) were seeking information on symptoms. Whether seeking medical advice, social support, or diagnosis of their own conditions. Often, responses to inquiries about specific symptoms urged the caregiver to consult the patient’s doctor or shared a similar experience. These solutions were typically encouraging and affirmative. Affirmation is sometimes all caregivers need to make the necessary decisions for the patient\textsuperscript{13}. 
Financial and legal advice

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

Limitations

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

Future Work and Conclusion

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

A common problem voiced in the 2,500 posts were questions about the website itself. Adults over the age of 65 are at a disadvantage when using technology due to age-related cognitive issues, vision impairments, and dexterity issues. Not only are the people with Alzheimer’s disease primarily over the age of 65 but also the people caring for them are nearing this age.
Due to the lack of knowledge and experience, questions regarding the use of the Caregiver’s Forum were common. Future research should be cognizant of this issue and the need to improve the usability of online user forms to accommodate an elderly audience.

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

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