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Studying Online Support for Caregivers of Patients With Alzheimer's Disease in China:
A Text-Mining Approach to Online Forum in China

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ABSTRACT

Owing to the constant physical and emotional stress suffered by patients of Alzheimer's disease, the need for a 24/7 care provision is not only challenging to the patients, but especially so for their caregivers. Past studies on how to support the caregivers of Alzheimer's disease patients have largely been conducted via qualitative analyses and/or studies based on survey data, in contrast, the present study examines online support for dementia caregivers by utilizing a text-mining approach to explore what caregivers have shared online. Specifically, the study shows that online support empowers caregivers with a convenient e-channel to share information, emotions, caring skills, and mutual support. Theoretically, the approach also reveals that text-mining techniques are an instructive method to assist future researchers on exploring digital health issues in this age of big data. Using the text-mining techniques, healthcare providers, researchers, and caregivers are poised to make good use of a diverse array of textual healthcare information from the Internet

KEYWORDS

Alzheimer's Disease, Caregivers, Online Support, Text Mining, Topic Modeling

1. INTRODUCTION

Over the past several decades, with rapid advances of innovative health technologies and new ways of practicing medicine, human life expectancy has increased significantly. According to the World Bank statistics, many developed countries have already entered the aging society, such as the United States (US), where about fifteen percent (15%) of its population has turned 65 years old as of 2017, and Japan, which has about twenty-seven percent (27%) of its population at the same stage (The World Bank Group, 2018). In developing countries, populations are also aging at an accelerating rate. Today, eleven percent (11%) of China's population is touted to reach 65 years of age or older, implying that up to 150 million people in China are now seniors (The World Bank Group, 2018).

A major health problem inflicting seniors is dementia. Alzheimer's disease (AD) is a chronic neurodegenerative disease that comprises sixty to seventy percent (60% to 70%) of all dementia cases.

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The most common symptoms of AD are memory loss, decline in language abilities and reasoning skills, behavioral changes, as well as uncontrollable mood swings (Burns & Iliffe, 2009; Alzheimer's Association, 2017). The symptoms of Alzheimer's disease and related forms of dementia (ADRD) can be difficult and overwhelming for caregivers, many are family members, to manage. Accordingly, caregivers for these patients are being placed at a greater risk of facing caregiving stress and increased mental health problems (Ornstein & Gaugler, 2012; Feast, Moniz-Cook, Stoner, Charlesworth & Orrell, 2016; Alzheimer's Association, 2017). In fact, online support for ADRD caregivers has gained increasing attention from healthcare practitioners, researchers, and patients (Glueckauf & Loomis, 2003; Robillard, Johnson, Hennessey, Beattie, & Illes, 2013). Today, online communication provides a platform for caregivers to access to convenient mutual support on a flexible schedule and beyond proximity compared with offline support. It is particularly important for caregivers for ADRD patients because these caregivers often almost need to care for their patients around the clock (Ferell & Wittenberg, 2017; Frambes, Given, Lehto, Sikorskii & Wyatt, 2018).

Over the next few decades, considering the high incidence of ADRD among seniors and the rapid increase of aging populations worldwide, taking care of the AD patients will become an even greater challenge. As of 2017, an estimated 9.5 million people in China suffered from various forms of dementia (Wu et al., 2018). Hence, a key question to be addressed in the face of an aging population worldwide is: *How do we support ADRD caregivers?*

The present study aims to address the caregiver support question from the perspective of deploying online support over the Internet and how to understand these virtual social support groups, which requires systematic detailed analysis of the contents in online support and communications.

Unlike the use of traditional methodologies such as focus groups, structured interviews and survey-based analyses in past studies, we leverage a statistical text-mining technique herein to examine a large number of textual online posts. Combined with qualitative analysis, the overall intent of this study has two folds. First, empirically, the study aims to explore the topics and content of support for AD caregivers from online forums - here, the primary objective is to examine and/or verify the usefulness of online support for caregivers and understand how such online support may have implications for future policy decisions, given that the examined online caregiver forum was sponsored by a national e-health grant. Second, theoretically, a secondary goal is to show how text-mining techniques can provide a meaningful and useful tool for research on digital communication and online support for caregivers. By taking advantage of emerging digital and transformational e-technologies in the current era of big data, our hope is to highlight the need to conduct future studies like these, as the power and intelligence of computer and software technology not only alleviate the labor burden of human coding but also make the analysis of massive amounts of textual data from online forums feasible. Moreover, the present study will also provide insights into the appropriateness and utility of online supportive health communication channels and their impacts on empowering care providers in China.

The organization of the reminding sections of this paper is as follows. Section 2 overviews the background on online support for caregivers and the methods used in textual analysis in healthcare. Section 3 highlights the text mining method and data used in the present study. Section 4 presents our text mining results. and finally, section 5 is the conclusion section.

2. BACKGROUND

Aside from the increasingly complex medical aspects of the aging society and its related healthcare costs, providing sustainable health care for dementia patients is also painfully challenging for informal caregivers, especially those who may be overwhelmed by family responsibilities and not having previous knowledge on or experiences with caring for the ADRD conditions. Individuals suffering from ADRD exhibit cognitive impairment and behavioral problems, which may in turn interfere with the daily care and adversely affect the emotional interactions and relationship quality in-between the patient-caregiver dyads (Ornstein & Gaugler, 2012; Feast et al., 2016).

To date, solid empirical evidence has shown that the burden of providing care for dementia patients affects caregivers' physical and mental health (Vitaliano, Zhang & Scanlan, 2003; Van der Lee, Bakker, Duivenvoorden & Dröes, 2014; Livingston et al., 2017). Among all informal caregivers, caregivers for dementia patients are the most likely to experience psychological distress (Bruce, Paley, Nichols, Roberts, Underwood & Schaper, 2005; Blom, Bosmans, Cuijpers, Zarit & Pot, 2013) and adverse physical health consequences (Pinquart & Sörensen, 2007). Examples of common mental health problems affecting these caregivers include depression (Schoenmakers, Buntinx & Delepeleire, 2010; Ornstein & Gaugler, 2012; Chiao, Wu & Hsiao, 2015), sleep disorders (Simpson & Carter, 2013), anxiety (Cooper, Balamurali & Livingston, 2007), and eating disorders (Sörensen Sörensen, Duber Sörensen tein, Gill, & Pinquart, 2006).

Griffiths, Cave, Boardman, Ren, Pawlikowska, Ball & Cohen (2012) argue that the future channel of communication and support among caregivers would rely hugely on social networking via the Internet. Researchers have since documented the existence of various online support for patients, family and informal caregivers, as well as healthcare professionals, for example, a diabetes patients' Facebook support group (Greene, Choudhry, Kilabuk & Shrank, 2011), an autism caregivers' online support group (Roffeei, Abdullah & Basar, 2015), a breast cancer caregivers' and patients' Facebook group (Bender, Jimenez-Marroquin & Jadad, 2011), a sentiment analysis of an online support for breast cancer patients (Cabling, Turner, Hurtado-de-Mendoza, Zhang, Jiang, Drago & Sheppard, 2018), and a cancer patient's caregivers' online communication channel (Namkoong et al., 2012).

In contrast with structured interviews designed by healthcare professionals, analyzing online content spontaneously generated by caregivers is an ideal way to observe their behaviors and may add a missing piece to the caregiving scholarship. Roffeei et al. (2015) employ a deductive content-analysis approach (human coding) to examine 3,637 messages from an autism caregivers' support group on Facebook, which helped these healthcare professionals to understand the wide array of challenges that patients or family caregivers face and shed light on how online social support for parents and/or caregivers may be improved. Namkoong et al. (2012) demonstrate that online support groups for cancer caregivers had positive effects on cancer caregivers' appraisal and coping strategies. More recent reviews of caregivers of cancer patients have been documented in Ferell & Wittenberg (2017) and Frambes, et al. (2018).

Dutta & Feng (2007) detail the benefits of online communities for caregivers, arguing that online communication is more flexible in terms of time and location than offline interactions. Moreover, the potential preservation of anonymity in online communication may be preferred to meeting in person, along with hyper-personal communication (Walther, 1996) and less pressured "weak tie" support. Weak tie support means that the relationships exist outside the typical close, strong, and dynamic family relationships. Studies have also found that, because the support offered by weak ties provided anonymity and objectivity, which do not exist in close personal relationships, it presented a helpful alternative option for social support (Adelman, Parks & Albrecht, 1987; Wellman & Gulia, 1999).

As observed by Glueckauf & Loomis (2003) and Boots, de Vugt, van Knippenberg, Kempen & Verhey (2014), online support can diplomatically meet the unique needs of the often-stressed dementia caregivers. Pagán-Ortiz, Cortés, Rudloff, Weitzman & Levkoff (2014) note that dementia caregivers reported a higher level of mastery and lower level of depression with the use of online support community. McKechnie, Barker & Stott (2014) conclude from a pre-post cohort survey on the impact of a UK-based online support forum for caregivers of dementia patients that many caregivers reported significant improvement in the quality of the patient–caregiver relationship.

Meanwhile, as Basit (2003) and many other researchers have pointed out, it is always a difficult choice between manual and electronic coding methods for such qualitative studies, depending on the size of the dataset and the inclination or background of investigators. Human manual coding, among one of the most classic and widely recognized coding methods, has clear disadvantages. Roffeei et al. (2015), for example, point to inconsistencies arising from using human manual coding approaches in textual analysis. When these authors use two inter-coders to code the data into themes,

the initial percent of agreement was only no more than forty-six percent (45.7%). When dealing with excessive amounts of data, manual coding can frequently be cognitively taxing for human coders. First, human brains have the subjective aspect when reading or coding textual analysis; second, the cognitive exercise can develop into mental fatigue, resulting in inaccurate judgment or inconsistency. Hundreds of, or thousands of, text messages are *de facto* not large for the current big data era but quite extensive for human coders. It is therefore difficult, sometimes inappropriate, for human coders to read a large number of textual documents and maintain a higher level of attention, especially for them to maintain a consistent level of evaluation standard so as to analyze, code, and categorize the topics or contents precisely.

Among the evolving electronic coding methods, text-mining is an innovative technique that has received much attention in content analysis. It is particularly useful when the scope of data is beyond what the human brain can process. Many studies have successfully applied text-mining techniques to textual content analysis, for example, mining an online health forum (Himmel, Reincke & Michelmann, 2009; Huh, Yetisgen-Yildiz & Pratt, 2013), mining nursing narratives in intensive care units (Moss, Andison & Sobko, 2007), and mining online doctor reviews (Hao & Zhang, 2016; Hao, Zhang, Wang & Gao, 2017). Consequently, a statistical text-mining technique, assisted with software and computer applications, is deployed in the present study to perform the theme analysis in organizing and separating out the content of the online health forum for dementia caregivers.

3. METHODS

3.1 Topic Modeling

Topic modeling (TM), a mature text-mining technique, is applied to explore what topics AD caregivers have been discussing and/or sharing in an online support group. TM is a statistical method used to uncover underlying abstract topics from a large collection of documents (a document can be a textual post or message, and/or any textual record) based on the frequency of the words appearing together (Blei, Ng & Jordan, 2003; Brody & Elhadad, 2010). For example, if many documents contain related words such as "old," "aging," "lose memory," "forgot," "Alzheimer's disease," and more, with those words frequently appearing together, then text-mining algorithms can effectively group those documents under one topic on the basis of statistical power, very likely, "dementia." Conversely, if a number of textual documents is all about "nursing homes," then we would expect that "care," "father," "mother," and other closely related words (e.g., "assisted living") would co-appear with a higher probability. Again, based on the related keywords, the researchers' analytics will determine the topic label, or the identified theme of a topic, that is, "nursing home."

In the present study, one of the key challenges is text-mining Chinese, which does not have clear word boundaries. We therefore have to develop our own TM program using Python 3.5. Aside from the basic Python libraries, we have also to employ several specialized Python libraries, including NLTK, Jieba, and lda.

NLTK was used for basic data cleaning such as removing stop words. A Chinese stop word list was adopted from https://www.ranks.nl/stopwords/chinese-stopwords. Jieba is a specialized Python library for Chinese word segmentation and has been demonstrated for a good performance (Miao, Zhang, Jin & Wu, 2018; Pang, Niu, Liu, Xiang & Wang, 2018; Huiqin & Weiguo, 2018). After data cleaning, Python lda library is then applied for TM. A number of algorithms can be used in the statistical text-mining process to extract the patterns of words from a large amount of textual material, such as latent semantic analysis (LSA), probabilistic latent semantic analysis (pLSA), and the latent Dirichlet allocation (LDA) method. Among all three, LDA generally performs the best. LSA generates topics from singular value decomposition (SVD), which is usually less advantaged compared with probabilistic models (e.g., pLSA and LDA). LDA uses a Dirichlet prior to improve the generalizability of the two distributions and, therefore, yields better performance than pLSA on

producing document-topic distributions. Accordingly, we use LDA for our TM analysis. This method has also been widely used in natural language (NL) processing in multiple disciplinary domains, including health care (Brody & Elhadad, 2010; Hao & Zhang, 2016; Hao, et al., 2017). Blei et al. (2003) offer more technical details of this text-mining approach.

The result of a text-mining algorithm is that a number of keywords associated with each topic (group) and each textual document will have an array of probability distributions for each topic that the document would belong to, for example, a post could have a probability distribution such as the following: 0.15 probability belong to Topic 1 (group 1), 0.2 to Topic 2, 0.001 to Topic 3, 0.5 to Topic 4, and so forth. Analytically speaking, we consider and likely would classify a textual document as belonging to the topic that has yielded the highest probability association.

3.2 Data

This study examines what AD caregivers have shared among themselves about patient care when online support is being deployed. All of the online textual posts are acquired directly from the organizer of an online community named "loveandhelp," an online health support group for AD caregivers on Sina Weibo (https://www.weibo.com/login.php), a Chinese social media platform. Sina Weibo is one of the most widely used microblog websites in China (King, Pan & Roberts, 2013), and open to any individuals or organizations.

Textual posts of the AD caregivers' forum from Sina Weibo (the AD forum) were actively tracked for a period ranging from August 2010 to July 2014, more simply, for forty-eight (48) months. A total of 12,267 posts shared by 381 users were examined, and the maximum number of posts contributed by an individual user (i.e., the key organizer of the group) is 1,742. The second-highest number of posts, contributed by a regular user, was 1,513. Overall, the median number of posts contributed by an individual user rounded to three (3). Among them, ninety (90) users posted more than 10 posts, whereas twenty-seven (27) users posted over 100 posts over the study period. Also, given that a forum manager regularly oversaw the order of the forum, we assumed all postings tracked came from caregivers of AD patients with no random online advertisements from random Internet users. The authors realize that many users did not post a lot of messages on this forum; nonetheless, our study focus is not on individual user's post contents, but the bigger picture of the forum; hence, the total amount of messages is emphasized for the present study, not the average message per user.

The final sample included 12,255 posts for the present text-mining study. As shown in **Table 1**, there are 3,487 original posts and 8,767 posts in reply to original posts. The number of Chinese characters for each post ranges from one to a maximum of 521 characters. The median length computes to 143 characters, and the average length is 183. Among original posts, the maximum number of characters is 521, the median is 292, and the mean is 262. Among the reply posts, the maximum is 472, the median is 120, and the mean is 151. That reply posts outnumber the original posts indicates that users of the forum are active participants. Once a new post is up, multiple replies followed. Broadly, original posts are typically longer than the reply posts.

4. RESULTS

But, the present study uses text-mining techniques to categorize the textual posts from the AD forum, which is based on the objective statistical text-mining result, which is among the contributions that the present study brings into the field, using cutting-edge text-mining techniques to analyze online health communication topics.

We applied a customized TM Python program to explore the topics of those narrative posts from the AD forum with various prior parameter settings, including, say, five (5) topics, seven (7) topics, ten (10) topics, and twelve (12) topics. Relatively consistent results were found corresponding to the different parameter settings. Thus, we chose seven (7) topics as the TM result for analysis, as shown in **Table 2**.

Table 1. Descriptive statistics of all posts

	Total # of Posts	Descriptive Statistics of the Length of the Posts in Chinese Characters			
		Min	Median	Mean	Max
Original posts	3,487	1	292	262	521
Reply posts	8,768	23	120	151	472
All posts	12,255	1	143	183	521

As shown in **Table 2**, Topic 1 and Topic 2 are about caring for parents. This suggests that most forum users are adult children of AD patients. However, the two topics on caring for parents appear to be coming from different perspectives. In Topic 1, the most frequent keywords that caregivers used are about *Mom* and *Dad*. Topic 2's keywords not only mentioned *Mom* but also *disease* and *love*, another aspect of caring for parents, but more sentimental and/or emotional.

Topics 4 and 7 are about caregivers' communication with each other, indicating that in the AD forum, caregivers not only cared for their family members with AD but also needed support from their peers who had experienced a similar caring journey, comparable stress, and resonating needs. Topic 4 highlights on the AD forum users, talking about themselves, whereas Topic 7 offers a few frequent users' net names directly, all of which suggests these users are communicating with each other.

Topic 3 focuses particularly on AD research advances, including news, Internet links, and research developments worldwide, with or without source information. Topic 5 discusses how to care for an AD patient; here, "*medicine*" and "*Mom*" are frequent keywords. Another keyword, "*reply*," also indicates that many posts are replying to other posts, which reflects the continuing discussion and support perspectives of the AD forum.

Finally, Topic 6 is about looking for persons with dementia who get lost, with frequent keywords on *senior*, *senior care*, *address*, and the like. Not surprisingly, Topic 6 is another focal topic among AD caregivers as AD patients experience memory loss and easily forget essential information about themselves, for example, they are more likely to get lost by forgetting their current address and family contacts and often end up wandering.

Table 3 samples the postings relevant to the different topics (Topic 1 through 7), based on the highest or higher probabilities for topics that each online post belongs to, allowing readers to visualize the real scenarios for our abstracted topics.

Table 2. Topic Modeling (TM) Results

No.	Top 10 Keywords of Each Topic	Topic Theme
# 1	old mom,[1] say, mom, old dad,[2] want, good, self, will, now, walk	Caring for parents
# 2	we, mom, life, self, they, say, toward, disease, love, able	Caring for parents
# 3	Alzheimer's disease, patients, treatment, study, disorder, in, toward, will, dementia	AD research
# 4	care, we, self, attention, want, dementia, toward, well, person, will	Communication
# 5	Take (medicine), reply, now, well, mommy, want, no, medicine, can, mom	How to care
# 6	Senior, senior care, month, address, original post, senior dementia, day, Weibo, please, year	Getting lost
# 7	reply, Bantou,[3] ah, good, thanks, Huoluo,[4] yard, Sanman,[4] old, month	Communication

Note. 1 & 2: "old mom" and "old dad" are oral expressions in Chinese for a person's own mom or dad. They express a mixed feeling of intimacy, respect, and close relationship.

3, 4 & 5: "Bantou," "Huoluo," and "Sanman" are net names of this online group's members.

Table 3. Selected sample posts from each topic

	Post #	Post Content
Topic 1	5701	Lunch time today, Old Mom almost lost her temper again. I asked her to take the afternoon nap, she said no. Then I said I will take a nap. I was a little afraid of her; hence, I hid all the scissors, etc., in case she stabs me when I am sleeping. When she saw I went to bed for nap, she went to bed, too. Once she lied down, she started to snore immediately.
	9907	Don't know why, Old Dad doesn't trust me and always thinks that I want to do bad to him. I ask him to eat, to wash, he always replies with angry, "My life is just a life, so what?" I cannot communicate with him.
	10224	11 pm. Old Dad suddenly sat up, repeated saying so sleepy, have to finish this. When I asked him, what is this? He could not answer clearly. When he saw I could not understand, he became impatient and angry and lost his temper. Old Dad was a poor thing. He could not express himself clearly. I cannot guess what he wants to say, worried and nothing can help.
Topic 2	1529	Under Dad's careful caring, with the help of a house maid, mom has gotten better. Her thought sometimes confused, sometimes clear. Mom cannot leave Dad for a second, but sometimes, she didn't know who is Dad, still holding Dad's hands tightly!
	4460	I don't like to hear others saying, "old fool." They just forgot something, but they never forgot the love to their children, to their partner.
	3227	Perhaps, the deeper motivation is, I imagine, depending on the last feeling … let Old Mom feel she is being loved. When she leaves this world, still feels the warmth, not the cold, then, what she leaves us, even not a smile, but a peaceful face, then that also will comfort us and bless us.
Topic 3	390	#Research development# A new research in Japan showed, a gene named "KLC1E" may be related to Alzheimer's disease….
	4958	[PNAS: a major breakthrough of Alzheimer's disease] Researchers have discovered a way to stimulate the brain's natural defense mechanisms in those with Alzheimer's disease. This major breakthrough opens the door to the development of a treatment for Alzheimer's disease and a vaccine to prevent the illness.
	9701	Dementia is an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities, and the process is irreversible. It includes Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies.
Topic 4	10739	DadMomTMC: Reply @Zhuangdebixiafeixiao: I believe we all take care of our parents by different ways, speak up at this platform, encourage ourselves, also can help others take care of their own parents, take others' good suggestions, then to take care of our parents is just like to take care of our children. We have a hope, then we will have a hope of a happy life!
	12211	HelpandLove_care_dementia: According to your opinion, what is the best way to enhance public education?//@ GreenPineCareElderly: Enhance public education and support the care givers can be the first step.
	5927	Huolanbantou: Sometimes, we all make a mistake such as "over care." We always think, to take care a little more should be better than to take a little less. Of course, it is difficult to draw the line.
Topic 7	10042	Huoluobantou: Reply@Sunshineyard: Thank you for the encouragement and care from an older sister.
	10059	PlayandSinging: Same happiness and same pleasantness! Wish our seniors Happy Chongyang Day! Also wish Aunt @ Sunshining-yard a happy holiday!
	10044	Huoluo Bantou: Reply@MyshadowMymom: Thank you for the encouragement; you are so kind.
Topic 5	1654	Zinuo Mommy: We also continue taking fruit flavored oligos; every morning one spoon before eating. The effect is good! Continuing
	7743	AD Carer: Does your patient feel better after taking Rivastigmine? How long do you have to take it? My patient has taken it for almost half year, no effect and the cognitive ability even decreases.
	1379	Sufeicat_6295: Unstable walking; it might be related to taking sleeping medicine. Sleeping pills can decrease muscle strength; thus, people cannot walk steadily.
Topic 6	11258	#Missing Person# @LiuErQi: Got lost at Lotus Park, Lotus Er Village, around 1 pm, Sept. 5th, female, about 50 years old, 163 cm tall, wearing long hair, unclear mind, mild dementia. Wearing flower-patterned cloth, black capris, speaks with nonlocal accent, very stiff back when walking, particularly the stiff neck. Please contact Ms. Hong 189XXXXX, Mr. Hu 186XXXX. Very appreciate.
	11413	#Missing Person# @customized to my season: Because of dementia, the person got lost on Jul. 25 at Liuchang. Male, 166 cm tall, blue jacket or white shirt, leisure black with yellow side stripped pants, white with yellow lined sneakers. Please contact me if you have any information. Ten thousand Yuan prize for finding this person. Phone: 158XXXXXXX or call 110. Aug. 17, he was seen at Ranghulu store.
	11747	#Missing Person# @Pingan Tianshui: Chen Bingxing, from Taizhou Wenling, dementia, got lost on Jul. 6, 2011 at 261, Stadium Road, Shimao Junting Hotel, Hangzhou. Please contact Mr. Chen, 0139XXXXXXX, or contact me 0571-851XXXXXX. Please forward this message.

Conventional textual data analysis uses a manual coding system to study the content for social support, such as the Cutrona-Suhr (1992) social support behavior code (SSBC) model. The SSBC model includes five categories: informational support; esteem support; network support; tangible support; and emotional support, which all depends on the subjective judgement by manual coder. Inspiringly, our text mining results based on automatic topic modeling program show similar major categories.

Providing emotional support seems to be essential in online and offline support groups. On the basis of the SSBC model, Atwood, Friedman, Meisner & Cassin (2018) deduce that the majority (90%) of online messages from a bariatric surgery online support group are emotional and informational, either before and/or after surgery. Davis, Anthony & Pauls (2015) examine online social support for surgery by measuring keywords in Facebook posts, and their results show that online emotional support is associated with keywords related to surgery, but they did not examined the actual content of those Facebook posts. A qualitative analysis of a Facebook support group for diabetes patients conducted by Greene et al. (2011) uncovers that almost 29% of posts are related to emotional support. Coulson, Buchanan & Aubeeluck (2007) discover that about 52% of online group postings are based on emotional support after studying an online group bulletin board for Huntington's disease. Roffeei et al. (2015) report that about 28% of online posts of a Facebook group for caregivers are based on emotional support. As for the online posts for the AD forum being studied here, we can see that the posts in Topic 4 and Topic 7 are linked closely to emotional support.

Aside from emotional support, informational support is another key activity of online support groups. Coulson et al. (2007), for example, argue that the most frequent support categories are based on informational support (56%), whereas Roffeei et al. (2015) report that informational-based posts accounted for 31% of their study posts. Similarly, in the present study, our text-mining result shows that one of the key topics uncovered, Topic 3, is on informational support.

Except for the present study, most, if not all, of the aforementioned studies have relied on manual counting or manual coding for categorizing online textual posts. In contrast, the present study utilizes a statistical method to text mine more than 12,000 textual posts from an online support group, and it reveals the seven (7) major topics to taxonomize those 12,000 posts examined. Qualitatively analysis of the typical posts from each of the seven (7) topics will now be discussed in greater details.

4.1 Topics on Caring

Posts under Topics 1 and 2 are based largely on taking care of parents. For instance, Post #5701 in **Table 3** describes the caregiver's mother's behavior and daily activities. The paragraph tells us many things. First, the mother is a patient who is difficult to deal with, just like many AD patients. Second, the adult child, who is the caregiver, has been patient with her poor-tempered mother. When she asks her mother to take a nap, she is cautious about her mother's intentions, fearing that her mother may act dangerously due to her dementia. Thus, this female adult child is both protective and acting preventively, while waiting for her mom to fall asleep first.

Post #9907 recounts the caregiver's father's behavior and conversation: "Don't know why, Old Dad doesn't trust me and always thinks that I want to do bad thing to him. I ask him to eat, to wash, he always replies angrily, 'This is just a life, so what?' I cannot communicate with him." This post provides a prime example of the frustration experienced by an adult child caring for a parent suffering from AD, that is, a parent who exhibits the emotional behavioral problems associated with AD that makes it so frustrating for family caregivers.

Post #10224 reflects similar stories; for example, as AD parents become impatient, confused, and depressed when they could not express themselves well, the adult children often could not effectively intervene. On reflecting upon these postings, we can more or less see and feel just how painful, stressful and hopeless these family caregivers must have felt should they be challenged beyond their abilities to care for their AD parents.

Topic 2 is also about caring for AD-affected parents, but the content of these posts is more about their emotional responses to their parents' AD situation rather than focusing on their parents' daily activities. Post #4460, for instance, reads: "I don't like to hear others saying, 'old fool.' They just forgot something, but they never forgot the love of their children, or their partner." Specifically, this post expresses the post owner's strong love for his or her parents. In Chinese, a layperson's label for AD is "old fool disease." This adage foreshadows a biased but common response against patients with AD. Post #3227 is more sentimental and expresses the post owner's deeply caring attitude; it reads: "Perhaps, the deeper motivation is, I imagine, depending on the last feeling about the world … let my Old Mom feel that she is being loved. When she leaves this world, still feels the warmth, not the cold, then, what she leaves to us, even not a smile, but a peaceful face, then that also will comfort us and bless us." In the Chinese culture, "Old Mom" or "Old Dad" is sort of an intimate or lighthearted way to address one's parents.

A survey infers that most AD caregivers in the US are adult children of AD patients (Alzheimer's Association and National Alliance for Caregiving, 2004). Given that the average age of care recipients is 78 as deduced from the data, it is easy to speculate that the caregivers of those care recipients might not be the spouses of AD patients being similarly aging because the similar age spouses would not be able to provide the level of care needed by AD patients. Moreover, while the present study data are extracted solely from Chinese online forums, the situation is likely similar for most other countries that the majority caregivers are adult children of the patients. Indeed, even without looking at the data, we would expect the majority of the AD forum users to be adult children of Chinese AD patients, not the patients' spouses. Also, another reason is that most elderly Chinese have not mastered the Pinyin Romanization system, which currently is the most widely used Chinese computer input system. Notably, this Chinese Pinyin system for Chinese language has been developed in the late 1950s; yet its popularity among users evolves over a much longer period of time. Conceivably, people who had their primary education earlier than the Pinyin system typically would have difficulty typing Chinese into computers, let alone use an online forum. This is another reason that why the majority of users of the AD caregiver forum tended to be adult children, and not the spouses of AD patients.

4.2 Topics on Information Support

Most of the postings on Topic 3 are about AD research news globally. This emphasizes that new developments are gaining the caregivers' attention in online forum discussions. As the selected posts show, many members of the forum quoted new studies or recent research on dementia worldwide, for example, Post #390. In Post #390, the tag label of "research development," a brief summary of the new development, and the Internet web link of the news source are noted. Post #9701 is not about new developments but the established scientific understanding of AD. Post #9701 obviously copies knowledge directly from an AD-related website. The purpose is to help AD forum readers and users understand what AD is and how AD relates to a broader category of dementia.

In many instances, family members and/or informal caregivers need and want to understand the disease that they are dealing with; as such, users of the AD caregiver forum have shown an eagerness to share what they have learned. In China, it is likely that most people do not know much about AD until their family members are inflicted with the disease. That people seem truly eager to learn and to share knowledge about the disease is a sign of the importance of feeling supported or supporting others through information provided within an online community ecosystem, which helps to sustain caregivers and give them hope. In 2013, Robillard et al. study on dementia-related tweets. Their finding unveils that the majority of tweets on dementia or AD contains links related to health information sites and that most tweets are about recent research findings. This finding also characterizes most, if not all, of the online health information on recent AD research developments.

4.3 Topics on Emotional Support

Topics 4 and 7 are about communications among caregivers.

Topic 4 has more online conversations and discussions among caregivers, for instance, Post #10739 replies to someone else's post or question. This individual expressed feelings about the AD caregiver forum and the benefits drawn from his/her capability to speak up and release emotions, encouraging and helping each other, and the like. The comparison with caring for one's child is important and is a way of indirectly endorsing the traditional reciprocity-centered family life in China: the cycle of caring for children and the elderly is a fundamental obligation in the Chinese moral system. Post #12211 represents a conversation between one caregiver and another: "HelpandLove_care_dementia: According to your opinion, what is the best way to enhance public education?//@GreenPineCareElderly: Enhance public education and support the caregivers can be the first step", and the discussion topic shows that the AD forum provides support for participating users to exchange ideas and ask questions that mean something to them.

Topic 7 has more posts that show the appreciation of and for caregivers, representing a way of solidarity demonstration and the importance of external support to and for each other, as in Post #10042. Post #10059 is a happy holiday post for Chongyang, which is a Chinese traditional festival for seniors. Post #10059 also expresses an appreciation of seniors.

Notwithstanding, caregivers of AD patients are often challenged with serious burdens and undue stress, including psychological, physical, and social stress. They need to take care of an elderly person who forgets important things, loses language abilities and reasoning skills, needs constant attention, and whose symptoms becomes worse and will never improve over time. Oftentimes, the frustration produced by those difficult experiences will have negative effects and consequences on caregivers. The National Study of Caregiving also found that caregivers are more likely to develop psychological pressures, social isolation, physical illness, financial hardship, and the like (National Academies of Sciences, Engineering, and Medicine, 2016). Research has already shown that psychosocial interventions can reduce caregiver burden and depression (Brodaty & Donkin, 2009). Greene et al. (2011) have argued that online participation in chronic disease groups could provide emotional support. Perhaps online communities will eventually contribute to these outcomes, or perhaps they do so already.

4.4 Topics on Medication

Topic 5 involves the discussion of medication and other treatments. Post #7743 is clearly about AD medication failure, which is, unfortunately, an evolving and abiding theme globally and represents the actual reality that no medication is effective for AD. Another post is more hopeful about a medication and/or supplement's effect: Post #1654 is specific enough for others to try the noted treatment.

Both of the aforementioned posts reveal that caregivers trust the online support group and conduct exchanges on treatment and other practical problems, such as those on medication use and effects. Indeed, details about individual treatments may also be found in certain postings.

4.5 Topics on Missing Persons

One of the most common concerns for many AD family caregivers is dealing with a wandering patient. Topic 6 is about missing persons, and most of its posts are copied from missing person's flyers, such as Post #11258. Sadly, Post #11258 gives a detailed level of the lost person's information, including her mild dementia. It includes where and when the person may have gotten lost, along with gender, age, height, hair, clothing, speaking accent, and gait, which are crucial characterization for finding a missing person. The intent here is to recruit others in search of the missing individual (see also Post #11747).

Wandering and becoming lost are common but dreaded experiences among AD patients and their families, as AD patients suffer from memory loss and forget their home address, past experiences, and names of family members, all of which is quite characteristic of and specialized to dementia patients and their caregivers.

Unlike caregivers of patients with other chronic diseases, such as diabetes, cancer, or depression, AD caregivers must occasionally deal with their loved ones getting lost and/or having wandered away as one of the most painful experiences. Here, they may post their lost family member's information, or they may share other missing dementia patients' flyers from the Internet out of emotional sympathy and moral solidarity. Reading these posts is upsetting even for researchers, suggesting that the posts need not contain emotional language to have emotional effects.

5. DISCUSSION AND CONCLUSION

The online health community, as represented via the AD caregiver forum in the present study, offers a platform that has become increasingly accessible and available to patients, providers, and caregivers. In particular, family members and informal AD caregivers need to support their patients 24/7, thus they want to be able to communicate more conveniently, effectively, and affordably; and they can now do so via online support or discussion mechanisms. In this section, we close the discussion with a summary of the practical significance and benefits of the AD caregiver forum, overview the limitations faced by the current study, and highlight some directions for potential future research.

5.1 Practical Significance & Benefits

As a solution to address the question given at the forefront of this discussion: *How do we support ADRD caregivers?* - the use of the AD caregiver forum appears to be of practical significance in benefiting and supporting AD caregivers, especially family members and informal caregivers. First, the AD forum has no spatial or temporal constraints. In other words, it is flexible for caregivers' unrestricted access, which is particularly critical for AD caregivers who are physically tied to their care recipients at home, thus finding it difficult to communicate, share information, or seek emotional support.

Second, almost no extra cost is involved because the Internet is a widely used infrastructure for most, if not all, families in developed and many developing countries, including China. Third, online support groups also provide a certain level of privacy as caregivers can log onto the system anonymously to share their healthcare concerns and personal stories; in other words, a weak tie communication. Last but not the least, the impact for support from the AD forum is as effective as is communication in person (face-to-face), as evidenced in previous studies (Lewis, Hobday & Hepburn, 2010).

Several contributions to the extant literature on online support for chronic patient caring are offered by the present study. First, to the best of our knowledge, this may be the first study that uses a text-mining technique to examine the content of online support groups for AD caregivers. Our study results suggest that text-mining techniques can be applied to the AD caregiver forum as well as similar online platforms via the use of TM analytic procedures to generate reasonable results. Statistical text mining tools particularly can help analyze the huge and growing amount of online textual posts. In the current era of big data, statistical techniques can be deployed meaningfully, given that the average human brain cannot process textual information or large and/or super-large amounts of data efficiently and effectively.

Second, empirically, it is further noted that the TM results from online discussion groups for AD caregivers are quite representative and close to the reality of caregiver needs. Text mining approach can assist healthcare researchers and providers to better understand the needs of the family caregivers of AD patients, thus providing them the proper support that caregivers need, leading to better treatment for AD patients with the aging population continuing to evolve into a global phenomenon.

One potential application scenario of our text mining method is that the healthcare website which provides online health forums or online health support services can develop a text mining product which takes their own website or other health websites' historical textual posts to perform the text mining analysis, such as TM analysis, then outputs the meaningful topics. In this way, the healthcare providers and/or researchers can have a good understanding of what specific topics that the forum

has covered or the caregivers or patients have discussed online, without reading thousands or millions historical textual posts. These researchers and/or providers can then learn from other patients or caregivers' past experiences on a specific chronic disease domain so as to be helpful in extending their research as well as providing better support.

Finally, the text-mining results can also directly help AD caregivers to explore what an online forum can provide to them. They can search more efficiently for answers via different websites about their needs, as these online discussions continue to grow. Similar, as the online health forum is open and free on the Internet, caregivers themselves can browse the topics of online forums that have been previously shared by other caregivers to learn if those topics would be useful or interesting to them. To this end, the present study also provides empirical findings of the situations of AD caregivers in China, showing that many adult children are taking care of their AD parents and are actively using online forum support. Just like caregivers in other countries, caregivers in China want to express their feelings, share informational posts, and yearn for mutual support.

Altogether, text-mining is a practical tool that can benefit family members and informal caregivers, healthcare researchers, and professional healthcare providers by assisting all parties to communicate effectively with each other, utilizing online information that is available and accessible in the most efficient manner.

5.2 Limitations

The present study has limitations.

First, our online support group textual data set is still a relatively small dataset, with only about 12,000 posts by a few hundred users. Also, the dataset may contain a self-selection bias by its very nature. Put simply, the content of the current dataset may not reflect the entire reality of all caregivers' online discussions.

Second, also due to the smaller size of the data, the text-mining technique, which is based on statistical power, might also be biased, albeit not significantly. The statistical power of text-mining is that it can be used to deal with a large amount of textual data, beyond an average human brain's processing capability. Therefore, only when a textual dataset is large can the advantage of text-mining become clearly significant. Notwithstanding, we are glad to see that even with the current dataset being not very large, the text-mining results made sense. Thus, we predict that when larger textual posts are available, our text-mining method can and will perform more powerful analysis, thereby providing more practical implications for online support.

Finally, the present research only examines the topics of the online support group's textual posts. We did not conduct a sentiment analysis of emotional content, which could be more interesting and valuable for a healthcare study as sentiment analysis can use NL processing to determine the writer's attitude or to classify the polarity of a given text to be positive, negative, or neutral or more advanced emotional states, such as "angry," "sad," and "happy." In light of this, the future direction of analyzing a large amount of textual document studies should utilize more text-mining techniques, such as sentiment analysis, to deepen the understanding of the online discussions among caregivers and thereby contribute to the science and service sides of care.

5.3 Future Research

Several venues come to mind to pursue future research in this interesting domain.

First, researchers could collect more textual data from online health support forums, either similar for AD caregivers as for caregivers of other patients, and apply TM technique to the posts to see what other topics could be extracted from those posts.

Second, within each TM result, we may apply sentimental analysis to those textual posts to see what further information may be acquired. Such efforts can lead to an entire series of new research directions for online community participation and sharing on patient care decisions.

Third, text-mining techniques are a major and fast developing method for big data research, which should be applied to more healthcare related research when we have more and more electronic medical records (EMRs) applied in healthcare with increasing amount of online health activity data available.

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