# Complementary and alternative medicine in an online support group for people with Alzheimer's disease

Sean N. Halpin MA[a],*, Kathleen Len BS[b]

[a]Department of Lifelong, Administration, and Policy, University of Georgia, Athens, GA, USA; [b]Department of Molecular, Cell, and Developmental Biology, University of California Los Angeles, Los Angeles, CA, USA; *Corresponding author: sean.halpin@uga.edu

## Abstract

**Background:** People with Alzheimer's disease (AD) and related dementias (ADRD) often use complementary and alternative medicine (CAM) without oversight from attending clinicians—leading to possible negative health consequences, such as polypharmacy. While there is evidence these individuals seek online health advice from others with ADRD, little is known about how online discussion boards support health-seeking behavior among this population.
**Objective**: The aim of the current study was to investigate how an online discussion board is utilized by people with ADRD ("*Contributors*"), to discuss CAM health treatments.
**Methods**: This descriptive study adopted a thematic analysis approach that was applied to data sourced from online discussion boards for people with ADRD.
**Results**: Contributors often referred to "*best practices*" and emphasized exercise and a special diet to complement the treatments they were prescribed by their treating clinician. CAM was also discussed addressing both physical and emotional concerns along with side effects of prescribed medications. Contributors referred to a variety of sources regarding evidence for treatments including referring to authorities (i.e., published research, websites or news, clinicians' recommendations) and asking their cohort for a second opinion based on the cohort's own experiences.
**Conclusions**: Understanding how people with ADRD talk about CAM is important for guiding treatment decision making, particularly when health decisions are made without clinical oversight. This study highlights the variety of methods people with ADRD discuss CAM in an online support group.

**Keywords:** Dementia, evidence, health-seeking behavior, online communication, symptom management

## INTRODUCTION

Alzheimer's disease (AD) is a progressive and irreversible type of dementia characterized by declines in cognitive and physical abilities. An estimated 5.7 million Americans have a diagnosis of AD, and 16 million family members and other unpaid caregivers provide care for these individuals (Alzheimer's Association, 2018). While AD is the sixth leading cause of death in the United States, it is the only condition in the top ten causes of mortality with no means of prevention or cure (Xu, Kochanek, Murphy, & Tejada-Vera, 2016).

There are currently five medications approved by the U.S. Food and Drug Administration (FDA) three cholinesterase inhibitors (donepezil, galantamine, and rivastigmine); a NMDA receptor antagonist (memantine), and a combination drug of memantine and donepezil (Namzaric) to help decrease the cognitive symptoms of AD (Alzheimer's Association—2019b). Unfortunately, the ef-

fectiveness of these medications is time-limited, only approved for specific stages of the disease, and not approved for mild cognitive impairment. Additionally, these medications have a high likelihood of producing undesirable side effects that may even run counter to their intended purpose. Aricept, for example, can result in nausea, vomiting, and loss of appetite, all of which, in turn, can affect a person's cognitive ability. Similarly, Namenda, another commonly prescribed medication, can result in confusion. In addition to the limited efficacy and side effects of these medications, there is controversy surrounding whether the statistical significance supporting these medications from previous clinical trials truly translates into clinically meaningful results for patients (Casey, Antimisiaris, & O'Brien, 2010). Given the complications associated with medications directed at AD, many patients seek out other treatments to either replace or augment their results, termed complementary and alternative medicine (CAM) (Dhikav & Anand, 2012).

CAM is "*a group of diverse medical and health care practices and products that are not presently considered to be part of conventional medicine*" (U.S. National Library of Medicine, 2018). These treatments are typically not FDA-approved to treat AD. Modalities of CAM can range from ingestible (e.g., herbs/herbal medicine, homeopathy, special diet, St. John's Wort, vitamins/minerals), physical (e.g., acupuncture/acupressure, chiropractic, exercise, massage), and psychological (e.g., imagery, meditation/prayer/spiritual healing, relaxation/breathing exercises, self-help), each with various purposes and each with varying amount of evidence supporting their efficacy in persons living with AD.

A large amount of evidence exists for the benefits of aerobic exercise on brain connectivity (Morris et al., 2017; Perea, Vidoni, Graves, Burns, & Honea, 2015; Yu, Vock, & Barclay, 2018), while less evidence exists for most other treatments (Alzheimer's Association, 2019a). The varying amount of evidence for CAM can be concerning regarding efficacy, safety, particularly for ingestible types of CAM that are regulated as food rather than drugs (Dietary Supplement Health and Education Act of 1994), and possible contraindications (i.e., negative interactions with other medications taken for AD or other conditions).

Worries over increased pharmacological burden and the risk of polypharmacy-related drug interactions is particularly concerning since CAM is oftentimes pursued independent of and unbeknownst to their clinical provider (Halpin et al., 2018; Halpin, Huang, & Perkins, 2014; Halpin, Potapragada, Bergquist, & Jarrett, 2020). Moreover, some patients may view CAM as a replacement to conventional medicine and as a result, forgo traditional medical treatment from their provider altogether.

Despite the significant number of individuals impacted by the disease, persons with AD are often socially isolated due to widespread stigmatization and avoidance by the general public (Batsch & Mittelman, 2012). Organized opportunities for socialization, such as support groups, may help alleviate this social isolation and provide opportunities for exchanging information about healthcare challenges and treatments (Halpin, 2018; Toms, Clare, Nixon, & Quinn, 2015). Yet, in-person support groups are often not feasible, especially for individuals with limited transportation options and a lack of available resources.

Online support groups have been identified as an effective means of communication to share common interests and experiences and provide support among difficult to reach populations (Rodriquez, 2013; White & Dorman, 2001). A 2014, national survey conducted by the Pew Research Center found that 72% of adults had searched online for information about health issues, with 16% having searched the internet for information from others who share a health concern (Pew Research, 2014). Online formats are especially endorsed by those with early-stage AD, and particularly those who are comfortable using a computer (Rodriquez, 2013). These groups are usually text-only discussion boards where participants can choose a username to identify themselves. People with ADRD and those with other chronic health conditions, tend to use online support groups for emotional support rather than a technical or clinical resource (Deetjen & Powell, 2016). Yet there is some evidence that participants in these online communities share knowledge and information about treatment options.

In one study using 354 posts by 32 members of an online discussion board for people with dementia, participants created a disease narrative in the online discussion board around their experience with AD (Rodriquez, 2013). Participants in this study used the discussion board to ask for and give general advice (i.e., clinical information), and offer encouragement (i.e., emotional support). In this way, the sharing and collecting of disease-centered information likely provide opportunities for people with AD to feel a sense of control over their disease (Czaja, 2015). As such, online-based communication such as blogs can also have an overall positive effect on increasing general communication and coping behaviors, termed "*cybercoping*" (Kim & Lee, 2014). Indeed, increased self-efficacy or the belief one can achieve a particular goal, coupled with the coping strategies necessary to achieve those goals have been identified as important for staving off negative emotions in persons with AD and other types of cognitive impairment (Halpin, Dillard, & Puentes, 2016; Halpin et al., 2020). Furthermore, some evidence exists that individuals with AD perceive the information provided by peers (i.e., other people with AD) in these online groups to be high quality (High & Solomon, 2011). While it is clear that people with AD do seek out treatment-related information in online support groups, the type of information, and how it is accessed and discussed remains relatively unexplored. It is especially critical to examine what types of treatments are discussed and the evidence to support these treatments as it relates to CAM, to identify the potential for misleading patient's healthcare decision making and how online platforms and clinicians alike can supplement and support online learning environments.

## METHODOLOGY AND RESEARCH DESIGN
### Context of the study
Hosted by a large non-profit organization focused on AD, the message board used for the current study is an open access online community for people impacted by AD both domestically and internationally. Individuals must register using a pseudonym to use the website, but the content can be viewed by non-registered persons. There are two message boards offered, one for people with Alzheimer's disease and related dementias (ADRD) and a second one for caregivers. Publicly available information (e.g., members' posts and responses) from the message board specifically for people with ADRD (not caregivers) was used for the current study. This message board is located online and referred to under the support group options available on the non-profit's main website. Participants are encouraged to start their discussion threads on whatever topic they choose and to contribute to other members' threads by posting responses. Responses are moderated by one or more individuals associated with the non-profit and protected under the terms and conditions.

### Ethical appendix
The possible risks to the individuals who post in the online message board used in the current study (contributors) include the possibility that contributors may not want their posts used in a research study, even though they are posting in an online discussion board. Meanwhile, the benefits of the study include a better understanding of how people affected by ADRD communicate about health treatments in an online support group. This is an important topic, particularly when there are no FDA-approved cures for the diseases and because ADRD patients often do not discuss -CAM treatments with their clinicians. Moreover, alternative treatments may create an increased risk of complications, including polypharmacy due to the use of multiple medications and supplements simultaneously.

Several steps were taken to ensure the data used in this study were handled in an ethical manner. The authors reviewed the non-profit's online Terms and Conditions prior to downloading any data in May 2018. The Terms and Conditions indicated that "*the 'non-profit' retains copyright on the content of the 'non-profit' site unless otherwise noted*". Language indicated anyone who wants to reprint or reuse the information from the website without a change must contact the non-profit's copyright department. This provided more protection of posted content compared to social media where online users face a risk that their posted information can be shared with others without their knowledge.

The first author contacted this copyright department to request permission to use the publicly available message board data on the 'non-profit' website. A reply email indicated it would be acceptable to use these data but any identifying information of the contributors and host site would need to be removed from any reports. Identifying information was not necessary for this study so all personal identifies were removed before analysis.

The copyright office verified that direct quotes would be permitted, which helps to ensure the integrity of the data but was asked to avoid any quotes that might include identifying information. As such, the pseudonyms used on the actual website have been changed and representative quotes have been selected to ensure no personal identifiers are present. Otherwise, the quotes used were not altered, including any spelling errors. The terms and conditions indicated that researchers may not post on the message boards. The blinded Institutional Review Board reviewed the proposed study and granted a non-research determination.

### Data extraction
*Bounding decisions and sampling decisions*
To select the data corpus, the first author downloaded all data available from the earliest posting (December 14, 2011) to the date when data were pulled (May 21, 2018). A total of 6963 posts were included across a total of 675 discussion threads. Data were pulled using the print feature available near the top right of each discussion thread which allows all text associated with that individual thread to be saved as a PDF.

Each file was saved using the date (year/month/day) of the first post in the thread. If there were multiple threads on the same date the discussion thread name was added to the file name. These PDF's were then converted to Word documents using the automatic conversation feature in Microsoft Adobe, since this file type allows for better utility and functionality in the qualitative data analysis software, NVivo 12.3. Files were reviewed to ensure no errors were made due to the conversion. Specifically, Word documents retain the same format posted online when codes are accessed in NVivo 12.3, whereas that format is lost if using the PDF version. The latter was a stylistic benefit that does not change data present in the file for NVivo analyses.

*Data analysis methods*
The authors used a qualitative thematic analysis approach to identify data on what kinds of complementary and alternative medicine (CAM) health treatments were discussed in an online discussion board for people with ADRD. The analysis followed Braun and Clarke's six steps of thematic analysis: (1) familiarizing yourself with

the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report (Braun & Clarke, 2006). Both authors proceeded with analysis through initial immersive and close reading and re-reading of the data multiple times to become familiar with the content (Braun & Clarke, 2006). Next, the researchers independently made unstructured initial notes throughout the text that were relevant to the main research question. These initial notes were then clustered into broader themes based on their similarities following an iterative process of reviewing the text and further analysis to refine the themes. Findings were reported through defined overarching themes along with representative quotes. The research team discussed the themes and reached a final consensus. Steps were taken to ensure analytical rigor and trustworthiness including a repeated and thorough examination of the data and a systematic outline of the analysis process.

## Results
### Description of the sample
A total of 294 unique usernames contributed to 675 discussion threads reviewed for the current study. Users were engaged and posting in the threads for an average of 99.5 days (Range: 3-178) with an average of six posts per thread (Range: 0-56), and an average of 5,498 (Range: 2,839-177,569) views per thread.

### Themes
Themes were sorted into overarching and subordinate themes, including (1) Referencing complementary and alternative medicine (CAM); (2) Sources of evidence for CAM; (3) Referring to authorities (clinicians, published research, websites, or news); and (4) Peer testimonials.

### Theme 1: Referencing Complementary and Alternative Medicine (CAM)
While a variety of CAM modalities were referred to regularly, they were rarely identified by a title such as alternative, complementary, or integrative medicine. Rather, a subset of highly active contributors often referred to a list of seven non-pharmacological health practices they called "*best practices*". These best practices emphasized special diet (including vitamins), physical activity, cognitive engagement, remaining social, resting, avoiding environmental hazards (e.g., air pollutants), and minimizing stress. The "*best practices*" also recommended "*take meds as directed*". While the best practices were sometimes listed out verbatim, other times they would simply be referred to as "*best practices*". The contributors who referred to best practices sometimes had an image next to their username identifying them as a peer volunteer, but this was not always present. Peer volunteers were diagnosed with AD or

another dementia and were tasked by the non-profit website with helping other users navigate the discussion board if help was needed. Other times a listing of treatment options that aligned with the best practice recommendations, without the best practice title, was applied to the posting. This was true for one user who stated, "*I think the best supplement is Cerefolin NAC. It is a brain food supplement. I find it helps me a great deal along with vitamins. all meds. Good nutrition and exercise both mental and physical. Being social helps too. This is a little harder for me but I continue to try*".

Other times contributors would provide a list of pharmacological and non-pharmacological treatments they thought were helpful. These were often unstructured lists of CAM treatments that did not express the intended purpose of use (e.g., decreasing cognitive burden). These lists highlighted ingestible types of CAM (e.g., special diet, herbal medicine) but they also included physical types of treatment such as massage. Another contributor initiated a posting with a list of CAM's.

### Theme 2: Sources of Evidence for CAM
The referenced CAM treatments were often, but not always, linked to some type of evidence. Contributors supported their claims about CAM modalities with different types of evidence including links to published research, clinician recommendations, and non-authoritative sources, such as peer testimonials. At times, users commented that the evidence shared in posts was difficult to understand due to technical language (i.e., medical terminology). This was exposed by the contributor/Poster1, who encouraged another contributor, "*Do go back and reread the posts. There may be things you overlooked at first reading*".

### Theme 3: Referring to Authorities
*Clinicians*
Participants discussed the recommendations they received from their clinicians, including their clinician's openness to discussing CAM. ContributorName123, for example, stated, "*my new memoey (sic) clinic and doctor is into alternative medicine more then my PCP is, and I like it. Always willing to try something (sic) new*". Another -contributor stated, "*Dr says diet has everything to do with vascular dementia. Cloged arteries restrict blood flow to the brain*".

*Published research*
Contributors referenced research studies published in academic journals as reliable sources for determining which treatment might be useful for people with ADRD. These references in the posts included a link to a published research study, some text describing the study, or a combination of the two. One contributor, for

example, stated, "*The best hope I've seen is a UCLA study, Reversal of cognitive decline – A novel therapeutic program (100690. It's about nutrition and metabolism*". While a website address was included, linking to the referenced study, the link was no longer active at the time of this analysis. However, another contributor, replied, "*THANK YOU for sharing the link*". In addition, the cited research was not always directly related to dementia. Another contributor, for example, posted a link to a journal article that discussed the impact of pomegranate supplementation on memory following heart surgery. Here the contributor modified the manuscript's abstract: "*I broke the Abstract into paragraphs to make it easier to read*".

*Websites or news*
In addition to linking to published research studies, participants provided links to news articles. These were sometimes accompanying journal articles, as was the case with a contributor who added a link to a news website and a published manuscript discussing the anti-inflammatory benefits of pomegranate compound on both Alzheimer's and Parkinson's disease.

## Theme 4: Peer testimonials
Contributors asked their peers for recommendations and testimonials for CAM treatments. These testimonials tended to be elicited following a recommendation by an authority, such as a clinician. This was the case for one contributor who initiated a discussion board focused on whether fish oil can improve memory. The initial post asked others about their experience with fish oil, "*At my meeting with my new memoey (sic) clinic doctor yesterday, he put me on 1000 mg a day of high Omega-3 fish oil. Said it helps improve memory. Any one elce (sic) take fish oil?*" At other times, contributors requested advice because they were unsatisfied with the advice given by their clinicians. One contributor indicated interest in recommendations from peers regarding "*vitamins or other supplements that are helpful in prolonging our healthy mental state*", since this contributor's doctor had not made any recommendations. This contributor was concerned about the validity of these categories of health treatments, "*There is a lot of 'snake oil' being peddled out there for memory*".

Importantly, while peers provided advice based on their own experience, they regularly suggested that readers consult with their physician about new treatments.

## DISCUSSION
Conversations in an online discussion board for people with Alzheimer's disease and other dementias involved reference to a variety of CAM

modalities, yet these conversations rarely referred to these treatments as CAM. Moreover, participants referred to multiple sources of evidence, some of which required the ability to sift through the academic literature, such as references to published manuscripts. People with AD and other dementias often have few social opportunities, limiting their ability to discuss treatment options (Batsch & Mittelman, 2012). Online discussion boards provide a unique opportunity for these individuals to discuss possible treatment options. It is important to understand the types of CAM being discussed and the evidence presented to help visitors to these websites evaluate whether trying the treatments discussed are worthwhile.

Increasingly, people of all ages are seeking health information from online sources (Jacobs, Amuta, & Jeon, 2017; Pew Research, 2014). Online health-seeking behaviours have the potential for either creating a divergence in information, with patients learning about and seeking treatments independent of their clinicians—or as one study found, online health-seeking behaviour can strengthen the patient-physician relationship by creating a more engaged patient experience (Tan & Goonawardene, 2017). However, a more engaged patient experience would necessitate mutual engagement by the clinician and patient. Yet to date, the type of health information sought online remains unexplored for specific populations, such as those with AD and other dementias.

Online support groups provide an opportunity to examine naturally occurring discussions to better understand the types of treatments discussed. In the current study contributors in an online discussion board for people with ADRD discussed a wide variety of CAM treatments, often with the purpose of slowing the progression of their cognitive decline. The treatments included ingestible types of CAM, such as pills meant to help improve memory along with vitamins and a special diet and other non-pharmacological methods such as increasing exercise and decreasing stress.

A variety of challenges exist for people searching for health information online, including the ability to comprehend the information being discussed (Diviani, van den Putte, Giani, & van Weert, 2015). Cognitive impairment and poor health literacy exacerbate these challenges for people diagnosed with ADRD. In the current study, contributors in an online discussion board for people with AD and other dementias often engaged with academic publications that contained complex language that requires specialized understanding. The studies were rarely converted into plain language by the contributors, and instead, the study's published abstract or a link to the original manuscript were provided.

Although the data used in this study included conversations from a discussion board meant for people with ADRD there was no way to verify that contributors themselves had a diagnosis of dementia. Similarly, several personal characteristics relevant to contributors' abilities to interact with online information were unavailable (e.g., type and stage of dementia, educational background). Nevertheless, these individuals were accessing the information presumably with the intent of learning about treatments for people with AD or other dementias.

Future studies may consider engaging directly with contributors of these types of websites to better understand their individual characteristics along with information on how they have engaged with the information they learned. Importantly, the individual contributors represent only a small portion of persons who are interacting with the material posted within these discussion boards.

Persons online are more likely to view information rather than actively contribute (Benevenuto, Rodrigues, Cha, & Almeida, 2012). While the 675 discussion boards included in the current study accounted for only 6963 individual posts, the boards had 3,711,150 views. Future studies may consider working with the web platform host to understand contributor and non-contributor statistics that go beyond the number of page views. Analytics including how long people access particular pages may be useful for better understanding of how the non-contributors are engaging with the information. Finally, future research may consider if and how CAM is talked about and discussed in comparison to conventional medicine.

## Conclusion

This study represents an initial attempt to understand how an online discussion board supports conversation around CAM and how the reported evidence used to support these treatments are being discussed in an online discussion board for people with ADRD. AD is a devastating progressive condition with few options for slowing the inevitable physical and cognitive declines. Furthermore, this population tends to be isolated and may turn to online support groups to seek out information, support, and potential health treatments, such as CAM. The current study identified instances where contributors to an online discussion board for people with AD and other dementias discussed CAM and the various types of evidence that were linked to these health treatments. While contributors did discuss CAM, they usually referred to the -specific types of CAM modalities rather than CAM as a larger construct. These CAM modalities were often linked to some source of evidence including references to authority (i.e., clinician recommendations) and peer testimonials. This study highlights the variety of ways people with AD discuss CAM in an online support group. It may be valuable for clinicians to monitor these types of websites in order to gain insights into the treatments that patients are discussing among peers. Understanding what types of CAM people with ADRD talk about is important for guiding treatment decision making, particularly when health decisions are made, and CAM treatments implemented without clinical oversight.

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