Published in final edited form as:
J Alzheimers Dis. 2021 ; 81(4): 1673–1684. doi:10.3233/JAD-210167.

A Conceptual Model to Improve Care for Individuals with Alzheimer's Disease and Related Dementias and Their Caregivers: Qualitative Findings in an Online Caregiver Forum

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Abstract

Background: As the population rapidly ages, a growing number of families are engaging in care for individuals living with Alzheimer's disease and related dementias (ADRD). The perceived challenges and burdens that face informal caregivers are enormous.

Objective: The objective of this study was to 1) explore from the family caregivers' perspective, the daily lives of individuals living with ADRD, and the challenges family caregivers encounter when caring for a family member with ADRD; and 2) to develop a comprehensive model with the endeavor to improve care for individuals with ADRD and their family caregivers.

Methods: Posts were extracted from the *ALZConnected* online caregiving forum in May 2019. Guided by a triangular model focused on *Caregiver, Individual with ADRD*, and *Context of Care,* two researchers independently analyzed 654 posts with a combination of deductive and inductive thematic analysis approach. Researchers all agreed on finalized codes and themes.

Results: Thematic analysis resulted in four themes: *Individual with ADRD*, *Caregiver, Dynamic between Caregiver and Individual with ADRD,* and *Context of Care*. The most frequently discussed topics among caregivers were informational and emotional support for caregivers, and the capabilities and functioning of individuals with ADRD.

Conclusion: Online forums provide a valuable platform for caregivers to support each other informationally and emotionally, share care strategies, and navigate caregiving burdens. An

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SUPPLEMENTARY MATERIAL
The supplementary material is available in the electronic version of this article: https://dx.doi.org/10.3233/JAD-210167.

expanded model was derived to support a comprehensive and dynamic approach to improve care for both caregivers and individuals with ADRD. The unique nature of the caregiver forum data is worthy of further data mining using a novel analysis approach.

Keywords

Alzheimer's disease; caregiver; dementia; peer group; quality of life; support; technology

INTRODUCTION

The combined effect of an aging population at heightened risk of an Alzheimer's disease and related dementias (ADRD) diagnosis, coupled with a yet unsuccessful search for a curative treatment, led to a growing number of families engaging in caregiving [1, 2]. There are an estimated 16.3 million family members who provide care to 5.8 million older adults living with ADRD [2]. Symptoms and progression of dementia, as well as family caregiving demands bring many challenges and strains for these family members, also known as informal caregivers [3-5].

Due to the increasing demand of care associated with a cognitive decline in ADRD, caregivers of persons living with dementia report poorer health [6, 7] and lower health-related quality of life as compared to the general population [8-10]. Despite evidence that factors affecting health and quality of life among caregivers and care are interlinked, provision of healthcare services remains focused on the individual rather than meeting the goal of person and family-centeredness [1]. Consequently, caregiver burden remains unaddressed and may harm quality of life in both caregivers and their recipients [11].

Support from peers going through similar experiences can lead to positive outcomes among ADRD caregivers [12]. Peer support may help informal caregivers realize they are not alone in their experiences and struggles. They may also benefit from talking with others freely and learning from each other regarding coping skills. A recent analysis [13] reviewed 36 studies to examine peer support interventions for caregivers of people living with dementia, reporting that a majority of studies utilized a multi-component intervention. These intervention components included: Information Sharing; Non-Healthcare Professional Support (e.g., signposting/raising awareness of social support networks); Skill Development; Personal Coping Skills; Self-management, and Healthcare Professional Support (e.g., peer support with healthcare professional contact), with the most common components being Information Sharing and Non-Healthcare Professional Support. In these studies, the burden/anxiety/depression compendium, in addition to health and wellbeing, were the most frequently measured outcomes, while perceived level of support was one of the least. The review also concluded that both face to face and online delivery of peer support interventions are effective, and there is no one best delivery model.

Online platforms have become a place where informal caregivers can express their feelings and concerns [14]. In recent years, social media platforms have been successfully employed to understand lived experiences of a population within a naturalistic online setting [15, 16]. Caregivers may be more comfortable talking about some aspects of caregiving with other caregivers rather than researchers, as other caregivers can better relate to their situation

[14]. However, little is known about how informal caregivers of people living with ADRD express the daily challenges they encounter in this role in a naturalistic setting, where concerns about social judgement may be reduced. Therefore, in this study, we qualitatively examined caregivers' entries and responses on an online dementia caregiving support forum. By analyzing caregivers' posts and identifying the discussion topics in the forum, this study aimed to 1) explore from the family caregivers' perspective, the daily lives of individuals living with ADRD, and the challenges family caregivers encounter when caring for a family member with ADRD; and 2) to develop a comprehensive model with the endeavor to improve care for individuals with ADRD and their family caregivers.

METHODS

Setting and study population

Phenomenology, in qualitative studies, refers to the study of individuals' lived experience of the world [17]. To explore the lived experience of individuals with ADRD and their caregivers from the caregivers' perspective, this study used a phenomenological approach, and analyzed posts extracted from the Alzheimer's Association *ALZConnected,org* caregiver forum. The forum was designed to provide a community for ADRD caregivers and people living with dementia alike. Informal caregivers make up the majority of users in the forum and are often the spouse or child of the care recipient. Users must be registered in the *ALZConnected* community before they can post in another user's thread or post new threads. However, all posts can be viewed publicly without creating an account. The study was exempt approved by the Institutional Review Board at the University of Texas Health Science Center at San Antonio.

Data collection and analysis

Posts were extracted from the forum backward in time via web scraping between May 21, 2019 and May 28, 2019. A total of 194,391 user posts across 23,806 threads were extracted from the forum. All extracted posts were imported into an Excel (Microsoft) file for analysis. Thematic analysis, a flexible method to identify ideas, overarching patterns or themes within qualitative data, was used to analyze the posts [18]. Our analysis included a combination of inductive and deductive coding to arrive at final themes [19].

A "triangular" model for improving the quality of life for individuals with ADRD and their caregivers developed by Fortinsky and his team [20] was first selected to guide the data analysis. The triangular model consisted of three interrelated components "Individual with ADRD", "Caregiver", and "Physical Environment". Authors proposed this "triangular" model to guide a 4-month home care intervention to optimize the functional independence of older adults with dementia, and to improve family caregiver's care skills and health-related outcomes. The model guided clinical interventionists to equally emphasize three domains of in-home assessments: the person with dementia, the caregiver, and the home environment. In addition, the model also provided an assessment focus within each of these three domains. For example, "clutter" is an assessment focus under the "Physical Environment" domain. A preliminary review of the posts we assessed indicated that "Physical Environment" could not fully capture the related concepts of posts in the online caregiver forum. Therefore, after reviewing the posts and previous literature [20,21], the study team determined to replace “Physical Environment” with the broader concept “Context of Care”. Ultimately, the three updated triangular model components “Individual with ADRD”, “Caregiver” and “Context of Care” were adopted to guide the analysis.

Following preliminary review of data by an experienced researcher, two trained research assistants with prior qualitative data analysis experience independently coded posts using an open coding style from the beginning of the post list. Each code was grouped into one of the three components of the modified triangular model. Notes and comments (e.g., for code name or code definition) were made during this process. After coding 322 posts, which was when existing codes could apply to the posts repeatedly, the study team stopped coding. The two research assistants reconciled their independent codes and co-developed code definitions. A senior researcher was consulted whenever needed regarding code names and definitions. An initial code manual with 44 codes was developed. To assess whether these codes could be applied to the rest of the posts, the research team drew upon a convenience sampling of posts starting from the end of the previous post list. Another 322 posts were originally intended to be selected for a second round of coding. However, to include the length of the last thread entirely, the selection was expanded to 340 posts for analysis. Three trained research assistants independently applied the previously developed codes to this second set of selected posts. While applying codes to these selected posts, 7 of the post slots were blank and 1 was a repeat, creating a total final of 332 posts for analysis and reconciliation. Coders again made notes and comments throughout the process of applying codes to posts. Researchers who coded overlapping sections of posts reconciled discrepancies through discussion after analyzing all selected posts. If in agreement, the 2 coders would reconcile code applications, which served as the final analysis of the respective post being discussed. If the 2 coders were unable to reconcile code differences, a third coder provided insight allowing for a finalized analysis of the post. During this step, the coding team determined that the initial code book could not capture all the concepts which emerged from the newly selected posts, and an additional 5 codes were identified. The research team met regularly, and two senior researchers assisted with the reconciliation and code definition refining process.

Lastly, codes were categorized into subthemes according to similarities and differences. Consideration was given to the coding processes, categorization, and noting patterns. However, while reviewing all subthemes and codes, it was difficult to display them only underneath the three predetermined major themes of the triangular model because the codes and subthemes generated, related to, but at the same time, went beyond “Individual with ADRD”, “Caregiver”, and “Context of Care”. Therefore, codes and subthemes that could not be grouped into these three major themes were further discussed as a team.

RESULTS

A total of 11,092 unique users were registered on the *ALZconnected* forum at the time of post extraction. Of these users registered on the forum, self-identified relationships to the person with dementia were as follows: 68% identified as being a child of the person with dementia, 12% as a partner or spouse, 7% as a relative, 5% as a grandchild, 0.16% as a neighbor, 1.8% as a friend, and 1% identified as being a sibling. These designations indicate that 95% of the users were an informal or family caregiver. In addition to this, 2% identified as a professional (or formal) caregiver and less than 1% identified as being an individual with dementia themselves.

Thematic analysis revealed 4 themes, 12 subthemes, and 49 codes (Supplementary Table 1).

The 4 themes (Fig. 1) and their subthemes are as follows: Theme 1. *Individual with ADRD* had 2 subthemes: 1a. ADRD *effect on individual with ADRD*, and 1b. *Health and medications of individual with ADRD*. Theme 2. *Caregiver* had 2 sub-themes: 2a. *Handling of the caregiving role and support within it*, and 2b. *Effects of caregiving on the caregiver*. Theme 3. *Dynamic Between Caregiver and Individual with ADRD* had 4 sub-themes: 3a. *Caregiver decisions impacting individual with ADRD*, 3b. *Caregiving role and individualwith ADRD*, 3c. *Behavioral and psychological symptoms of ADRD affecting the caregiver*, and 3d. *Relationship between the caregiver and individual with ADRD*. Theme 4. *Context of Care* had 4 sub-themes: 4a. *Managerial aspects of care*, 4b. *Care and caregiving arrangements*, 4c. *Physical environment and activities*, and 4d. *Healthcare context*. These four themes served to develop the scheme of the conceptual model for improving care (Fig. 1). The related discussion topics (codes) under each of the four themes are displayed in Fig. 2. The most frequently discussed topics within each subthemes were *information* and *emotional support for caregivers*, and the *capabilities and functioning of individual living with ADRD* (Supplementary Table 1).

Individual with ADRD

This theme focused on the individuals living with ADRD and their journey or struggles through an ADRD diagnosis and progression. Since less than one percent of the users on the forum were people living with ADRD, the most common way of talking about the individuals with ADRD was through the caregiver’s perspective. Posts pertaining to this theme often revolved around either the ADRD diagnosis itself and how it was presenting in an individual, or the health of and medical factors for individuals with ADRD.

Sub-theme 1a: *ADRD effect on individual with ADRD*, focused on how ADRD presented in an individual, as well as the history or current status of dementia such as which stage of ADRD the individual was in. In addition to information on dementia stage or diagnosis, posts often discussed an individual’s level of capabilities and functioning (coded 114 times) in which they could or could not complete, such as activities of daily living.

> “My mom was diagnosed with ALZ two years ago. She is in the early stages and can hold conversations and do laundry. However, she has stopped cleaning, cooking and getting groceries.”

> “She’s so fragile, can barely talk, but she is still able to take in fluids, and even a few small spoons of pureed food. Though not much.”

> “My mom has moderate/middle stage Alzheimer’s. Short term memory gone.”

Sub-theme 1b: *Health and medications of individual with ADRD*, focused on the medical comorbidities and other complications in an individual confounding with ADRD. The health of the individual included any hospitalizations, and comorbidities. Medications included any pharmacotherapy the individual utilized, including prescribed or administered medications and any side effects along with them.

> "Now he [ADRD care recipient] is suffering with a heart condition … He will have reduced functionality for the rest of his life. He is also going through diagnostic tests for COPD."

> "[My sister] suggested something was off and I should take our LO to the ER … so I called the paramedics and off to the hospital she went… After a few days on the medical floor and a few doses of haladol to control her… They inform me that she needs to be moved because they think that her anti-seizure medication Keppra is causing agitation and need to be switched to Depakote and she needs to be monitored."

Caregiver

This theme reflected caregiver's first-hand experiences through the ADRD caregiving journey, including the unique struggles and emotions which occurred. This theme expands upon how caregivers handled or managed the caregiving role, support received or given within the role, and the effects and burdens associated with caregiving. As most of the users posting on the forum were caregivers themselves, the caregiver theme was the most commonly used theme (Supplementary Table 1). This theme had two sub-themes as described below.

Sub-theme 2a: *Handling of the caregiving role and support within it,* focused on how caregivers handled the caregiving role, emotions that accompanied caregivers in the caregiving role, and the support either elicited or received to posts in the forum when discussing their caregiving journey. Support came in many forms, most notably emotional (coded 196 times, e.g., comforting or reassuring another caregiver) and informational (coded 186 times; e.g., passing along web links) support. Caregivers described emotional aspects of caregiving, such as frustration, as well as ways of coping with these emotions, such as self-care, religious belief and faith, and learning to recognize ADRD as a disease and not to take things personally.

> "Their passing takes a long time to adjust to … Go at your own pace, be patient and kind to yourself. I think most of us second-guess ourselves and think about what we would have, should have, could have done differently. This is natural, this is what grief does … There was a book I read that helped me, by Elisabeth Kubler Ross, On Grief and Grieving … I'm sorry for your loss, I wish you peace."

> "Lost my cool tonight on the phone with Mom … [which ended with] me feeling progressively more guilty.. My mother It is just so frustrating… I am just venting, thanks for being supportive listeners."

> " I do feel guilty when I take time for myself, but I recognize that some respite is necessary to be at all effective."

Sub-theme 2b: *Effects of caregiving on the caregiver*, focused on the effects or burdens that caregiving had on the caregiver. Effects of caregiving often included caregivers trying to balance a normal life (e.g., hobbies, relationships), employment, family life or activities in the caregiving role as well as the physical and mental health of the caregiver, including conditions either pre-existing or as a cause of the caregiving role, as well as how the family of the caregiver was affected. Caregivers often discussed burden in terms of feeling overwhelmed or having a heavy weight of responsibilities or stress associated with the caregiving role.

> "Meanwhile, my 71 years are showing. My BP is up, my lab work is not normal, palpitations, so tired and my nerves are shot. There is a distinct possibility that she could outlive me.

> "After moving my Mom into my home, I'm wearing out. And I face the moral question whether I succumb to placing her in a nursing home or continue down the path of threatening my own life, my relationship with my girlfriend and my sense of sanity. My own work has suffered. My personal goals have taken a back step to overseeing care for my mother. … The stress of dealing with the expense, the constancy of people coming and going have been taking its toll on my life."

Dynamic between caregiver and individual with ADRD

This theme referred to the interaction and dynamic between the caregiver and their ADRD care recipient, which incorporated both the interactions and impact that the caregiver had on an individual with ADRD, and which the individuals with ADRD had on the caregiver, along with the unique challenges and insights caregivers discussed for this dynamic. This theme highlights the overall dynamic and interaction between the two parties and how that could affect not only the caregiver quality of life, but also the individuals with ADRD.

Sub-theme 3a: *Caregiver decisions impacting individual with ADRD*, focused on decisions that caregivers made regarding or ultimately impacting their ADRD care recipient. Decisions that caregivers made varied, but included topics such as medical decisions, deciding to place a care recipient in assisted living, and the moral dilemmas caregivers go through when making decisions in the caregiving role, such as the decision of to revoke a driver's license or car.

> "I have a facility picked out that I believe will be a good fit for him but I don't think that I can get him there because he is so angry with me, … Any ideas?"

> "We removed the car from her home a little over a month ago … We we're actually very fortunate she hasn't already had any serious accidents and should have done this over a year ago … None of us can even talk to her now because all she wants to do is talk (more like scream) about getting her car back."

> "I said that I did not want her having any surgery where she had general anesthesia. She already has dementia, and I believe that with the anesthesia will make it worse. Also, she may have complications from procedure … I would treat with meds, but no surgery."

Sub-theme 3b: *Caregiving role and individual with ADRD*, focused on how caregivers directly or indirectly affected the individual living with ADRD. This was sometimes dependent on aptitude of the caregiver in their role. Examples of low aptitude included care recipients being left unmonitored when this might be unsafe or caregivers expecting too much from care recipients. Examples of efforts to provide high quality care were also identified, such as the caregiver going above and beyond to ensure the care recipient was comfortable or caregivers using various strategies to communicate with their care recipient, such as to promote compliance with care.

> "[About care recipient obsessing on one topic] Pause, then change the subject… Reply "hmmm," change the topic, get up and go to the bathroom, hang up the phone, whatever."

> "I'm trying to logically identify the supports needed (clean home, food, breaks for my dad, monitoring/preventing my mom from leaving, etc.) to give them both as good a quality of life, as possible, in their own home."

> "You could tell her that her help is needed at this place … to make your mom think she has a "volunteer job" helping with the seniors there."

Sub-theme 3c: *Behavioral and psychological symptoms of ADRD affecting the caregiver*, focused on how the individuals with ADRD or their behavior exhibited, most likely a result of their cognitive condition, impacted the caregiver. This behavior could include challenging behaviors such as wandering, aggressive behavior, delusions, fear and depression in an individual with ADRD, non-compliance with care, and anosognosia. This also included realization of the disease progression, which discussed caregivers realizing ADRD had progressed further than originally thought.

> "I relate totally. Until I got full time caretakers for my mother she would scream at me that I left her alone "like a dog", no matter that I was with her many hours every day. She told my daughter that I was living high off the land by using her money, that I had forged checks. That I wanted her to die, that I had no heart… on and on and On. … It was a nightmare.… "

> "She is probably being resistant and fighting tooth and nail because she cannot reason through the filter of the disease, no matter how many different ways you approach it."

Sub-theme 3d: *Relationship between the caregiver and individual with ADRD*, focused on the dynamic between the caregiver and care recipient, including both positive and negative aspects of the relationship. The relationship between caregiver and care recipient often changed through an ADRD diagnosis, such as perceived role reversal. Caregivers also found purpose in the caregiving role by wanting to better improve the relationship with their care recipient or by taking pride and gratitude from the caregiving role.

> "One thing she has always had is a great sense of humor, and I try to make her laugh, or at least smile. And sometimes she really does laugh. She's more loving than I ever remember her, and even sometimes says "thank you" – something she hardly ever said to me before."

> "I think both he [care recipient husband] and I valued our time together. It was enough to be together.…me reading to him, or singing (we did a lot of that),

> watching something on TV or going over memories. It was a very intimate time that I am grateful to have had with him."

Context of care

The context of care theme referred to the wide-ranging external factors in which caregiving occurs. The context of care surrounding an individual with ADRD sometimes changed as the capacities of the caregiver changed (e.g., health conditions), the function and capacities of the ADRD individual applied, or as the available resources and support changed (e.g., family support). It includes the micro-environment where an individual with ADRD lives, such as the environment safety and activity stimulation, and the macro-environment of the society at large such as the healthcare system, the legal policy, and the available living and care options (e.g., remote caregiving).

Sub-theme 4a: *Managerial aspects of care,* focused on some of the administrative and managerial contexts caregivers needed to deal with in caring for an individual with ADRD. These aspects included logistics of care, in which caregivers discussed general coordination such as daily transportation needs, dispensing medications and managing finances for an individual with ADRD. Also included here were financial and legal matters, which included discussions on cost of care or facilities, federal health insurance options (e.g. Medicare), seeing eldercare attorneys, and the process for power of attorney for an individual with ADRD.

> "I remember those frustrating years of … having my hands completely tied, legally. Your mother is still a legally competent adult in the eyes of the law, and she could rescind her POA's [power of attorney]."

> "I have found a local daycare option for my mother … I was very encouraged when I spoke with them on the phone … They will pick up and drop off. Mom's not eligible for medicaid yet but the cost is only $50. a day. That seems so reasonable to me. To start with I plan on using two days a week and i will also take her in person and not use the pick up service."

Sub-theme 4b: *Care and caregiving arrangements,* pertained to living arrangements made for individuals with ADRD based on their capacities and the caregiver's tolerance and capacities, as well as available resources and options. This frequently came up in terms of less care being provided than the level needed for the care recipient. This also included caregivers discussing their experience of caregiving remotely and caregivers turning to a last resort, such as giving their care recipient over to the state when feeling like they were out of options.

> "This is my personal opinion… If your mom is already to the point of having difficulty with meds, hygiene, and eating … [if] these are things you are observing from seeing her once a week, and the observations from a weekly CG [caregiver], then things are probably more advanced than what you realize … "

> "I was several hours away from my parent. Even at a drivable distance of several hours, you cannot provide or oversee adequate caregiving. You are unable to monitor the often sudden changes that occur with the disease. Your stress level

> will triple as a long distance caregiver, and it will become an ‘I cannot do anything about it today, I am too far away’ scenario.”

Sub-theme 4c: *Physical environment and activities,* referred to the physical environment and activities individuals with ADRD engaged in. Examples in the forum included discussions of the environment and safety for the individual, including any assistive or safety devices (e.g., baby monitor), any activities and stimulation available for the individuals with ADRD such as activities in adult daycare and ADRD appropriate activities, and visits and routines set based on the individual’s needs and capacities.

> “She was well taken care of, in a clean peaceful environment. She listened to her favorite music, ate delicious food, played cards and watched old movies all day long. She sat outside every day, even in cold weather for sunshine and fresh air… She went to Day Care once a week for stimulation.”

> “We use an audio/visual baby monitor in her bedroom, the camera on our home security system and motion detectors in other areas of the house. The baby monitor helps us monitor her throughout the night … The camera also has given us a sense of security when she is in her room alone while also helping her to feel somewhat independent”

> “Even though we kept structure and routine to her days at home … she was undone by watching housework being done, meals being prepared, even laundry being folded.

Sub-theme 4d: *Healthcare context,* focused on the context of caregiving as it related to the healthcare field, such as faults in the healthcare system which led to inadequate care for an individual living with ADRD, and the quality of care that they received. This included both high and low quality of care, from any medical provider, other caregiver or healthcare professional who interacted with the individual with ADRD.

> “Gosh, you and your mother were indeed treated horribly. The medical community as evidenced by your experience, appears to still be lacking in places … No MD can order placement [into a facility]…”

> “The XX hospital system failed him [ADRD care recipient], our health-care-insurance failed him, there are no programs other than super brief respite stays.”

> “With my mother, I eventually hired a lovely lady I met at our church; she was experienced as a “companion” and that was all my mother needed at that point… She was wonderful; we hired her privately and she charged far less than an agency would have. She also had a wonderful reputation and came highly recommended. Lucky us.”

DISCUSSION

Principle findings

This study, with its unique data source, provides a relatively comprehensive and vivid picture of the struggles, burdens, challenges, and concerns of informal caregivers while fulfilling their role of caring for their loved ones with ADRD as discussed with peers undergoing a shared life experience. The most frequently discussed topics were informational and emotional support for caregivers, and the capabilities and functioning of care recipients. The various challenges facing each of the care dyad, the dynamic interactions between the persons in the dyad, and the context of the care suggest that a comprehensive, person-and-family centered approach to healthcare and services should be adopted for the care of individuals with ADRD. The findings also demonstrate what and how caregiving peer support and interactions with each other in this dynamic virtual community can have an impact. Furthermore, a conceptual model, involving various aspects of caring for a loved one with ADRD was derived. Researchers, advocate agencies, and health care professionals may all draw information and knowledge from the study findings to improve the care for individuals living with ADRD and their family caregivers. Lastly, the unique nature of the data on the caregiving forum is worthy of further data mining using novel analysis approaches.

This study found, from the *ALZConnected* caregiver forum, that informal caregivers discussed numerous aspects of caring for their loved ones with ADRD. The most frequently discussed topics (e.g., informational support and emotional support of caregivers, and capabilities and functioning of individuals with ADRD; Supplementary Table 1) in the forum also reflect the consistent efforts to focus on these same areas by health care providers, researchers, and the society at large [3, 22-24]. Meanwhile, findings resonate with prior studies of patients with long-term diseases who use online health communities to facilitate self-management behaviors by collectively self-identifying as a community [25, 26] exchanging health information and disease experiences [25-28], and socializing and emotionally supporting which ultimately extends beyond illness [25, 26, 29]. In this digital era, online communities provide a valuable place for people with long-term conditions to expand self-management knowledge and skills, particularly for those with limited access to support groups and resources [25, 26]. However, due to the unique characteristics of ADRD, such as progressive cognitive loss, the functions of the online community for caregivers of individuals with ADRD goes beyond the patients per se. A previous study reported that unlike other health forums which are comprised of patients themselves, most *ALZConnected forum* users are informal caregivers [30]. Therefore, the discussions on this caregiving forum involved the circumstances of the care partners, which partially reflected the overwhelming discussion of topics as shown in Supplementary Table 1.

In addition, a significant amount of the content caregivers discussed in the online forum was related to the interactions or the interrelationships between the caregiver and individual with ADRD. In addition to the three components in the modified “triangular” model (Caregiver, Individual with ADRD, and Context of Care), the theme: *Dynamic Between Caregiver and Individual with ADRD* reveals the bidirectional effects between caregivers and individuals with ADRD. This is consistent with previous qualitative studies reporting that caregiving negatively influenced family caregivers’ self-care management (e.g., physical self-care, mental and social self-care) [31, 32]. In turn, caregivers’ health status would influence the quality of care for individuals with ADRD [30]. The interaction and influence effects between the care dyad could be applied to healthcare practice. For example, when a health provider observes signs of poor quality of care, they may use this information to expand the scope of their assessment to include caregiver wellbeing/emotional burden.

Additionally, unlike displaying *Context of Care* as one of the triangular points as Fortinsky and his team [20] displayed “Physical Environment”, the model in this paper (Fig. 1) exhibited *Context of Care* as the overall environment in which a caregiver and individual with ADRD interact and deal with. The complexity of individual characteristics and capacities of both the caregiver and care recipient, their interactions, and the context of care the care dyads were in makes caring for a loved one with ADRD extremely challenging. The complexity found in this study echoes results from previous studies. For example, a prior qualitative study [33] highlighted the complex interchange between the family caregiver and individual with dementia, as well as other individuals and external services, and reported that the complex interactions with others made family caregivers feel as though they were in the paradox state of being “in a large network, but alone”. Given the complexity of this dynamic, there is no one fits all strategy to provide to caregivers to ease the care burden. However, standards for each of the components might be helpful to inform caregivers where they are, what to predict, where to find resources and support, and how to proceed and cope. It could also be very helpful for providers and communities alike to collate a list of the most frequently recommended resources for caregivers and their care receipts to address concerns listed under each topic. Future studies are recommended to purse a deeper understanding regarding each aspect of the discussed topics in the model, assess the various relationships among the aspects involved in the care of individuals with ADRD, and explore the feasibility to provide comprehensive and dynamic interventions centering on both the care partners.

One of the biggest strengths of this study was the nature of the data, which was extracted from an online caregiver forum. The data vividly reflected caregivers’ daily life, covering various aspects and dimensions of first-hand knowledge of daily living while caring for an individual with ADRD, which may otherwise not be captured in more formal environments. These study results revealed several care factors which were important, but have previously been under studied, such as difficult medical decisions caregivers have to make for the care recipients, facility placement and relocation for persons living with ADRD, and moral dilemma and legal matters caregivers could get involved in. These are complex issues involving numerous factors, such as legislation, culture, family relationships and so forth [34-36]. More studies are warranted to explore decision making recommendations and guidelines for informal caregivers of individuals with ADRD. Additionally, data to illustrate caregivers’ real life was abundant, and which breaks the limitations and boundaries set by traditional research data collection, in terms of the characteristics of enrolled participants or the pre-established open-ended questions (e.g., survey questions and qualitative interviews); instead, the data in this study may provide us with much-needed insights to understand the multicomponent support caregivers need [37, 38]. However, the attempt of reaching code saturation failed, as more codes emerged while applying the initial code book to another set of posts on the forum. This suggests that despite identification of numerous aspects informal caregivers of individuals with ADRD face, there might be still more left unidentified in the forum data. Novel analysis approach (e.g., machine learning) is needed to further conduct data mining [39].

In this study, even though it was infeasible to analyze all data and identify all possible challenges care partners encountered, we still could sense how important peer support is for informal caregivers. Peers on this forum provided much support to each other to navigate the uncertainties, hopelessness, helplessness, overwhelms and exhaustion. This is confirmed with previous studies which demonstrate the important role of online health communities to manage health conditions [29, 30]. Recent interventions for ADRD caregivers have applied peer-based self-management approaches to improve caregiver self-efficacy and even quality of care measured by reduced healthcare utilization for care recipients [40, 41]. The success of these programs and the caregivers own self-management using forums suggest online health communities are a promising approach for caregiver support. The findings of this study may provide useful information and new angles for future studies exploring peer support interventions for informal caregivers of individuals with ADRD.

Limitations

There are several limitations of this study. First, a majority of the discussions on this forum were posted by informal caregivers. Therefore, the findings may not capture the experiences and perceptions of individuals living with ADRD. In addition, all data was collected via an online forum, and the findings may not be generalizable to those who have limited access to internet and/or computers. However, the nature of the data collection in a natural (non-research) setting of the study is a strength as well. Further, overwhelming data was available on the forum, leading us to combine concepts for the sake of presenting data in a concise manner. For example, the physical activity level of individuals with ADRD was in the code named “activities and stimulation”. This did not explicitly reflect the physical activity and exercise status of the care partners. Therefore, a novel approach to analyze and present the data is warranted, such as machine-learning approaches [42]. Furthermore, for the posts included in the analysis, we were not able to trace posts generators’ characteristics and their relationship to their care receipts. Therefore, it is difficult to estimate to what extent the findings could represent the experiences of the forum users. Other limitations using this online forum data have been reported previously [30].

CONCLUSION

This study found that the online caregiver forum provides a valuable platform for informal caregivers to support each other informationally and emotionally, to share care strategies, and to navigate caregiving burdens. The conceptual model derived from the abundant data available on the online *ALZconnected* forum involves various aspects caregivers face when caring for a loved one with ADRD. The model may offer direction and guidance for research scholars, policy makers, health care providers, and caregivers to better address needs for care partners to improve care quality and health for individuals with ADRD and their family caregivers. However, a manual analysis approach is overwhelming, and a novel analysis approach (e.g., using machine learning) may help dig more valuable information from the vast amounts of data.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGMENTS

The authors would like to thank the study participants who shared their data on ALZConnected. The study was supported by the Center on Smart and Connected Health Technologies at the University of Texas Health Science Center at San Antonio. YD is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through grant TL1 TR002647.

Authors' disclosures available online (https://www.j-alz.com/manuscript-disclosures/21-0167r2).

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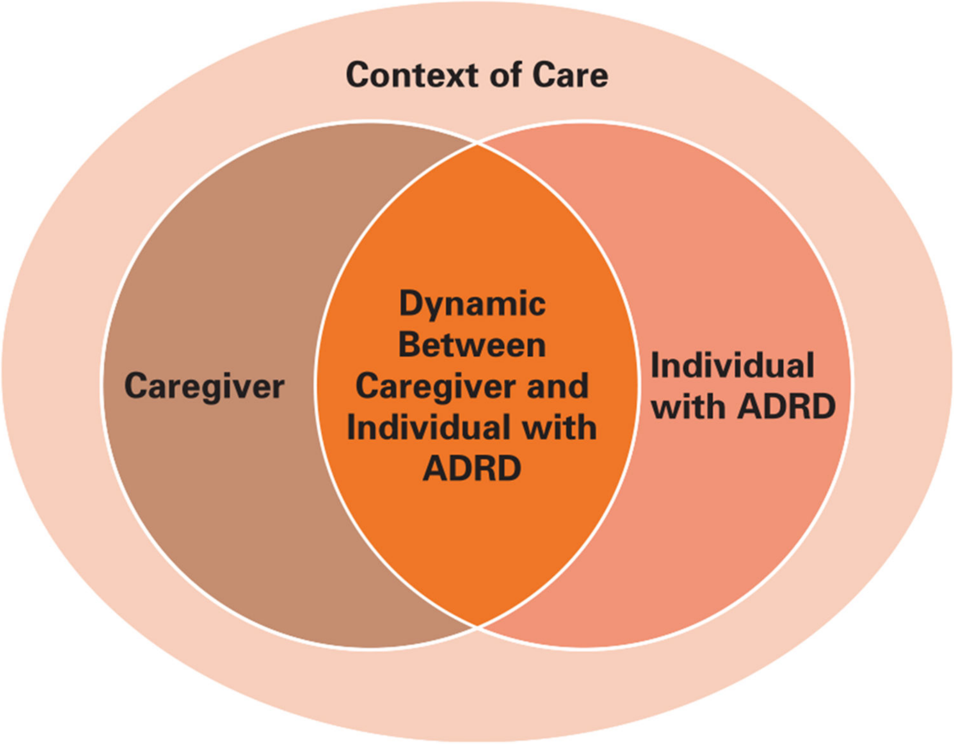

Fig. 1.

A conceptual model to improve care for individuals with Alzheimer's disease and related dementias (ADRD) and their informal caregivers.

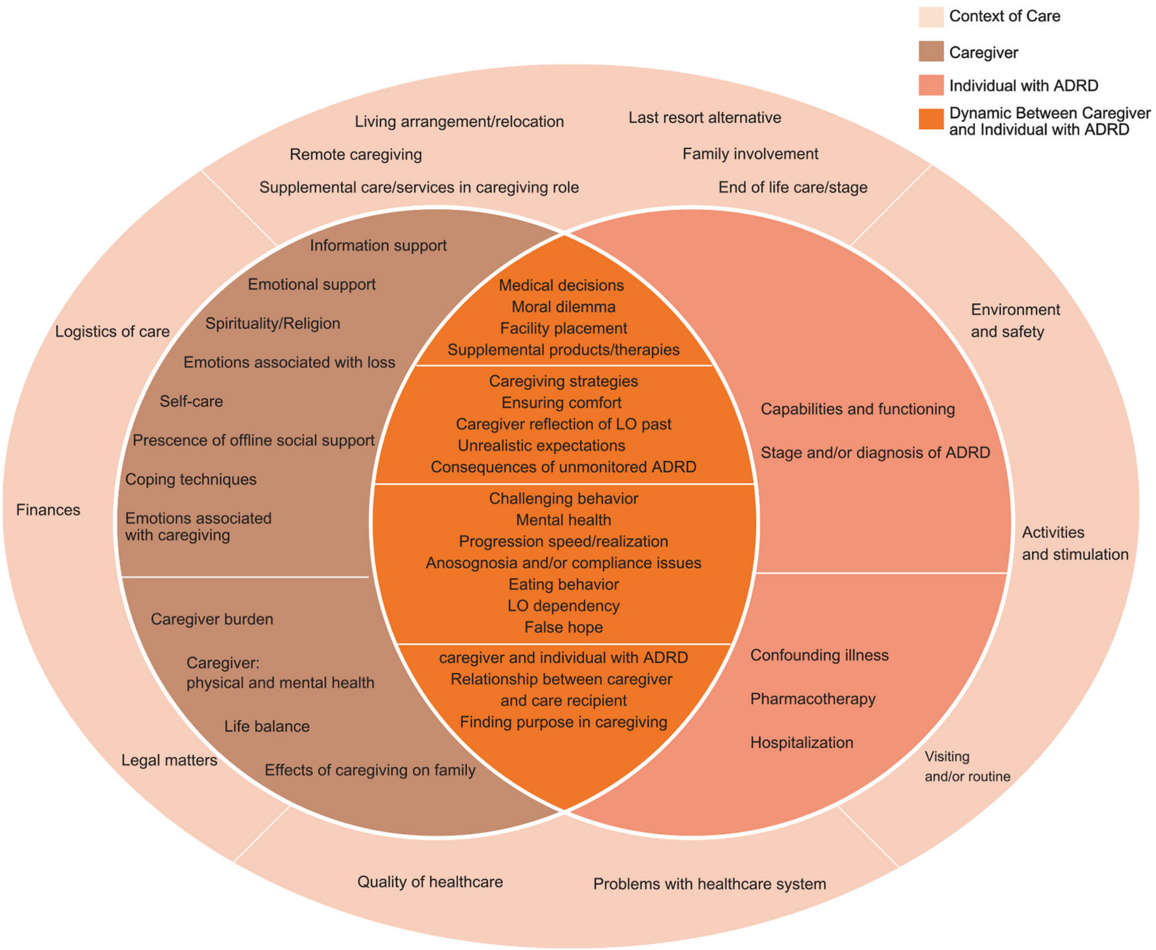

Fig. 2.

A conceptual model, including each care related topics, to improve care for individuals with Alzheimer's disease and related dementias (ADRD) and their informal caregivers. LO, loved one.