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Abstract

Background: Alzheimer's disease and related dementias (ADRD) is a growing global health challenge. ADRD places significant physical, emotional, and financial burdens on informal caregivers and negatively affects their well-being, particularly their mental well-being. Online social media platforms have emerged as valuable sources of peer support for these caregivers. However, there has been limited investigation into how online peer support might influence their mental well-being.

Objective: We examine the dynamics of sentiment, one major indicator of mental well-being, among ADRD informal caregivers in online communities, specifically how their sentiment changes as they participate in caregiving experience discussions within two ADRD online communities.

Methods: We collected data from two large online ADRD caregiving communities, ALZConnected and TalkingPoint, covering November 2011 to August 2022, and March 2003 to November 2022, respectively. Using the Valence Aware Dictionary for Sentiment Reasoning (VADER) and Linguistic Inquiry and Word Count (LIWC), we calculated the sentiment scores for each post and evaluated how the initial sentiment of a topic initiator evolves within a discussion thread. Structured topic modeling and regression analysis were used to identify the primary topics that were consistently associated with sentiment changes within these threads. We investigated longitudinal sentiment trends to identify patterns of sentimental stability or enhancement due to prolonged engagement in online communities by plotting linear interpolation lines of the sentiment values of each individual user.

Results: The ALZConnected dataset was composed of 532,992 posts, consisting of 57,641 topic threads and 475,351 comments. The TalkingPoint dataset was composed of 846,344 posts, consisting of 81,068 topic threads and 765,276 comments. Our research revealed that topic initiators experienced a notable increase in positive sentiment as they engaged in subsequent discussions within their threads, with a significant uptick in positivity in the short term. This phenomenon is part of a broader trend of steadily rising positive sentiment among ADRD caregivers across both communities. Using structured topic modeling, we cataloged a diverse range of topics that included both emotional aspects, such as family emotions (5.4%), and practical concerns, like diagnosis and treatment (6.9%), and everyday care practices (4.5%). We observed that sentiment scores were positively aligned with discussions about family and daily routines life (coefficient is 3.53, $p<0.0001$), while topics related to illness (coefficient is -1.37, $p<0.0001$) and caregiving facilities (coefficient is -1.98, $p<0.0001$) tended to correlate with lower sentiment scores. This This evidence highlights the significant impact that both the time of participation and the posting content have on the sentiment changes of caregivers.

Conclusions: Our study identifies sentiment changes among informal ADRD caregivers through their interactions in two extensive online communities. These findings emphasize the importance of early emotional support within a topic thread and demonstrate a predominantly positive sentiment in these communities over time. These findings further highlight the value of online peer support and its potential to enhance emotional well-being of informal ADRD caregivers.

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Keywords: Informal caregivers; Alzheimer's Disease; dementias; online community; sentiment analysis; topic modeling

Introduction

Alzheimer's disease is the most common cause of dementia, a clinical syndrome that severely impairs a person's memory, language, and judgment and planning abilities [1]. Alzheimer's disease and related dementias (ADRD) are increasingly prevalent health issues all over the world [2]. The responsibility of caring for people living with ADRD (PLWD) falls primarily on the unpaid informal caregivers, typically the family members and friends of the PLWD [3,4]. These informal caregivers face a wide range of physical, emotional, and financial challenges that can cause significant stress and negatively affect their health and well-being [5]. Notably, many informal ADRD caregivers claim to have emotional exhaustion that manifests in caregivers as a result of prolonged emotional stress and the constant demands of caregiving. [6].

Understanding the emotional challenges informal ADRD caregivers face and offering appropriate support to enhance their well-being is of vital importance. Prior investigations into these issues have primarily relied upon traditional offline strategies, such as surveys [7,8] and interventions [9]. Additionally, the primary support for ADRD caregivers mainly comes from local, offline resources like charities and community support groups [10,11]. While these methodologies play an important role in studying and assisting informal ADRD caregivers' needs, they come with inherent challenges. Caregivers may face hurdles in accessing offline support due to geographic constraints [12], resource limitations [13], and individual preferences. As for researchers, offline studies demand financial and manpower resources and can introduce potential geographical and demographic biases in the collected data.

Online social media platforms have emerged as a valuable, convenient resource for caregivers to gain informational and emotional support that may not be easily obtained in traditional offline face-to-face interactions [14,15]. A recent survey indicated that online communities could provide informal caregivers with a sense of understanding, empowerment, support, and belongingness, thus reducing social isolation and improving the emotional well-being of these caregivers [16]. Despite the potential benefits of online support, there is a lack of research examining whether informal ADRD caregivers receive positive emotional feedback when discussing their caregiving experience or challenges in online communities. This is important because an improved sentiment change observed from online posts may indicate a positive impact of online peer support on a caregiver's emotional well-being.

In this study, we investigate the changes in the sentiment exhibited by informal ADRD caregivers through their published online posts in two large online communities, ALZConnected and TalkingPoint. ALZConnected is an online community powered by the Alzheimer's Association for any person affected by

ADRD in North America, while TalkingPoint is an online ADRD community organized by the Alzheimer's Society from the UK. Online peer support has been shown to offer a wide range of benefits, including informational and emotional support, which can be particularly valuable for caregivers facing complex challenges of ADRD [17,18]. Therefore, we hypothesize that the sentiment of informal ADRD caregivers revealed in their published posts will be improved after interacting with other online caregivers. Specifically, we investigated the following three research questions to test this hypothesis:

- **RQ1**: How did the sentiment of the topic initiator change within a topic thread?
- **RQ2**: What topics in initial posts were associated with sentiment change?
- **RQ3**: How did the sentiment of an online caregiver change over time within the community?

To investigate these questions, we apply sentiment analysis and statistical methods to determine whether engaging in online communities can provide emotional benefits to informal ADRD caregivers.

Methods

For context, there are several key terms that we rely upon in this paper. Online communities generally structure discussions into disparate topic threads. Each thread contains an initial post, followed by several subsequent comments. We refer to the user who initiates a topic thread as the "topic initiator" of the topic thread. The comments published by topic initiators within their own topic threads are called "self-comments".

Data Collection and Preprocessing

We collected data from two large, representative online communities that create a unique environment for ADRD caregiving discussions: 1) ALZConnected[1] and 2) TalkingPoint[2]. ALZConnected was established by the Alzheimer's Association [19] as the first and the largest online community for any person affected by ADRD in North America. TalkingPoint, on the other hand, is an online community organized by the Alzheimer's Society [20] in the UK for PLWD or their caregivers to share information, advice, and support with one another.

We focused our analysis on a specific subset of forums that are dedicated to ADRD caregivers who share caregiving experiences, seek assistance, and engage in caregiving discussions. To ensure relevance and coherence, we conducted a preliminary selection process, manually reviewing the most popular posts within each relevant forum to assess their alignment with caregiving topics. In TalkingPoint, we focused on users with a label of a *registered user* or *new member.* In ALZConnected, we focused on users who self-identified as ADRD caregivers. We gathered all publicly accessible data from these two communities using a web crawler built with the BeautifulSoup v4.11 Python package. We removed punctuation, special characters and emojis, and converted the text to lowercase.

Ethical Considerations: Our research was deemed to be exempt from human subjects research by the Institutional Review Board (IRB) at Vanderbilt University Medical Center. All quoted texts have been paraphrased to prevent user identification.

Sentiment Evaluation

To mitigate measurement bias that can result from applying off-the-shelf models on our dataset, we applied two popular sentiment analysis tools, specifically, Valence Aware Dictionary for Sentiment Reasoning (VADER) [21] and Linguistic Inquiry and Word Count (LIWC) [22], to calculate the sentiment scores of online communications.

[1] https://www.alzconnected.org/
[2] https://www.alzheimers.org.uk/get-support/dementia-talking-point-our-online-community

VADER is a module of NLTK (The Natural Language Toolkit) [23] that provides sentiment ratings based on the words used. It operates as a rule-based sentiment analyzer, where terms are categorized as positive or negative based on their semantic orientation. In our study, we selected the VADER compound score, calculated by summing the valence scores of each word in the lexicon and then normalizing it to a range between -1 (most extreme negative) and +1 (most extreme positive), as the sentiment evaluation score.

LIWC calculates the percentage of words in each linguistic category by mapping the words of a given text into a pre-defined word list of that category [24]. This tool has been widely adopted in online content-based research [25]. In this study, we focused on the tone category in LIWC, which summarizes the two dimensions of positive and negative emotions into a single variable. The LIWC tone score ranged from 0 to 100 (%), with higher scores indicating a more positive emotional tone. The delineation occurred at 50(%), where scores above (below) indicated a positive (negative) tone. In this study, we standardized the LIWC tone score to a range of -1 to 1 to align it with the VADER score range.

RQ1: Sentiment Changes of Topic Initiators

To measure a topic initiator's sentiment changes within a topic thread, we focused on the topic initiators who published at least $M(M>0)$ self-comments with a topic thread. This threshold ensures that the topic initiator contributes sufficient conversational involvement. In this study, M was set to a value that ensured at least 95% of the users posted at most M self-comments.

For each topic thread with at least M self-comments, we define an array, $S=[S_0, S_1, \ldots, S_M]$, to represent the sentiment scores of the initial post and the following M self-comments in chronological order. As such, S_0 is the sentiment score of the initial post, while the S_i where $i \in \{1, \ldots, M\}$ is the sentiment score of the i^{th} self-comment. We defined sentiment change, S_Δ, as the difference between the average sentiment score of m self-comments and the initial post's sentiment score: $S_\Delta = S'_m - S_0$, where $S'_m = \sum_{i=1}^{m} \frac{S_i}{m}$, and $m \le M$. We analyzed the sentiment score changes and generated distributions of these changes with a 95% confidence interval (CI).

To address potential bias from highly active users who contributed a large number of topic threads, we repeated the comparison by randomly selecting a group of $P \in \{5\%, 10\%, 25\%, 50\%\}$ of the total number of topic threads in each community. We conducted a pairwise t-test to evaluate the difference between $[S_0^0, S_0^1, \ldots, S_0^{N-1}]$ and $[S'^0_m, S'^1_m, \ldots, S'^{N-1}_m]$, where *N* represents the number of selected topic threads in each comparison. We examined the difference at the significance level of $\alpha = 0.05/4$ with Bonferroni correction. This adjustment ensures that the error rate remains at the conventional 5% level across all four of our testing groups.

RQ2: Association between Sentiment Changes and Initial Post Topics

We employed the structural topic model (STM) [26] to infer the topics that were communicated in the initial posts, with the subsequent goal of exploring their correlation with sentiment changes. Next, we applied Ordinary Least Squares (OLS) regression, as implemented in the python package *statmodels* (v 0.14.0), to investigate what kinds of topics in the initial posts are associated with sentiment change.

Before applying topic modeling on the initial posts, we removed stop words and special symbols, and discarded words that occurred less than 10 times in the dataset. Since STM is an unsupervised machine learning strategy, we rely on two metrics - exclusivity and semantic coherence - to determine the appropriate number of generated topics. Exclusivity refers to the uniqueness of the most frequent words in a topic, while semantic coherence [27] quantifies the co-occurrence of words in a topic in a general context or all the posts. We assess STM for topic numbers ranging from 5 to 30 and select the optimal number K of topics for further analysis [14].

Subsequently, we rank the topics by their prevalence across all documents, a process that involves examining the expected proportion of words in each document attributed to each topic. We calculate the expected topic proportions (ETP) using the *estimateEffect* function in the STM package. With this distribution, we conducted a regression analysis where the topic proportions served as independent variables, and the changes in sentiment scores—calculated by VADER compound scores or LIWC tone changes—served as the dependent variable. In this regression, we only considered the topics that held an ETP greater than the mean ETP of K topics. For instance, in a model with 20 topics, we would expect an ETP of 5% per topic (1/20 or 100%/20) on average and only include topics that exceeded 5% in the regression analysis for each initial post.

RQ3: Temporal Changes of Caregiver Sentiment

We defined the active time of an online caregiver in the community, up to the point of writing a specific post, as the duration from their account registration to the posting date of that particular post. We analyzed sentiment changes over various fixed time intervals, as one week, two weeks, one month, three months, six months, one year, three years, five years, and ten years. For each time interval, we selected posts from active users who had contributed within the designated time frame (0 to the specific interval) and continued to post at least once after that period. For example, to assess sentiment changes for active users within one year, we only consider users who have published at least two posts (either initial posts or comments) within a year and still have at least one post beyond the one-year period. As such, we ensure that every user included in a time-period analysis is still active in contributing posts. We focused on time intervals where at least half of the users remained active.

To quantify the change in sentiment for active users over time, we plotted linear interpolation lines with 95% confidence intervals to analyze trends in the sentiment values of each individual user. We calculated Spearman's coefficient of correlation [28] to analyze similarities in trends across communities, as well as to validate results across different sentiment analysis tools.

Results

Basic Statistics

We collected data from ALZConnected from November 14, 2011, to August 6, 2022, and TalkingPoint from March 31, 2003, to November 3, 2022. Table 1 provides basic statistics for both datasets. The different time periods for each dataset reflect the respective forum's establishment dates and the availability of their archival data, with no inter-community comparison being made.

Table 1. Summary statistics for the datasets in this study.

Community	Total Posts	Topic Threads	Comments	Authors	Topic Initiators	Commentors	Time Period
ALZConnected	532,992	57,641	475,351	18,569	12,590	14,964	Nov 14, 2011 - Aug 6, 2022
TalkingPoint	846,344	81,068	765,276	34,551	27,907	26,651	Mar 31, 2003 - Nov 3, 2022

The ALZConnected dataset covers 532,992 posts, consisting of 57,641 topic threads and 475,351 comments. It involves 18,569 unique users, 12,590 (67.8%) of which are topic initiators and 14,964 (80.1%) are commenters, indicating that a non-trivial proportion of users engage in both creating and discussing content. The TalkingPoint dataset covers 846,344 posts, consisting of 81,068 topic threads and 765,276 comments. It involves 34,551 unique users, 27,907 (80.7%) of which are topic initiators and 26,651 (77.1%) are commenters.

Both datasets exhibit a long-tailed distribution with respect to the number of comments per topic thread (Figures 1a and 1c). For example, most topic threads contain around 10 comments while a few inspire extensive dialogue. Similarly, the distribution of posts per user (Figures 1b and 1d) indicates that, although many users occasionally participate, a small subset of highly active users contribute the majority of the content. These phenomena hold true in both ALZConnected and TalkingPoint. The consistency in posting and user activity patterns across both communities highlights common behaviors in user engagement within online caregiving forums.

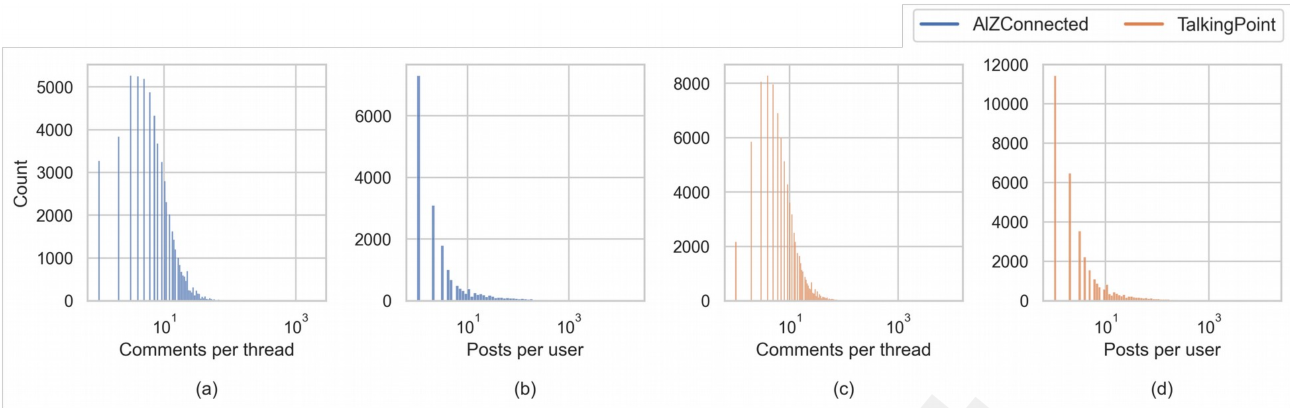

Figure 1. The distribution of the number of comments per topic thread (a)(c) and the number of posts per user (b)(d) in the ALZConnected and TalkingPoint online communities. The plots show the log-scaled x-axis for ease of viewing.

RQ1 (Sentiment Change of Topic Initiator)

After removing threads lacking self-comments, there were 30,739 topic threads (53.3%) from ALZConnected and 53,995 (66.6%) from TalkingPoint, comprising 79,869 and 181,049 self-comments, respectively. In ALZConnected, 95% of the topic initiators have fewer than 6 self-comments, while in TalkingPoint, 95% of the topic initiators have fewer than 8 self-comments. To minimize the influence of highly active users, we focused on measuring sentiment changes for the first $M=10$ self-comments, encompassing 30,209 (98.3%) and 52,370 (97.0%) of topic threads, respectively in ALZConnected and TalkingPoint.

Figure 2 shows how the sentiment score changes within a 95% confidence interval, in terms of VADER compound (Figure 2a) and LIWC tone (Figure 2b), throughout the count of self-comments m. The $m=0$ on the x-axis corresponds to the initial sentiment score S_0 while $m>0$ corresponds to the average score of the first m self-comments S_m'. Thus, it is evident that initial engagement in online community discussions is associated with a notable sentiment boost, suggesting immediate emotional support for topic initiators (RQ1). Both VADER and LIWC indicate a substantial increase in the sentiment score as the number of self-comments m grows from 0 to 1. This is followed by a slow, gradual increase as the number of self-comments further increases. This suggests that online community interactions effectively provide immediate emotional support to topic initiators. However, these positive changes in sentiment do not escalate rapidly with the frequency of topic initiators' activities within the online communities.

VADER and LIWC show different patterns of changes in sentiment scores. Notably, the VADER compound score indicates a higher initial sentiment in ALZConnected compared to TalkingPoint. However, when the number of self-comments exceeds 1, the sentiment value in TalkingPoint surpasses that of

ALZConnected. Conversely, the LIWC tone score shows an opposite trend, though the differences between the two communities are less distinct. This dissimilarity might arise from variations in the training corpora utilized by VADER and LIWC.

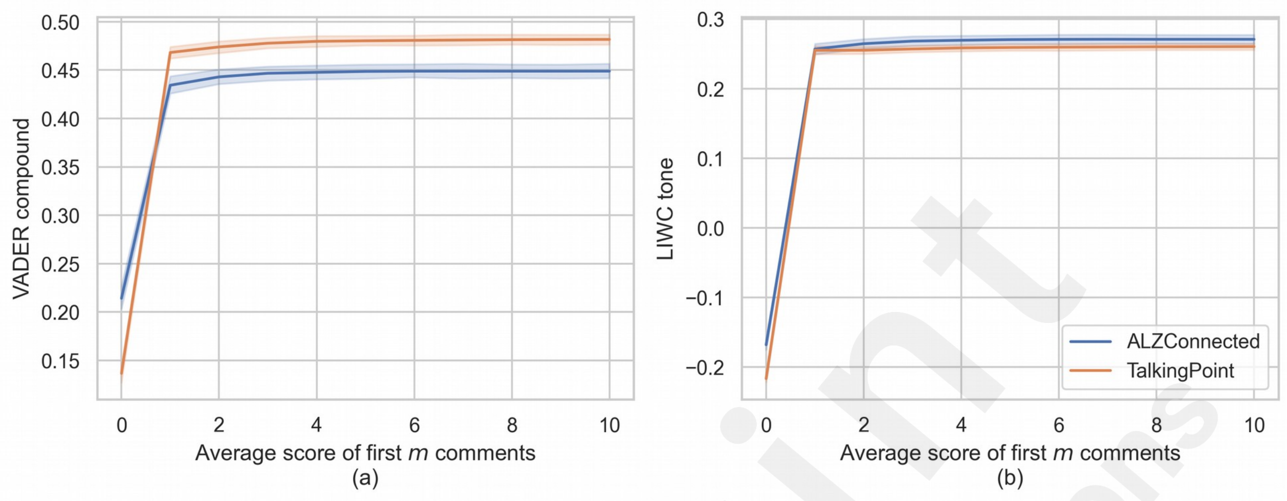

Figure 2. Sentiment changes as a function of the number of self-comments. The x-axis indicates the count of self-comments. For example, m=2 represents the average sentiment of the first two self-comments under each author's thread.

We investigated whether the initial sentiment significantly differed from the average sentiment across up to the first ten self-comments. The results indicated statistically significant differences between the two sentiment values in both online communities for all test groups, with p-values approaching 0 - significantly lower than the significance level of α=0.0125 (Bonferroni-corrected from $\alpha=\frac{0.05}{4}$). These findings emphasize that online interactions have an immediate and noticeable impact on the sentiment of online caregivers.

RQ2 (Sentiment Changes Correlates with Initial Post Topics)

In determining the ideal number of topics for our STM, we evaluated metrics of exclusivity and semantic coherence across a spectrum ranging from 5 to 30 topics. The analysis indicated that a set of 20 topics achieved an optimal balance between word distinctiveness and thematic relevance. Thus, we retrained STM on this number of topics. Figure 3 visualizes this topic modeling, showing the most representative words for each topic and indicating the relative topic proportions, which quantitatively reflect the prevalence of each topic across all analyzed documents.

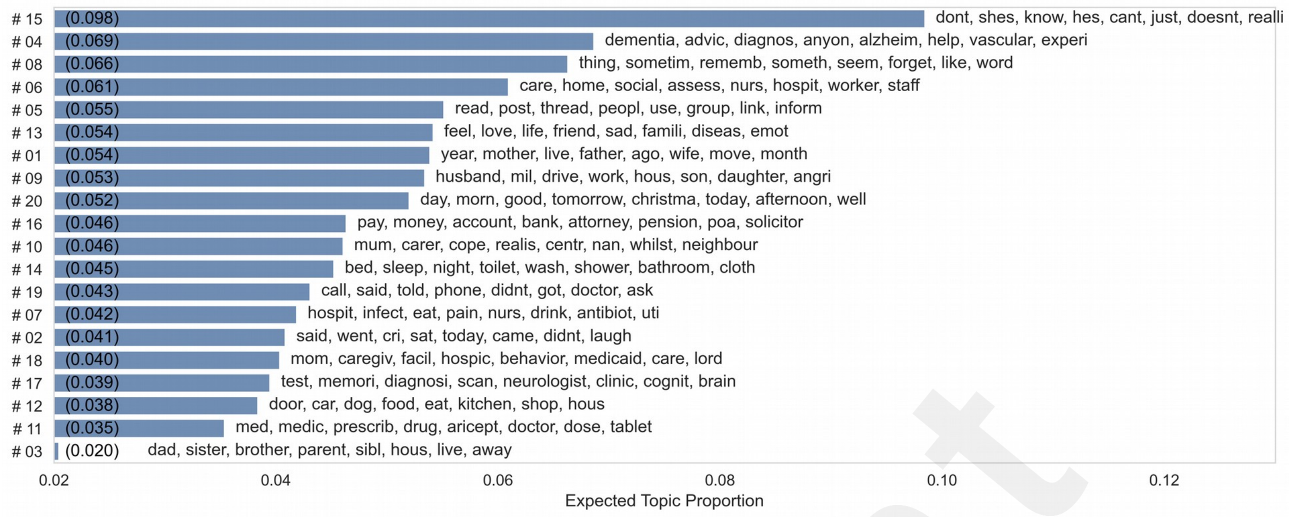

Figure 3. Topics generated by STM, sorted in decreasing order of expected topic proportions. The proportion of each topic is shown to the right of each bar, while the top 8 most representative words in the topic are shown to the right.

From Figure 3, it was evident that several topics were related to sentiment. For instance, topic #13, which is about "family members feelings", is characterized by frequent words like "feel", "love", and "sad". The estimated topic proportion (ETP) of this topic is 5.4%, which stands out as notably high when considering an even distribution across 20 topics would average 5% per topic. This suggests that discussions related to family members' feelings are more prevalent in the data set than what would be expected by chance. The following posts are representative examples of this topic:

"*Sadly, I am letting you all know that my poor mother has left this earth; she passed away peacefully surrounded by her family.*"

and

"*I am so blessed to have shared these moments, even though he started to forget me.*"

These topics are related to sentiment changes and offer insights into the deeply personal and heartfelt experiences of community members. Additionally, we identified topics that convey specific emotional actions. For example, topic #2 contains the keywords "*cries*" and "*laughter*", reflecting the diverse sentimental landscape caregivers are facing. A typical initial post from this topic is:

"*When I was a little boy, I often dropped my spoon, and now my old man does the same thing, which makes me laugh and cry at the same time*."

In addition to sentiment-related topics, we identified other commonly discussed topics. For example, Topic #4 (*dementia, advic, diagnos*) delved into information related to diagnosis and treatment, providing a relatively objective description. Topic #14 (*bed, sleep, shower*) centered around caring for PLWD's daily life, while Topic #16 (*pay*, *money*, *account*) was about financial matters. Notably, Topic #1 (*mother*, *father*, *wife*) and Topic #09 (*husband*, *son*, *daughter*) specifically addressed personal relationships such as those with spouses or adult children. Those topics aligns with previous studies, which have shown that spousal caregivers and adult-child caregivers make up a significant portion of informal ADRD caregivers [29].

To clarify the relationship between the content of initial posts and subsequent sentiment changes, as outlined in RQ2, we present in Figure 4 the influence of each topic on the VADER compound sentiment scores. Blue (positive) and orange (negative) dots represent correlation, where '.' ($p \leq 0.05$) and '*' ($p > 0.05$) indicate the level of statistical significance. This analysis indicates that most topics are statistically significant ($p \leq 0.05$), indicating that various topics are significantly linked to sentiment changes within the topic threads.

When considering specific topics, Topic #9 (*husband*, *mil*, *drive*), exhibits the highest positive correlation with changes in the VADER compound score. This topic talks about family relationships and daily life. This suggests that many online users find comfort in sharing their daily experiences and connecting with others. As a result, emotions tend to become more positive as individuals engage in such sharing and communication. By contrast, the most negatively related topic is Topic #20 (*day*, *mom*, *good*), which is primarily related to time. It is possible that, due to the progressive nature of dementia, as time elapses, symptoms tend to worsen, and caregivers' moods understandably decline.

Furthermore, topics directly tied to sentiment, such as Topic #2 (*said*, *went*, *cri*) and Topic #13 (*feel*, *love*, *life*), exhibit strong positive associations with sentiment changes. This indicates that the forum effectively caters to individuals seeking to express their emotional experiences. Topic initiators may receive positive emotional support, likely due to the compassionate and empathetic nature of users in online communities; while topics closely related to illness and caregiving facility, such as Topic #4 (*dementia*, *advic*, *diagnostics*) and Topic #18 (*mom*, *caregiv*, *facil*), display a negative emotional correlation, underscoring the stress and difficulties that caregivers encounter.

It is worth noting that the performance of LIWC tone scores closely mirrors that of the VADER compound hence we didn’t present the figure here.

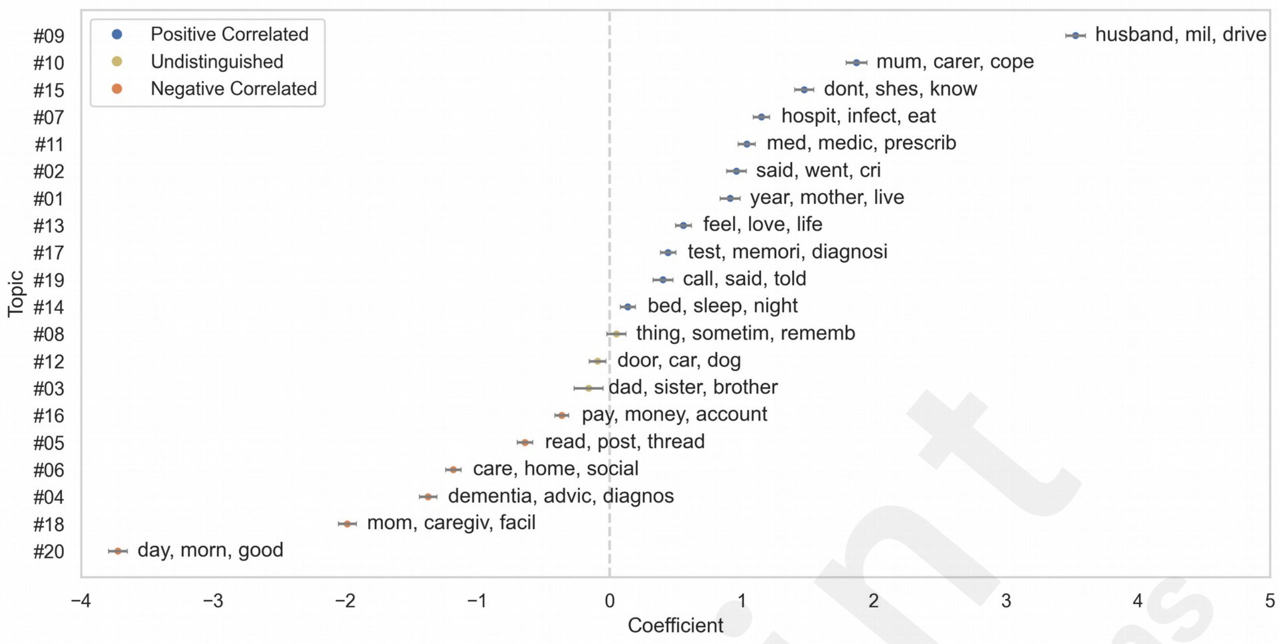

Figure 4. The coefficients of each topic with VADER compound sentiment changes: Blue (positive) and orange (negative) dots indicate correlation, while yellow dots indicate undistinguished features where p>0.05.

RQ3 (Temporal Changes in Caregiver Sentiment)

Next, we computed the changes in sentiment according to the VADER compound score and LIWC tone over time. We partitioned users into different timespan groups (from 1 week to 10 years) based on their active time and displayed the sentiment trends in each phase.

Figure 5 presents the number of users active in each timespan, revealing a notable drop in the number of users active for more than a year. For instance, in the ALZConnected community, out of 4,430 users who were active for over a week, only 796 (18.0%) were active for over 3 years, while only 299 (6.7%) were active for over 5 years. Interestingly, there is a small fraction of users, 0.4% in ALZConnected and 0.7% in TalkingPoint, who remain active for over 10 years. Due to the substantial reduction in active users after the one-year mark, our subsequent sentiment trend analysis concentrates on the one-week to one-year timespan, capturing a more representative (50%) sample of the community's active users.

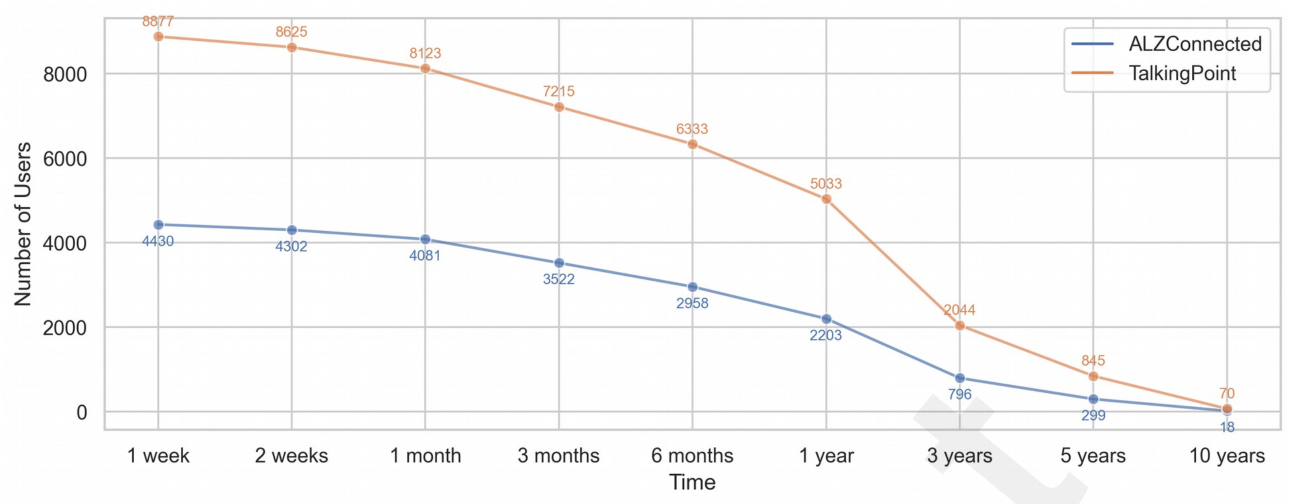

Figure 5. The number of users that are active in each timespan in the two online communities.

This analysis examines the sentiment trajectory of caregivers over time and to understand the effect of sustained participation in online communities. To improve the readability of the figure, we employ linear regression lines, along with linear interpolation and its 95% confidence interval, for the data points in each subplot. Figures 6 and 7 provide a comprehensive view of the VADER compound and LIWC tone sentiment changes, respectively, in the online communities. Each subplot demonstrates the trend of sentiment change for eligible users in various timespans.

The analysis reveals an overall positive sentiment trend in both online communities, suggesting that engagement in these forums is generally associated with positive emotional expression. Notably, as the active time interval grows, the increase in sentiment weakens. The Spearman rank-order correlation between the VADER compound score and active time for - within one week, 1 month and within 1 year are 0.062, 0.038 and 0.021 (all statistically significant at $p<0.001$), respectively. This finding suggests that participation in the online community increases a user’s sentiment. However, the effect becomes less pronounced as users spend more time in the online community. Third, in both sentiment score measures, there is no substantial difference between ALZConnected and TalkingPoint, showing that both communities provide an environment for ADRD caregivers to express their feelings, supporting the validity of analyzing sentiment changes in ADRD caregivers in either community.

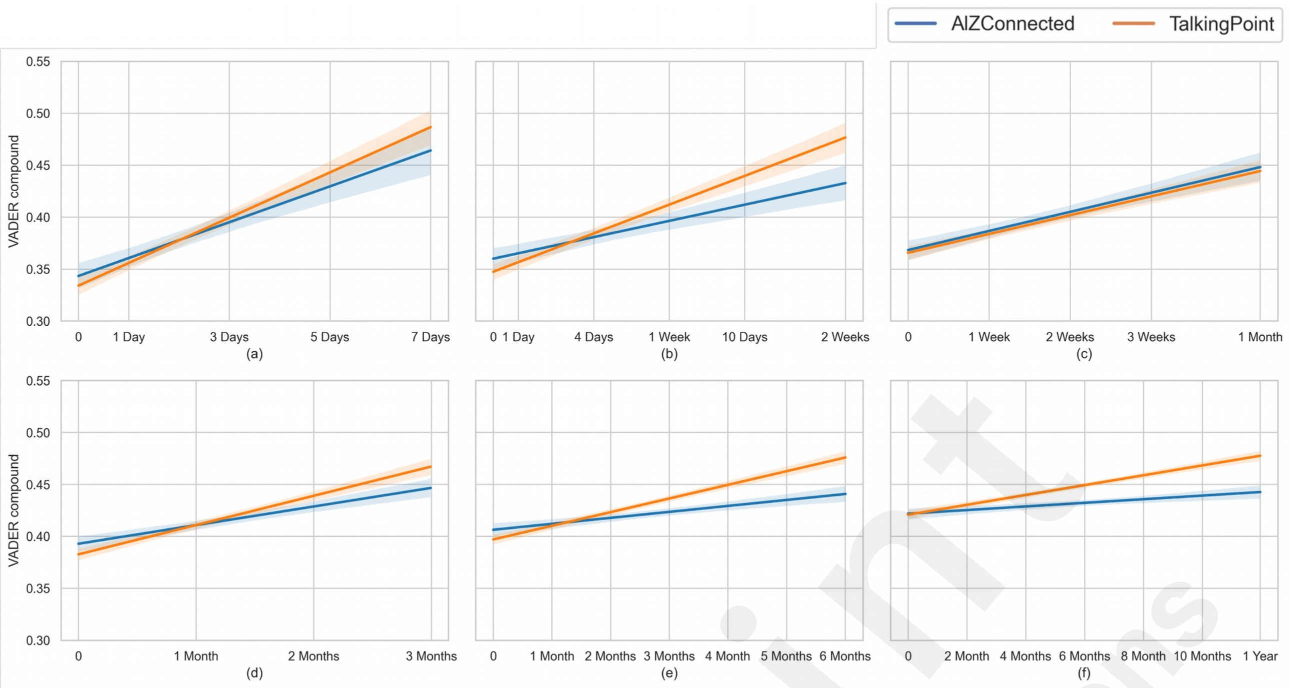

Figure 6. VADER compound sentiment score temporal trend via active time separated into certain time spans.

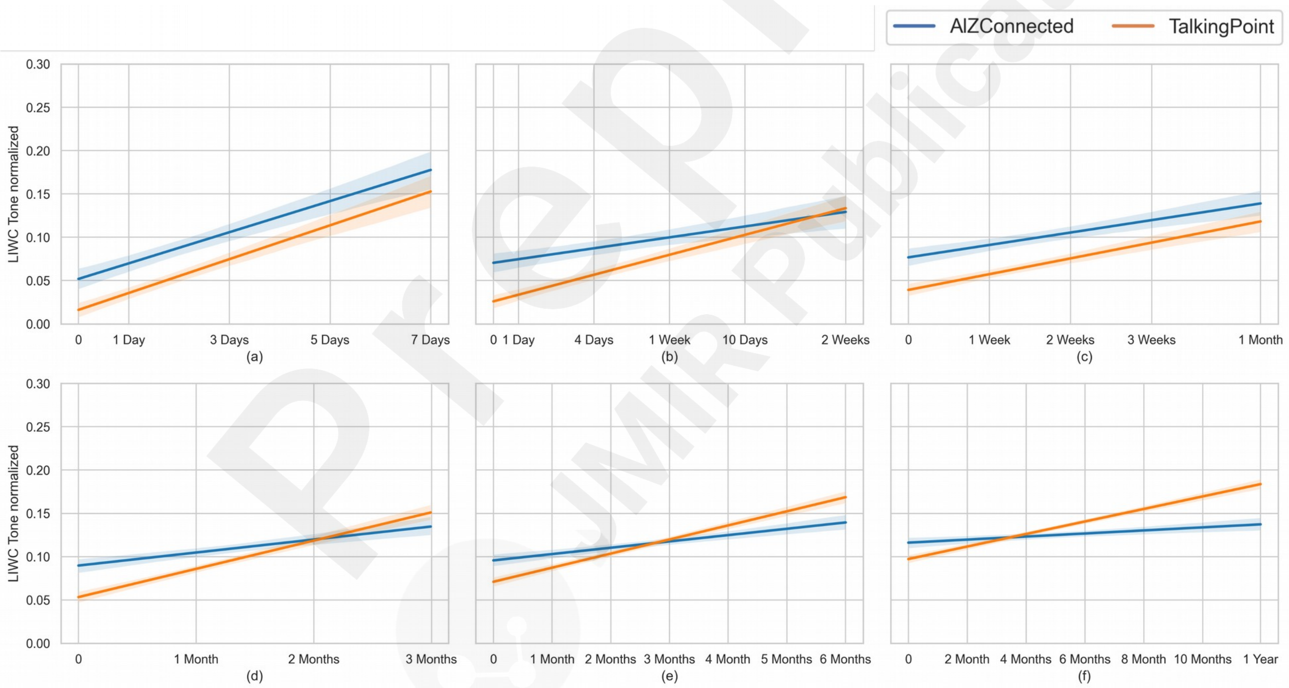

Figure 7. LIWC tone sentiment score temporal trend via active time separated into certain time spans.

Discussion

Principal Findings

Our study illustrates patterns related to the sentiment changes of informal ADRD caregivers within two large online communities, shedding light on the role of online peer support in enhancing their emotional well-being.

Our investigation into the sentiment changes of topic initiators revealed an immediate elevation in sentiment scores compared with their first self-comment. This initial boost was followed by a gradual yet continuous improvement as the number of self-comments increased, emphasizing the efficacy of online communities in delivering prompt and ongoing peer support to caregivers. Jenkins et al. found that online support can significantly contribute to the well-being [30], suggesting a similar benefit for ADRD caregivers who actively participate in online communities.

Moreover, the continual increasing sentiment temporal trends suggest that online peer support is effective in increasing social inclusion [31], which helps to maintain an emotional balance. A plausible explanation is that long-term online caregivers, when becoming more capable of caring for PLWD through learning from online peers, may sustain stable sentiments. As long-term online caregivers progressively enhance their caregiving skills through continued engagement with the community [32], their increased proficiency makes their caregiving responsibilities more manageable [33], thus improving their overall quality of life.

However, the sentiment trends of long-term users exhibited a slower sentiment improvement rate compared to short-term users. One possible reason could be that the trajectory of caregiver burdens is highly dynamic and complex due to increased behavioral impairment and decline in functional status in PLWD [34]. This complexity makes it unrealistic to remove all the stressors along this often-long-term caregiving journal. In other words, informal caregivers will be in stressful situations, and an upper limit of their emotional well-being may exist even when receiving support from online peers. This complexity is reflected in the findings in Ajrouch K etc. [35] that, although often overlooked in research and service delivery, the role of cultural complexity in ADRD care has been recognized.

Furthermore, our topic modeling analysis identified various ADRD caring topics, including those discussing diagnosis, treatment, daily care, and financial matters. We found that topics discussing personal and heartfelt caregiving experiences exhibited a significant positive correlation with sentiment improvement. For example, an initial post in Topic #9 aligned with this trend: "(rephrased) My husband has been taking [drug] for anger for about [specific] days now, but it's not working. Nothing he's tried seems to work. It drives me crazy." In response, subsequent commentors provided valuable support, sharing experiences with this drug or offering emotional support through sympathy and comfort. These interactions collectively contributed to a more positive sentiment in the self-comments.

However, our topic analysis also revealed that posts associated with ADRD illness and caregiving facilities displayed negative emotional correlations, which might be due to the inherent challenges of ADRD caregiving related to these topics. The complexity of ADRD poses significant emotional and psychological challenges for caregivers [39]. For instance, an indicative initial post from Topic #4 reads, "(rephrased) Hi, I am a full-time carer for my [age]-year-old husband who has vascular dementia and is profoundly deaf. Is there anyone on the forum who is in a similar situation? Thank you." The responses to this post included, "(rephrased) Hi [topic initiator name], my [age]-year-old husband has vascular dementia but without the added complication of being deaf. He lives so much in his own world most of the time that he often seems to be deaf, though. It doesn’t feel nice." These interactions led to the topic initiator's self-comment: "Thank you all for your responses. It seems to be totally deaf and have dementia is quite uncommon. You are right—I do often feel lonely and isolated, as he must as well. I feel very sad." This is a typical example of negative sentiment change resulting from communication with other online users in the community. ADRD caregivers often witness their loved ones struggling with a loss of identity and independence. As caregivers provide care and support for individuals with ADRD, they often experience feelings of sadness, frustration, and helplessness [40]. In this situation, the decrease of sentiment may be caused by the continued narrative of their negative caregiving experience. However, sharing these challenging experiences with other online peers may foster a sense of belongingness among caregivers [41,42], which may lead a long-term sentiment improvement, as shown in our sentiment temporal trends analysis.

Limitations and Future Works

While sentiment analysis tools provide valuable insights, they may not fully capture the intricate nuances and complexity of human emotions within the ADRD caregiving context. Future analyses may consider combining supervised machine learning for more precise sentiment classification. Although our study identified a correlation between topic initiators and positive sentiment change within threads, it's important to delve deeper into understanding whether online interactions directly cause sentiment changes. Further research may unravel the causal mechanisms behind these relationships. Our study only examined the online registered users who write online posts. Since both online communities are open to anyone, there are far more caregivers or even the registered online users who only read rather than write online posts. It will be interesting to investigate how online discussions as collective knowledge can influence their emotional well-being through qualitative research. Such findings will help to expand the impact of online peer support, which is unique to open online communities.

Conclusions

To the best of our knowledge, this is the first study to investigate how sentiment changes among informal ADRD caregivers within two open, large existing online communities using computational methods. We observed improved sentiment trends at both topic thread and community level, highlighting the positive impact of online peer support for both short-term and long-term online caregivers. However, we did find some topics that are negatively associated with sentiment improvement, which reflects the complexity of some caregiving burdens that might not be easily solved at the emotional level. Overall, our findings indicate that peer support in online communities can be powerful in assisting informal ADRD caregivers.

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Conflicts of Interest

Disclose any personal financial interests related to the subject matters discussed in the manuscript here. For example, authors who are owners or employees of Internet companies that market the services described in the manuscript will be disclosed here. If none, indicate with "none declared".

Abbreviations

ADRD: Alzheimer’s disease and related dementia

PLWD: People living with ADRD

VADER: Valence Aware Dictionary for Sentiment Reasoning

LIWC: Linguistic Inquiry and word count

NLTK: The Natural Language Toolkit

STM: Structural Topic Modeling

LDA: Latent Dirichlet Allocation

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