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Exploring the Dynamics of Online Social Support for ADRD Caregivers: A Study on Online Peer Support Groups

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***Abstract*—Alzheimer's Disease and Related Dementias (ADRD) pose substantial caregiving challenges, impacting caregivers' mental health and overall wellbeing. The increasing role of online platforms in providing social support to these caregivers marks an emerging research field. This study seeks to explore the nature of online discussions and social support dynamics within peer support groups for ADRD caregivers. A qualitative analysis was carried out on posts and comments from three distinct ADRD caregiver support communities on two popular online platforms – two sub-Reddits, and ALZ Connected. We found recurring themes across these platforms including the stressors associated with ADRD caregiving. Caregivers on these platforms not only engage in information exchange but share emotional expression, and mutual provision of empathy and courage. Emotional support seeking was found to be more prominent on Reddit than the Alzheimer Association's online support community, ALZConnected. We also found that COVID-19 significantly impacted the support-seeking strategies among caregivers on these platforms. Therefore, these insights underscore the pivotal role of online communities in providing providing relief and guidance to ADRD caregivers. Based on the prevalent support-seeking patterns and discussion themes identified, we propose recommendations for future research and design considerations for online support platforms tailored for ADRD caregivers.**

Keywords*— Alzheimer's Disease And Related Dementias (ADRD); Online Caregiving Communities, Social Media Analysis, Support-Seeking Behavior, Online Peer Support Groups, Online Health Communities

I. INTRODUCTION

Alzheimer's disease and its related dementias (ADRD) pose substantial challenges not only to the afflicted individuals but also to their dedicated caregivers, who bear the weight of providing relentless care and support. The digital age has introduced new avenues for caregivers to find camaraderie and empathy through online communities. This research endeavors to thoroughly analyze data obtained from these virtual communities, aiming to illuminate the prevailing topics within spontaneous online discussions and explore the intricate dynamics of social support among caregivers navigating the complexities of Alzheimer's disease and related dementias.

The digital era has revolutionized the caregiving landscape, with caregivers increasingly relying on virtual platforms to find solace in like-minded peers who understand the intricacies of their unique journeys [1]. Within the platforms, caregivers engage in open dialogues, express their emotions, share insights, and seek advice within a supportive and empathetic environment [2]. By carefully examining the content and interactions within these communities, we seek to identify the most prominent topics and recurring themes that resonate with caregivers, providing valuable insights into the key concerns faced by this community.

Moreover, emotions play a pivotal role in the caregiving experience, influencing the well-being of caregivers and the quality of care they provide [3]. Our investigation delves into the emotional expressions and sentiments prevalent in the posts and comments made by caregivers across the analyzed online communities. Understanding the emotional dynamics within these platforms can shed light on the nature of support exchanged and the bonds formed among caregivers, contributing to a nuanced comprehension of the caregiving experience in the virtual realm.

Furthermore, we aim to explore potential variations in support-seeking patterns between the pre-COVID and post-COVID periods. The outbreak of the COVID-19 pandemic brought about unparalleled challenges for caregivers worldwide, prompting shifts in how individuals sought support and interacted within online communities [4]. By examining any discernible differences in the support-seeking behavior during these distinct temporal phases, we can glean insights into the adaptive capabilities of caregivers amidst the pandemic's adversities and its lasting impact on social support dynamics.

Therefore, in this work, we aim to gain a holistic understanding of online peer support dynamics among ADRD caregivers by addressing three fundamental Research Questions (RQs):

- **RQ1:** What are the prevalent topics and themes in naturally occurring online discussions within the ADRD caregiving communities on social media platforms?
- **RQ2:** How do caregivers' express emotions and sentiments in their online interactions, and how do these emotional expressions influence social support dynamics?
- **RQ3:** Is there a significant difference in the patterns of support seeking between the post-COVID and pre-COVID periods in the online ADRD caregiving communities?

To approach these questions and gain profound insights into the online support space for the ADRD caregivers, we started trough qualitative thematic analysis of textual content from three prominent online communities—namely, the "Alzheimer's" and "Dementia" subreddits, alongside ALZConnected. Our findings reveal that caregivers and family members of ADRD patients actively utilize these platforms for both venting their emotions and seeking diverse forms of ADRD-related assistance, encompassing help-seeking, medication inquiries, validation of feelings, and

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more. Notably, the social support dynamics exhibit variability across different communities. Our contribution lies in its distinction from previous studies, which predominantly focused on individual platforms and overlooked the exploration of emotional boundaries and sentiments expressed within these caregiver spaces. To address this gap, our cross-community study enhances the generalizability of findings, yielding specific implications for researchers, designers, and policymakers involved in online ADRD caregiver communities and similar intervention platforms. We endeavor to illuminate the emotional and sentimental aspects among caregivers and their influence on the dynamics of social support, while also aiming to discern any plausible differences in conversational patterns between the pre-COVID and post-COVID periods. Throughout our discussion, we outline implications for online health community researchers and policymakers.

Our research begins by reviewing previous studies on both offline and online social support for ADRD caregivers, as well as existing support systems. We then detail our data collection and analysis methods, presenting key findings such as user statistics, post content, comments, and online social support dynamics. Finally, we discuss targeted support interventions to enhance the caregiving experience for those impacted by ADRD.

II. RELATED WORK

ADRD caregiving presents substantial emotional, physical, and financial challenges. Access to dependable social support, providing emotional comfort, practical advice, and information, is thus vital in mitigating these burdens [5]–[7]. Research confirms the significant role social support plays in caregiver well-being, from reducing stress and improving mental health to enhancing the overall caregiving experience [8], [9]. Prior work suggests that social support has a significant impact on the emotional, physical, and psychological well-being of ADRD caregivers. Park et al in their study [10] observed associations between social support, self-efficacy, and better psychological well-being in dementia caregivers. Roth et al [11] found that increased satisfaction with social support networks in Alzheimer's caregivers led to reduced depression.. Morris [12] found that higher social support was linked to less perceived strain and depression in dementia caregivers. Finally, Williams et al [13] in their study explored informal social support correlated with better physical health in end-of-life caregivers. These studies emphasize the pivotal role of social support in boosting ADRD caregiver well-being.

Diving into the realm of online health support groups, a multitude of research studies have surfaced valuable insights. Investigations like those by Keyang Zheng et al., Eamar, and J Chung [14]–[16] have provided a deeper understanding of the emotional content, the nature of social support exchanged, and the fulfilment of emotional needs within these online spaces. Cornelia F. et al [17] ventured further to analyze potential disadvantages and exchanges among participants in these groups. Zhao [18] brought forth a gendered perspective, highlighting that female users express more positivity in discussions than males. P Biyani [19] emphasized the importance of identifying sentiments to comprehend community dynamics better. Collectively, this research provides vital knowledge about online health support groups, enhancing our understanding and directing improvements for these crucial digital support mechanisms.

Online support communities have become invaluable tools for ADRD caregivers, offering platforms for connection, advice-sharing, and reassurance. Their anytime, anywhere accessibility is key, providing a secure, anonymous space for caregivers to express concerns without judgment[20], [21]. However, challenges such as misinformation and the impersonal nature of online interactions need acknowledgment. Mckechnie [20], found online forums improved caregiver-ADRD patient relationships. O'Connor [21] discovered virtual groups reduced caregiver stress, depression, and loneliness. Lagervall's work [22] suggested caregivers' online behavior could reflect their mental health, with certain coping strategies indicating heightened distress. Meanwhile, Glueckauf's study [23] outlined the development of an online education network for dementia caregivers, offering crucial lessons for future endeavors. While online communities offer substantial support for ADRD caregivers, it's vital to consider the potential limitations and biases of each platform.

While prior research has provided valuable insights into the dynamics of online ADRD caregiver communities, but those investigations primarily focused on single online platforms, hence lacking a cross-community perspective. This led to a lack of comprehensive understanding of how caregiver support-seeking behaviors might differ across various platforms. Additionally, most studies did not incorporate the profound impact of COVID-19 pandemic, on these communities. Lastly, there is a glaring gap in exploring the emotional nuances within these communities. Sentiment and emotion analysis, crucial for grasping the underlying affective states of caregivers, were largely absent in past research. Our study aims to fill these gaps by adopting a cross-community approach, considering the impact of COVID-19, and introducing sentiment and emotion analysis to thoroughly comprehend the emotional landscape within these caregiver communities.

III. METHODS

A. Data Collection

In our pursuit to investigate major online communities dedicated to ADRD caregiving, we focused on two prominent platforms: Reddit and ALZConnected. Reddit, known for its expansive online forums or 'subreddits', provides anonymity to its users, a critical feature for our study criteria. We carefully selected two specific subreddits, "Alzheimer's" and "Dementia," boasting 23.7k and 11.8k members, respectively, based on their active participation and substantial discussions relevant to our research objectives. Alongside this, we incorporated data from ALZConnected, which exhibited a high level of activity despite the absence of member count visibility. Importantly, our utilization of ALZConnected data was based on information previously collected and analyzed in an earlier research [9], providing a robust comparison point for our Reddit-based findings.

By integrating data from these two prominent online communities, our study aimed to glean comprehensive insights into the emotional landscape and support-seeking behavior of ADRD caregivers participating in these digital platforms. While we acknowledged the existence of other online support groups, such as the "Alzheimers and Dementia Caregivers Support Chat Group" on Facebook, with 10k members, we encountered limited discussion activity due to user identity revelation on Facebook, hindering free sharing of experiences. Additionally, "HopeHealth" and "Family

Caregiver Alliance's Online Caregiver Support Group – Caregiver-Online" conduct discussions through Zoom meetings and email, respectively, making data collection impractical for our study.

By focusing on Reddit and ALZConnected communities, we were able to analyze a comprehensive range of naturally occurring online discussions within ADRD caregiving communities on widely used social media platforms.. While we acknowledge the potential value of exploring additional groups, our study concentrated on the most active and accessible online communities, offering a representative overview of the ADRD caregiving landscape on social media. This approach allowed us to provide valuable contributions to the field of ADRD caregiving support through online platforms.

Using a custom Python script with the Python Reddit API Wrapper (PRAW) library, we collected 2000 top posts from each subreddit, posted between January 1, 2014, and March 2023. Top posts were filtered based on the most upvoted posts during the timeframe. Similarly, Another peer reviewed research study collected 2500 posts using a web crawler from ALZConnected [24]. All these posts were in English, ensuring linguistic consistency for analysis. This approach enabled us to track the evolution and shifts in ADRD-related discussions over time.

Furthermore, we harvested 31k comments associated with these posts to gain deeper insights into the nuances of ADRD caregiving discussions, allowing a comprehensive understanding of the online social support dynamics in these communities.

B. *Data Analysis*

Our initial research question revolves around identifying the prevalent themes and topics within naturally occurring online discussions within the ADRD caregiving communities on social media platforms. To this end, we set our sights on a detailed analysis of the discussions in these online communities.

In order to create a straightforward comparison, we chose to mirror the same problem categories that were identified in the previous ALZConnected study [9] . The categories are symptoms, doctors and nursing homes, general information, conflicts, basic hygiene, emotions of the caregiver, legal/financial, physical safety, medicines, ethics, and solutions. Their study got this category by using three coders going through a subset of posts to manually tag them in each category. Using the same categories allowed us to draw direct comparisons between two distinct online communities, Reddit and ALZConnected, offering insights into any potential shifts in support-seeking behaviors across a significant span of time. The ALZConnected study had covered the period from 2012 to 2016, whereas our study extends the timeline to cover discussions from 2014 to 2023.

A critical part of our analysis involved ensuring objectivity and minimizing bias. To achieve this, we employed Fleiss' kappa statistic [25], a robust measure of inter-rater agreement. This statistic evaluates the degree of agreement between two or more raters when assessing categorical data. In our case, two independent coders were involved in categorizing the data in 11 pre-defined categories. In case of conflicts between two coders, it was solved through an adjudication or coder consensus process, where the researchers collaboratively review and discuss cases of disagreement to reach a consensus. This ensures objectivity and minimizes bias in the analysis.

Our analysis yielded a Fleiss' kappa result of 0.83, denoting 'almost perfect agreement' according to Cohen's interpretation [25]. This robust level of inter-rater agreement underlines the reliability of our categorization process, bolstering the credibility of the findings and subsequent analysis.

To answer our second research question—how caregivers' emotional expressions and sentiments influence the dynamics of online social support—we first dissected community sentiment within each category by analyzing the associated comments. This was executed using the sentiment analysis model based on the BERT base model [26], an advanced transformer-based tool for various natural language processing tasks, including sentiment analysis. Particularly, a python toolkit [27] trained on SemEval 2017 corpus[28] was used to evaluate the sentiment. It is a robust database consisting of approximately 40,000 English-language tweets. Its task is to identify the sentiment—positive, negative, or neutral—within the comments. This approach allowed us to get a broad understanding of the overall sentiment orientation associated with each category.

However, to fully unravel the emotional landscape that colors these online interactions, we delved deeper into the emotions expressed in each category. We accomplished this through a state-of-the-art BERT-based uncased model for emotion detection [29]. Achieving an impressive accuracy rate of 93%, this model is designed to identify a wide spectrum of emotions, thus offering us a more detailed and comprehensive picture of the emotional dynamics within the online communities of ADRD caregivers.

To address the third research question - whether there exists a significant difference in the patterns of support-seeking between the pre-COVID and post-COVID periods in online ADRD caregiving communities - we divided our collected dataset based on the timing of the COVID-19 outbreak. We classified discussions occurring before 2020 as 'pre-COVID' and those from 2020 to 2023 as 'post-COVID.' We then proceeded to analyze the trends in support-seeking posts within these two timeframes. This approach aimed to reveal any notable shifts in the nature and intensity of support needs expressed by ADRD caregivers in the face of the global pandemic, which potentially added unique stressors and challenges to their roles.

IV. FINDINGS

Our analysis of online ADRD caregiver support groups reveals key findings. We examine prevalent discussion categories, compare platforms (Reddit and ALZ Connect), explore emotional dynamics and social support, and note changes in support-seeking behaviors between pre and post-Covid periods. These insights provide a richer understanding of these online communities, presenting valuable implications for researchers, designers, and policymakers within the domain of online ADRD caregiver support.

A. *Prevalence of Major Discussion Categories*

We wanted to gain a comprehensive understanding about the prevalence of major discussion categories within the online support groups for caregivers of individuals with ADRD. To ensure a comprehensive comparison, we adopted the problem categories identified by the ALZ Connected study[24], By analyzing a substantial dataset of two sub-Reddits spanning from 2014 to 2023. To determine the most prevalent themes from both platforms (Reddit and ALZConnected), we combined the data into a single dataset and calculated the total occurrences of each theme. Themes that appeared more than 10% of the time were selected as the most prevalent themes across both platforms. This approach ensured that we focused on themes that were consistently discussed and represented a substantial portion of the ADRD caregiving conversations in these online platforms.

Emotions of the Caregiver: The online communities provided a safe haven for caregivers to express their emotional burdens and vulnerabilities. Through heartfelt posts, caregivers shared their struggles, stress, and the emotional toll of caregiving. A total of 28.5% of the discussions across both platforms revolved around these raw and deeply personal emotions, making this category significantly more frequent than any other. Family members bravely opened up about their innermost feelings, illustrating the immense emotional challenges they face on a daily basis. For instance, one caregiver candidly expressed,

> *" I just want her to die already. She's not my mom anymore. Please just let her die. Please."*

These conversations underscore the critical role of these platforms in allowing caregivers to find empathy, and support from others who share similar experiences.

Symptoms: Discussions within the online support groups extensively revolved around the symptoms experienced by individuals with ADRD. Caregivers openly shared their accounts of witnessing the progressive decline in cognitive and physical abilities. A total of 17.85% of the discussions across both platforms centered on these crucial aspects, indicating their significant prevalence among caregivers seeking support and understanding. for example, a user emotionally expressed,

> *" I knew my mom was getting bad, but she didn't recognize me as her son for the last few days. It makes me very sad when she looks me right in the eye and says I am not her son. I try to keep a brave smiling face, but it gets me down. I just needed to tell someone..."*

These heartfelt stories provide valuable insights into the profound effects of ADRD symptoms on individuals and their caregivers, highlighting the importance of open discussions and support within the caregiving community.

General Information: Caregivers actively engaged in sharing educational content, facts, and statistics related to Alzheimer's disease, enriching the online support groups with valuable resources. These engagements play a crucial role in empowering caregivers, enabling them to make informed decisions and gain a deeper understanding of the complexities of ADRD care. Discussions pertaining to general information constituted a significant portion of the conversations, accounting for a total of 13.26% over both platforms.

Doctors and Nursing Homes: Within the online communities, caregivers openly shared their experiences and sought support while navigating the complexities of the healthcare system, including interactions with medical professionals, hospitals, and nursing homes. These heartfelt narratives encompassed a range of emotions, reflecting the challenges and successes of caregiving within the medical context. Notably, one caregiver's moving account shed light on the value of seeking hospice care for individuals affected by Alzheimer's, offering invaluable insights and recommendations to others. They said,

> *" For anyone with a loved one affected by Alzheimer's, I wanted to recommend asking your doctor if they qualify for hospice care. The patient doesn't need to be near end of life to qualify which is something we didn't know and wished we did. My mom was diagnosed about 6 years ago and is in the later stages of the disease. Her neurologist helped us by making a recommendation to start hospice care and it's been a huge help. As soon as we were approved, they came THE NEXT DAY and did an assessment and by the end of the week they had started coming twice a week to assist with bathing, they brought supplies, oxygen and medications, a social worker and a nurse visited, and other services were offered. All covered by Medicare."*

Discussions related to doctors and nursing homes accounted for a substantial portion, approximately 10%, of the conversations on both platforms combined.

While our study examined a total of 11 themes as previously discussed, our findings suggest engagements around expressing emotions by the caregivers, discussion on symptoms, general information sharing, experiences and suggestions regarding doctors and nursing homes are more prevalent, capturing significant attention and engagement among caregivers. However, it is crucial to acknowledge that the remaining themes, while equally important and relevant, were found to be less discussed in these digital forums. These topics encompassed a range of critical aspects, including conflicts (6.55%), basic hygiene (4.77%), physical safety (4.65%), legal/financial matters (4.42), solutions (4.28), medicines (3%), and ethical dilemmas (2.38). Despite their lower occurrence in online discussions, these themes hold immense significance and play vital roles in the caregiving journey. Our findings underscore the need to pay closer attention to these less prevalent but crucial topics, as they contribute valuable insights to empower and support caregivers facing the challenges of ADRD.

B. Differences and Trends among Different Social Media Platforms(Reddit & ALZConnected)

Exploring ADRD caregiving discussions on Reddit and ALZConnected, two prominent online support platforms, we found intriguing differences in the distribution of discussion categories. These findings offer valuable insights into the unique priorities and patterns within these digital communities. Table I represents the comparison of frequency of the major discussion topics among two significant online community Reddit and ALZConnected.

The most striking difference lies in the prominence of 'Emotions of The Caregiver' posts on Reddit, which account for over half of the total discussions (50.22%), contrasting sharply with only 7.64% of such discussions on ALZConnected. This highlights the unique role of Reddit as a platform where ADRD caregivers extensively share, explore, and validate their emotional experiences.

Conversely, 'Symptoms' related posts were more prevalent on ALZConnected (26%) compared to Reddit (9.70%), indicating that ALZConnected might be a preferred platform for seeking and providing information about disease manifestations.

TABLE I. COMPARISON OF MAJOR DISCUSSION TOPICS AMONG REDDIT AND ALZ CONNECT

Category	Reddit	ALZ Connected
Emotions Of the Caregiver	50.22%	7.64%
General Information	14.00%	12.52%
Symptoms	9.70%	26.00%
Solution	8.08%	0.56%
Doctors And Nursing Homes	5.32%	14.36%
Conflicts	3.10%	10.00%
Physical Safety	2.51%	6.80%
Legal/Financial	1.97%	6.88%
Ethics	1.77%	3.00%
Medicines	1.72%	4.28%
Basic Hygiene	1.58%	7.96%

'Solution' oriented posts were also significantly more common on Reddit (8.08%) compared to ALZ Connected (0.56%), perhaps due to the community-based, peer support dynamics on Reddit that encourages the sharing of practical coping strategies. 'Conflicts' were discussed more on ALZ Connected (10%) than on Reddit (3.10%), possibly indicating the community's comfort in discussing interpersonal issues and seeking conflict-resolution advice. Posts discussing 'Doctors and Nursing Homes' were more than twice as common on ALZ Connected (14.36%) than on Reddit (5.32%), possibly suggesting that ALZ Connected users are more likely to seek or provide advice about professional medical care. Interestingly, 'Ethics', 'Medicines', and 'Basic Hygiene' were relatively less discussed topics on both platforms. However, 'Basic Hygiene' was mentioned more frequently on ALZ Connected (7.96%) compared to Reddit (1.58%), suggesting that personal care issues might be a more significant concern for the ALZ Connected community.

This comparison underlines the unique discussion trends and support-seeking behaviors of the ADRD caregiving communities on these different online platforms, highlighting the need for tailored approaches to offer support and resources to caregivers.

C. *Emotions Expression and Social Support Dynamics*

The sentiment and emotion analysis of various discussion categories within the online ADRD caregiving communities provides a compelling understanding of the emotional tone attached to different facets of caregiving.

Results of Sentiment Analysis: Our sentiment analysis of caregiver community discussions reveals varied patterns. 'General Information' and 'Doctors and Nursing Homes' categories skew towards positive sentiment (40.55% and 39.84%), suggesting that caregivers appreciate useful ADRD info, successful interactions with healthcare professionals, and satisfactory nursing homes. However, 'Conflicts', 'Basic Hygiene', 'Legal/Financial', and 'Physical Safety' show more negative sentiment (42.58%, 37.38%, 37.85%, and 40.54% respectively), reflecting stress from disagreements, challenges in managing personal care, complexities of legal/financial matters, and worries over loved ones' safety. Despite these, 'Emotions of the Caregiver' and 'Medicines' categories manifest more positive sentiments (41.93% and 36.04%), likely due to supportive responses to shared emotional experiences and appreciation of medication benefits. Interestingly, 'Symptoms' discussions exhibit a balanced sentiment distribution - positive (35.58%), negative (34.17%), and neutral (30.25%), indicative of a balanced dialogue on managing symptoms. 'Ethics' has the highest negative sentiment (46.90%), underlining the difficulties of ethical decisions. 'Solution' discussions, marked by a high positive sentiment (58.59%), emphasize the value caregivers place on practical advice and community support. These results, summarised in Table II, portray the emotional landscape in these communities.

TABLE II. RESULTS OF SENTIMENT ANALYSIS

Category	Positive	Negative	Neutral
Symptoms	35.58%	34.17%	30.25%
Doctors and nursing homes	39.84%	30.49%	29.67%
General Information	40.55%	28.34%	31.11%
Conflicts	23.99%	42.58%	33.43%
Basic hygiene	30.33%	37.38%	32.29%
Emotions of the caregiver	41.93%	31.76%	26.31%
Legal/Financial	27.12%	37.85%	35.03%
Physical Safety	24.03%	40.54%	35.44%
Medicines	36.04%	28.27%	35.69%
Ethics	18.30%	46.90%	34.80%
Solution	58.59%	13.84%	27.57%

To supplement our sentiment analysis and achieve a more multifaceted comprehension of caregivers' experiences and interactions across distinct discussion categories, we sought to delve into the emotional aspects associated with each category. This advanced exploration of emotions facilitated a more nuanced understanding of the intricacies of the caregiver journey.

Results of Emotion Analysis: An analysis of emotions across different discussion categories uncovers a common trend: 'Joy' often emerges as the most prominent emotion, followed by 'Sadness' and 'Anger.' Despite the challenges and hardships associated with ADRD caregiving, the overwhelming prevalence of 'Joy' may initially seem paradoxical. However, on closer examination of the comments tagged with 'Joy', it appears that the community's camaraderie and concerted effort to boost spirits is instrumental in this emotion's prominence. The caregivers frequently provide emotional assistance to each other, uplifting the collective mood with encouraging words, sharing moments of positivity, and heartening experiences amid their shared trials.

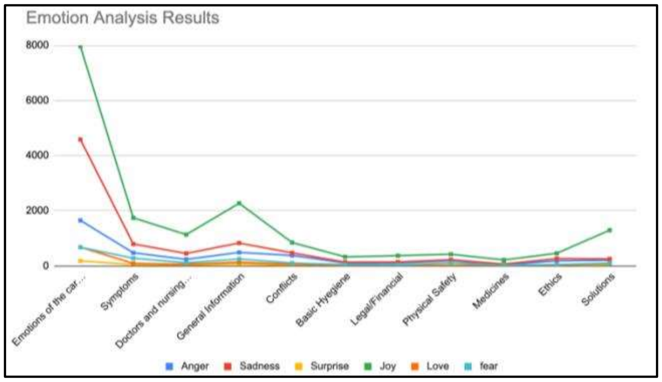

Fig. 1. Visualization of Emotional Analysis

The prevalence of 'Sadness' directly after 'Joy' is reflective of the emotional struggles and distress inherently linked to the caregiving journey. The constant grappling with a loved one's cognitive decline, coupled with the challenges associated with care, often elicits feelings of sorrow and loss, making 'Sadness' a prominent sentiment in these communities.

'Anger' is the third most observed emotion, likely indicative of the frustrations and stressors associated with caregiving roles, from handling patient symptoms to navigating healthcare systems and managing familial conflicts. This suggests that caregivers frequently turn to these communities to vent and seek understanding from peers who are likely to empathize with their experiences.

'Surprise' and 'Love' are generally less prominent emotions across the board. However, a noteworthy exception is observed within the 'Emotions of the Caregiver' category, where expressions of 'Love' supersede those of 'Surprise'.

This is likely due to the personal narratives shared by caregivers, often punctuated with their profound love for the individuals they care for. Amid the hardships, caregivers continue to express love, reinforcing their deep emotional bonds, and possibly drawing strength from these affirmations for their demanding roles.

D. Changes in Support Seeking Behavior during the Pre-Covid and Post-Covid Period

To ascertain whether there is a significant difference in support seeking between the pre-COVID and post-COVID periods, we employed the Wilcoxon Signed-rank test. This non-parametric test was chosen because our data set did not adhere to the normal distribution prerequisite for a paired t-test. Table III represents the summary of support seeking behavior during the pre-COVID and post-COVID period.

TABLE III. TRENDS OF MAJOR DISCUSSIONS DURING PRE-COVID AND POST-COVID PERIOD

Category	**Pre-Covid**	**Post-Covid**
Emotions Of the Caregiver	47.96%	50%
General Information	20.14%	12.69%
Symptoms	7.43%	10.28%
Solution	11.27%	7.41%
Doctors And Nursing Homes	4.08%	5.63%
Conflicts	0.96%	3.65%
Physical Safety	1.68%	2.8%
Legal/Financial	2.64%	1.8%
Ethics	0.96%	1.98%
Medicines	2.88%	1.42%
Basic Hygiene	0%	1.67%

The Wilcoxon Signed-rank test evaluates the null hypothesis that asserts no significant difference between two periods. The p-value (probability of the observed data under the null hypothesis) guides our inference. Typically, a p-value less than 0.05 rejects the null hypothesis, while one greater indicates insufficient evidence against it. In our study, the p-value was 0.0009765625, significantly less than 0.05. Thus, we reject the null hypothesis, suggesting a significant difference in support-seeking patterns pre- and post-COVID.

The table compares discussion category distributions in pre-COVID and post-COVID periods, revealing shifts in ADRD caregivers' online support-seeking during the pandemic. 'Emotions of the Caregiver' constituted half of total discussions both pre and post-COVID, underlining the emotional intensity of caregiving. This category saw a slight increase post-COVID, suggesting the pandemic exacerbated caregivers' emotional distress.

'Symptoms' discussions rose noticeably post-COVID (10.28% from 7.43%), indicating increased concern about symptoms amid pandemic-related health uncertainties. However, 'General Information' and 'Solution' categories saw decreased discussions post-COVID, implying caregivers prioritized dealing with immediate, practical issues over seeking general information or solutions during the pandemic.

Finally, 'Conflicts' and 'Basic Hygiene', while less discussed pre-COVID, had increased discussions post-COVID. The surge in 'Conflicts' might reflect heightened tensions in caregiving during the pandemic, while the rise in 'Basic Hygiene' discussions likely corresponds to new hygiene practices introduced due to COVID-19. This comparative analysis of pre and post-COVID discussions offers unique insights into the shifting dynamics within online ADRD caregiving communities during the pandemic.

These shifts hint towards the changing priorities and concerns of ADRD caregivers in the wake of the pandemic, underscoring the need for targeted support measures.

V. DISCUSSION

The results of this study reveal the prevalent themes of discussions, emotional expressions, and support-seeking patterns in both pre- and post-COVID periods on online communities among ADRD caregivers. This discussion section elaborates on these findings and their implications for research and platform design.

Our analysis reveals several prevalent topics within the online ADRD caregiving communities on social media platforms, suggesting a rich tapestry of discussions reflecting the multifaceted challenges of caregiving. Notably, 'Emotions of the Caregiver,' 'General Information,' and 'Symptoms' emerge as some of the most dominant themes, indicating caregivers' need to express their feelings, share knowledge, and discuss the symptoms of ADRD. These prevalent topics signify the interplay of emotional, informational, and practical aspects within the caregiving journey. By engaging in online discussions revolving around these themes, caregivers seek to navigate the complexities of their roles and derive solace and support from their shared experiences.

The sentiment and emotion analyses provide an insightful portrayal of how caregivers express emotions and sentiments in their online interactions, and the influences of these emotional expressions on social support dynamics. Despite the inherent challenges of caregiving, 'Joy' surprisingly emerges as the most prominent emotion. This is indicative of the resilience and communal support within these online communities, where caregivers uplift each other through shared positivity and mutual understanding. The high prevalence of 'Sadness' and 'Anger' underscores the emotional struggles associated with caregiving, further highlighting the communities' role as a safe space for emotional expression and empathetic engagement. The varied sentiment distribution across different discussion categories elucidates the interplay of positive and negative experiences in caregiving, underscoring the importance of online communities in facilitating balanced and nuanced dialogues.

The comparative analysis of pre-COVID and post-COVID discussions reveals a significant shift in support seeking patterns, as evidenced by our Wilcoxon Signed-rank test results. The increase in discussions under 'Emotions of the Caregiver' and 'Symptoms' categories during the post-COVID period, as well as the decrease in 'General Information' and 'Solution' discussions, signify the heightened emotional distress and immediate health concerns due to the pandemic. These shifts reflect how global crises like the COVID-19 pandemic can exacerbate the complexities of caregiving, altering caregivers' support-seeking behaviors within online communities.

These findings provide a wealth of insights for future research and platform design considerations. Given the significant role of online communities for ADRD caregivers, it is paramount to optimize these platforms to better serve the caregivers' evolving needs. Future research could explore the potential understanding the differences in support-seeking behaviors across diverse caregiver groups, based on factors like relationship to the patient (e.g., spouse, child), caregiving stage (e.g., early, late), and geographical location. As for design considerations, online platforms should prioritize fostering a safe and supportive environment that encourages open sharing of both positive and negative experiences. Tools for quick and easy access to critical resources and personalized recommendations, based on the prevalent topics and sentimental trends, could also enhance the user experience and the overall effectiveness of these platforms.

In conclusion, this study reveals the complex dynamics within online ADRD caregiving communities, shedding light on the central themes, emotional expressions, and changes in support-seeking behaviors amidst global crises. These findings underline the significance of these online platforms as vital support systems for caregivers, illuminating potential avenues for future research and platform design enhancements.

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