Ethics Review

Dementia Research on Facebook and Twitter: Current Practice and Challenges

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Abstract.

Background: Social media is a powerful tool for engaging diverse audiences in dementia research. However, there is little data summarizing current content exchange in this context.

Objective: To inform ethical dementia research engagement on social media, we characterized current practices by analyzing public social media posts.

Methods: We retrieved Facebook (2-year period, $N = 7,896$) and Twitter (1-year period, $N = 9,323$) posts containing dementia research-related keywords using manual and machine learning-based search strategies. We performed qualitative and quantitative content and sentiment analyses on random samples (10%) of the posts.

Results: Top Facebook users were advocacy (45%) and health organizations (25%). On Twitter, academics/researchers were the largest user group. Prevention was the most frequently coded theme (Facebook 30%; Twitter 26%), followed by treatment (Facebook 15%; Twitter 18%). Diagnostics had the highest Facebook engagement. Sharing knowledge was the primary form of content exchange (Facebook 63%; Twitter 80%). Most shared journal articles were peer-reviewed and open access. Emotional tone was overall more positive on Facebook. Justice was a prominent ethics topic regarding inequalities related to identity and intersecting modes of marginalization in dementia research.

Conclusion: The findings indicate the importance of social media as an engagement tool of current topics in health research and reveal areas of potential for increased engagement. These data can inform consensus-based best practices for ethical social media application in dementia research.

Keywords: Access to information, Alzheimer's disease, dementia, internet, qualitative research, social media

INTRODUCTION

As of January 2022, there are approximately 2.9 billion monthly active Facebook users and 436 million Twitter users globally [1]. Social media has the potential to drive greater engagement for dementia research, as people living with dementia, and their advocates and relatives, maintain active online communities [2]. These platforms afford new types of content exchange between dementia researchers and the greater community. There are existing examples of social media use in various health research domains as a cost-effective means to target and recruit diverse prospective participant populations [3–5]. Some dementia studies used social media to increase community awareness and improve recruitment effectiveness, mostly with positive outcomes

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[6–10]. Twitter and Facebook are often used for activism, spreading awareness, and communication between health organizations and members of the public [2, 11, 12]. This dynamic online presence amplifies the reach of social media. To date, however, there is no empirical overview of the dementia research landscape on social media. More data is needed to understand the range of social media usage in the context of dementia research and inform future uses to the benefit of the dementia community.

Dementia is typically a progressive syndrome affecting cognitive function (especially memory loss) that deteriorates beyond a healthy aging trajectory, and results from a variety of brain-related diseases or injuries [13]. Dementia prevention research specifically may benefit from the use of social media to engage healthy individuals or individuals in prodromal stages of the disease. An estimated 40% of dementia cases may be prevented by addressing modifiable risk factors [14]. Dementia prevention, therefore, is a leading priority for many national dementia strategies [15, 16]. Traditional in-person clinical methods may not adequately engage healthy individuals who are not currently seeking treatment [15]. For healthy individuals, popular online spaces on social media provide additional opportunities to interact with prevention research content.

Social media use brings collective research ethics concerns surrounding challenges of informed consent, the blurring of public and private user data, storing and protecting data, and navigating website terms of service. Within health research, traditional biomedical ethics [17] and the four main principles codified in the decades-old Belmont Report are a cornerstone of normative reflection. Frameworks specific to the use of internet and social media platforms have since been developed in response to persistent ethical concerns [18–20]. However, existing approaches are limited to *a priori*, theoretical guidelines that leave an enormous gap for interpretation and contextual application.

There is a growing case for the importance of understanding context to identify and guide ethical norms [19, 21–23]. Limited data demonstrates how users' and researchers' attitudes of social media use vary by research context [24, 25], and variations exist across research discipline norms or research ethics board evaluations [19]. The role of context in ethical research practice is largely attributed to Nissenbaums' concept of contextual integrity [22]. In this view, the foundation of ethical internet research is through contextual understanding of the specific online spaces of interest, as opposed to the application of universal guidelines. One example of ethical misalignment occurs because social media platforms afford relatively easy content distribution; wide reach exposes one's research to both intended and unintended audiences on a potentially large scale. This leads to a context collapse and subsequent researcher uncertainty on the normative expectations of unknown audiences, such as expectations of language [26]. On the back end, ethical tensions surround the duality of online research engagement and the surveillance context entailing disclosure to commercial entities via the monetization of clicks [27]. Some internet frameworks address context using strategies to identify its constructed elements and determine relevance for ethical application (e.g., [22, 23], summarized by [21]). A recent research ethics discussion outlined three dimensions by which to understand social media context from a data, cultural, and commercial viewpoint [21]. Altogether, these arguments support the exploration and delineation of specific research contexts to inform the ethical use of social media.

It remains unclear how to apply existing social media frameworks to guide engagement within the dementia research context. Studies about social media research recruitment focus on targeted advertising or make comparisons with traditional recruitment methods [6, 7, 20, 28–30]. Few approach the subject from the context of dementia research specifically [7]. Other studies examining the content of social media posts either focus broadly on health research [31, 32] or utilize a small sample of posts relevant to dementia [33]. Context as a concept is not clearly defined, which is another barrier to its practical and ethical application. It is therefore necessary to investigate the social media presence of dementia research to identify elements pertinent to its context.

A comprehensive overview of the dementia research landscape on social media is needed to better understand the types of posts that users may encounter. Parameters relevant to the study context include: the user types posting dementia research content, the dementia research topics posted and engagement of these topics, and the format and intended purpose of dementia research content. To build on existing knowledge, the aim of this study is to capture an empirical overview of content exchange practices on Facebook and Twitter within the dementia research context.

MATERIALS AND METHODS

Design

We performed a cross-sectional study using content and sentiment analysis of public social media posts from Facebook (2-year period) and Twitter (1-year period). Data collection took place on 2021-04-16 for Facebook and 2021-08-22 for Twitter. The study methods entail previously established approaches for mining and analyzing social media data [34].

Data collection

Searching for Facebook communities

To create an initial list of Facebook communities, we manually searched Facebook for public pages and groups focused on dementia using various keyword combinations (see Supplementary Table 1). We assessed the page or group by name and created a preliminary list. For each community we recorded the follower or member count, date of last post, date of last research-related post, URL, relevant keywords, and location. Keywords such as "research," "study," and "participant" guided our search for research-related posts within the communities. The definition of research-related was iteratively developed after reviewing the posts from a random sample of communities. Research-related posts are defined in Table 1 and data collection in Fig. 1.

Relevance of Facebook communities

To further refine our sample to include only relevant Facebook communities from our preliminary

list, we reviewed a subsample of the pages/groups to generate inclusion and exclusion criteria. The subsample included Facebook pages and groups with large (>20,000) and moderate (100-20,000) subscriber/member counts. Within these communities, we searched for research-related posts and recorded the following: date of last post, the research study information (university, name of study, type of study), purpose of the post, number of reactions (i.e., likes) and shares, call to action, hashtags, media types (i.e., image, video), screen recordings of the posts and comments, and URL. We quantified the availability of the research study information in each post, reflecting how many clicks a user must go through to acquire the research study information. This pilot data aided in the generation of inclusion and exclusion criteria for Facebook groups and pages. The possible disruption of research activity due to COVID-19 warranted lenient cut-off dates in the exclusion criteria.

Using the search strategy, the preliminary list of Facebook organizations and communities included 132 pages and 82 groups. After applying inclusion and exclusion criteria (Table 1), the final list consisted of 81 pages and 48 groups.

Facebook sample

Using a python script we developed, 48,158 posts were retrieved from the final list of Facebook communities. Manual review of 300 randomly sampled posts helped to refine dementia research-related posts appropriate for analysis. Posts that were determined not to be dementia research-related were scanned for keywords to exclude posts, for example "cycling," "retreat," and "helpline." The inclusion and exclusion criteria for relevant posts are in Table 2.

Table 1
Inclusion and exclusion criteria for Facebook groups and pages

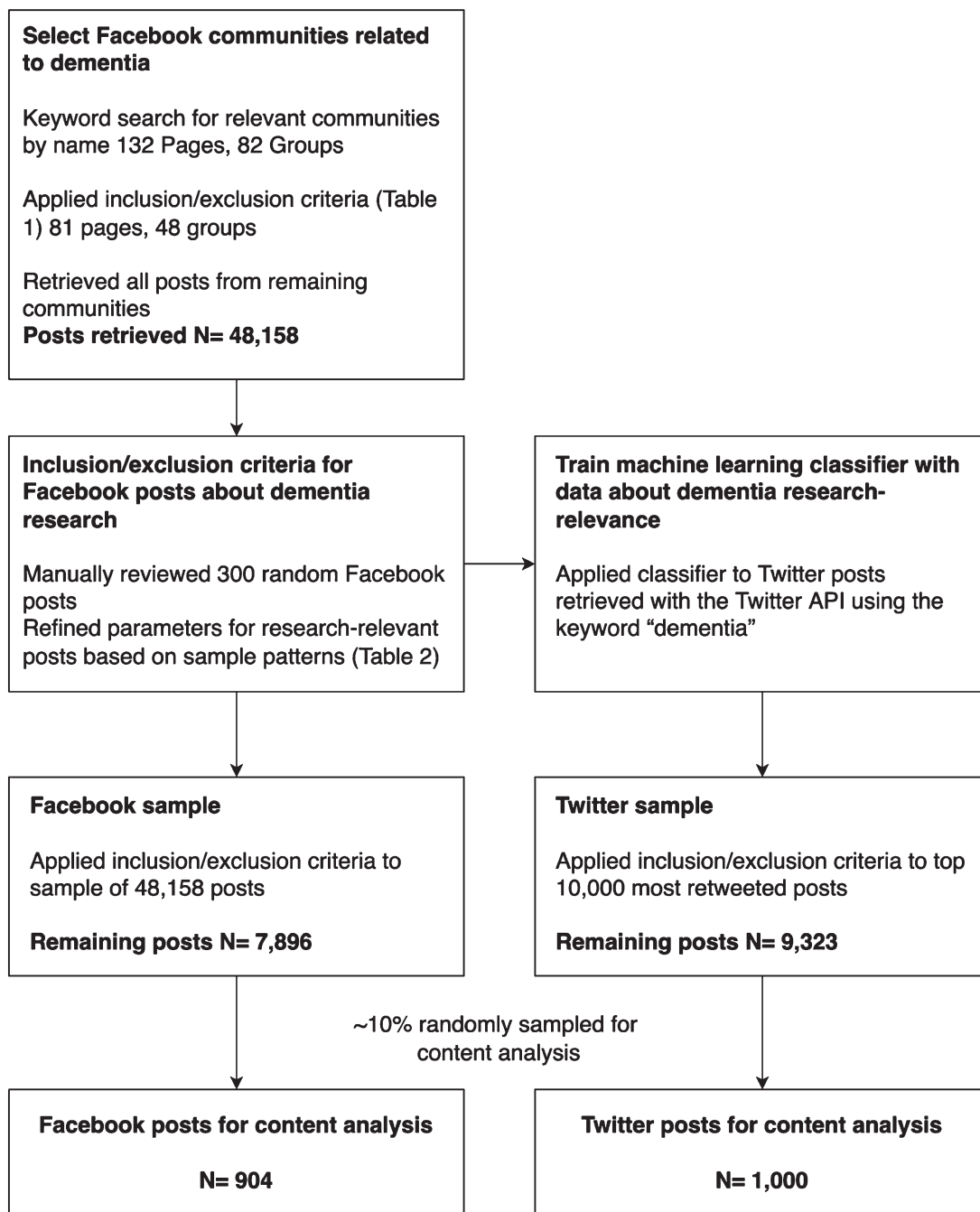| Inclusion criteria	Exclusion criteria
• English	• Not dementia-specific
• Minimum 100 followers/members	• Date of most recent post older than 2 months from date of search
• Dementia-specific page/group name	• Most recent research-related post older than February 2020, with
• Public	**research-related post** defined as a post that includes:
	○ Link/DOI to paper from academic journal (e.g., Nature)
	○ News article about dementia research of any kind (i.e., preventative, therapeutic, experiential)
	○ Requests for feedback on dementia study or study materials
	○ A dementia research organization
	○ Link or media to sign up, engage in, or learn more about dementia research
	■ Media: image, video
	○ Words from a predefined list of research words (e.g., "research," "study") and refers to the content of the research topic
	• Personal blogs
	• Groups with comments turned off

Fig. 1. Flowchart of Twitter and Facebook data collection.

Table 2
Inclusion and exclusion criteria for social media posts

Inclusion criteria	Exclusion criteria
• English	• Only contains a link and no other text in the post
• Dementia-specific	• Contains a keyword identified for exclusion
• Research-related (defined in Table 1)	• Facebook posts older than 2019-01-01
	• Twitter posts older than 2020-08-04

After applying inclusion and exclusion criteria, 7,896 Facebook posts were eligible for content analysis. Application of inclusion and exclusion criteria did not remove all ineligible posts, but it did improve the percentage (40%) of relevant dementia research posts.

Twitter sample

We used a similar approach for Twitter data collection. Twitter's Academic API and the keyword "dementia" produced a list of all the Twitter accounts mentioning dementia in their posts. We made a short-list of accounts, excluding irrelevant accounts (e.g., only tweet about political issues, accounts that cannot be found or deleted all tweets, or bot accounts).

With the Facebook data, we created a social media machine learning classifier to identify dementia research-related Twitter posts ($N = 600,000$). By applying a state-of-the-art transformer language model BERT [35], we implemented a supervised machine learning approach to classify whether the posts were dementia research-related or not with labeled human annotated data. After filtering for inclusion and exclusion criteria, 9,323 of the top retweeted posts were eligible and included for content analysis.

Content analysis

Codebook development followed a qualitative manual coding strategy employed in previous content analysis research [34]. Two researchers (VH, ES) reviewed randomly selected posts from the corpus to develop preliminary categories for the codebook using a combination of inductive and deductive approaches [36]. For each category, the creation of codes and subcodes captured recurring themes within popular categories. Each coder recorded example posts, potential concerns, and preliminary definitions for each code created. We reviewed more posts with the codes for continuous refinement and discussion until intercoder reliability reached 80%, at which point the remaining sample was split between the coders.

We performed manual content analysis on a 10% random sample of Facebook and Twitter posts eligible for content analysis. Manual review included confirming a post's relevance to dementia research; irrelevant posts were removed. Two coders (VH, YJ) used a rich coding strategy to allow the assignment of one or more codes from each coding dimension for each post. All codes developed for the same dimension were mutually exclusive to each other to eliminate ambiguity. Coders took reflexive notes and held weekly meetings to discuss any disagreements to reach a consensus. If new codes arose, we added posts to the coding sample. Coding ceased when thematic saturation was achieved. We quantitatively visualized the results and qualitatively interpreted patterns in the data. Major themes entailed concepts that consistently reappeared and tied together significant portions of the data.

Sentiment analysis

We performed sentiment analysis to determine the emotional tone of dementia research content on social media. We used the general model of MeaningCloud™ (https://meaningcloud.com), an application program interface employed in other types of social media research [37, 38], to measure the sentiment of the posts. MeaningCloud™ uses a rule-based method to express relationships between concepts in a certain context to identify local and global polarity values of a text [39]. The resulting tone of the posts ranged from very positive, positive, neutral, none (no tone), negative, and very negative.

RESULTS

Final samples

The Facebook sample consisted of $N = 904$ posts. The Twitter sample consisted of $N = 1,000$ posts. Table 3 includes a summary of the results shared below. Illustrative quotes for themes are provided in Supplementary Tables 2 and 3.

Social media users sharing dementia research content

On Facebook, 87% of posts were shared by organizations rather than individuals. The top 5 most frequent Facebook user types were: advocacy (45%), health organization (25%), academic/research (15%), health information (5%), and industry (3%). On Twitter, users with at least partially identifying data had the following top 5 user types: academic/research (47%), media organization (10%), health professional (9%), health organization (7%), and academic journal (4%). Some users posted multiple distinct posts in the data set. See Fig. 2.

Table 3
Summary of similarities and differences by social media platform

		Facebook	Twitter
User types			
	Most frequent (N = 95; N = 660)	**Advocacy (45%)**	*Academic/research (47%)*
		Health organization (25%)	*Media (10%)*
		Academic/research (15%)	*Health professional (9%)*
		Health information (5%)	*Health organization (7%)*
		Industry (3%)	*Academic journal (4%)*
Aspect of dementia			
	Most frequent (N = 933; N = 946)	**Prevention/risk (30%)**	*Prevention/risk (26%)*
		Treatment (15%)	*Treatment (18%)*
		Diagnostic (9%)	*Diagnostic (11%)*
		Caregiving (8%)	*Technology (10%)*
		Symptoms (8%)	*ELSI[a] (9%)*
	Most engagement (N = 63,168; N = 95,503)	**Diagnostic (29%)**	*Prevention/risk (26%)*
		Treatment (25%)	*Treatment (26%)*
		Prevention/risk (19%)	*Diagnostic (11%)*
		ELSI (6%)	*COVID-19 effects (10%)*
		COVID-19 effects (5%)	*Technology (9%)*
	Excluding posts by academics/researchers		
	Most engagement (N = 58,688; N = 64,664)	Diagnostic (30%)	*Treatment (34%)*
		Treatment (26%)	*Prevention/risk (27%)*
		Prevention/risk (18%)	*COVID-19 effects (9%)*
		ELSI (6%)	*Diagnostic (8%)*
		COVID-19 effects (5%)	*Technology (6%)*
	ELSI sub-themes		
	Most frequent (N = 72; N = 92)	**Race, ethnicity, & CALD[b] (50%)**	*Race, ethnicity, & CALD (24%)*
		Sex & gender (31%)	*Sex & gender (20%)*
		LGBTQIA2S+(3%)	*Risk-Benefit (17%)*
		Access (3%)	*Access (12%)*
		Socioeconomic (3%)	*LGBTQIA2S+(5%)*
	Most engagement (N = 6,249; N = 6,738)	**Race, ethnicity, & CALD (48%)**	*Risk-Benefit (28%)*
		Sex & gender (45%)	*Sex & gender (23%)*
		Access (5%)	*Race, ethnicity, & CALD (20%)*
		Risk-Benefit (1%)	*Access (9%)*
		Socioeconomic (0.3%)	*Resource allocation (4%)*
Type of post			
	Most frequent (N = 1,092; N = 1,056)	**Research findings (27%)**	*Research findings (46%)*
		General information (20%)	*General information (23%)*
		Recruitment (12%)	*Study/Org update (9%)*
	Poster's own content	45%	*37%*
	Journal articles (N = 34; N = 192)		
	Peer-reviewed	91%	*89%*
	Open access	69%	*78%*
	Most frequent fields	**Healthcare (24%)**	*Neurology & neuroscience (21%)*
		Neurobiology (24%)	*Mental health (12%)*
		Neurology & neuroscience (15%)	*Neurobiology (11%)*
		Public health (15%)	*Public health (9%)*
Sentiment analysis			
	Very positive	6%	*5%*
	Positive	48%	*34%*
	Neutral	14%	*14%*
	No polarity	3%	*2%*
	Negative	21%	*26%*
	Very negative	7%	*20%*

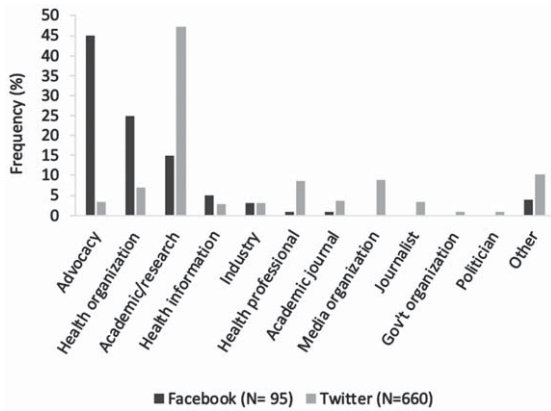[a]ELSI, ethical, legal, and social issues. [b]CALD, cultural and linguistic diversity.

Fig. 2. User Types. Percentage of Facebook and Twitter user types sharing dementia research content. Percentages for each user type are of a total of the N unique users indicated for each platform.

Fig. 3. Dementia research content. Percentage of dementia research themes under 'aspect of dementia' on Facebook and Twitter. Percentages for each theme are of a total of the N codes indicated for each platform.

Content analysis and engagement with dementia research posts

Content analysis of the social media posts revealed two dimensions: 1) aspect of dementia and 2) type of post. Aspect of dementia captured the area of dementia research described in the post. Type of post identified details on the purpose of the post and any supporting media.

Aspect of dementia

Social media posts typically described the specific aspect of dementia research pertaining to the shared content. Some posts included multiple discrete aspects and a minority of posts did not identify one. Dementia research content on social media covered a range of medical, social, and cultural aspects (Fig. 3). Prevention/risk was the most frequently discussed dementia research theme on both Facebook (30%) and Twitter (26%). We grouped prevention and risk into a single theme because they were often difficult to discern in the text. The main areas of prevention research included both primary and secondary strategies to prevent or mitigate risk or delay the onset of dementia. Examples included: modifiable factors, such as individualized diet or exercise, environmental (e.g., pollution) and social factors (e.g., loneliness), and other factors linked to illness (e.g., traumatic brain injury, inflammation) or genetics.

After prevention, the two most frequent themes were treatment (Facebook 15%; Twitter 18%) and diagnostics (Facebook 9%; Twitter 11%). Ethical, legal, and social issues (ELSI) were more frequent on Twitter (9%) over Facebook (7%). Technology
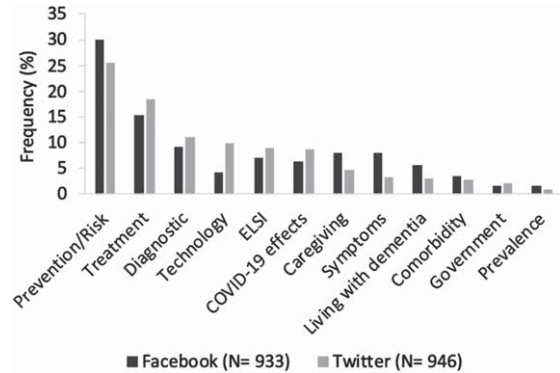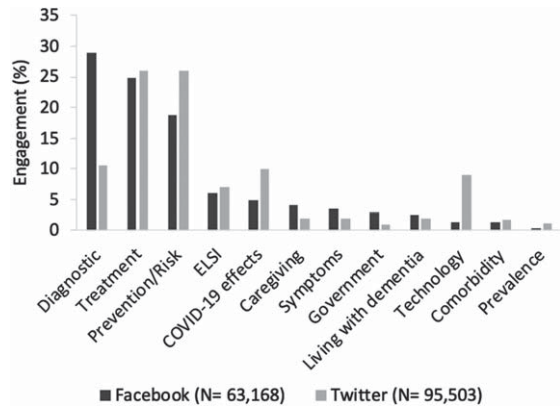

Fig. 4. Engagement of aspect of dementia. Percentage of social media engagement for dementia research themes on Facebook and Twitter. Facebook engagement is a sum of reactions, shares, and comments. Twitter engagement is a sum of likes, retweets, replies, and quote tweets. Percentages for each theme are of a total of the N codes indicated for each platform. ELSI, ethical, legal, and social issues.

was also more frequently coded in the Twitter sample (10%).

Figure 4 shows the engagement (i.e., likes, shares) of posts covering different dementia research topics. On Facebook, posts about diagnostics (29%) received the largest overall engagement in the form of reactions, shares, and comments. Treatment had the second highest engagement (25%), followed by prevention/risk (19%) and ELSI (6%). On Twitter, prevention/risk (26%) and treatment (26%) had the largest overall engagement for likes, retweets, and replies. Following this were posts at the intersection of COVID-19 and dementia research (10%), technology (9%), and ELSI (7%).
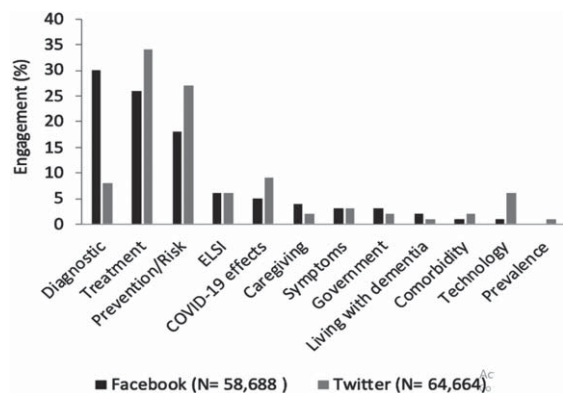
Fig. 5. Engagement of aspect of dementia excluding posts shared by academics/researchers. Percentage of social media engagement for dementia research themes on Facebook and Twitter. Facebook engagement is a sum of reactions, shares, and comments. Twitter engagement is a sum of likes, retweets, replies, and quote tweets. Percentages for each theme are of a total of the N codes indicated for each platform. ELSI, ethical, legal, and social issues.
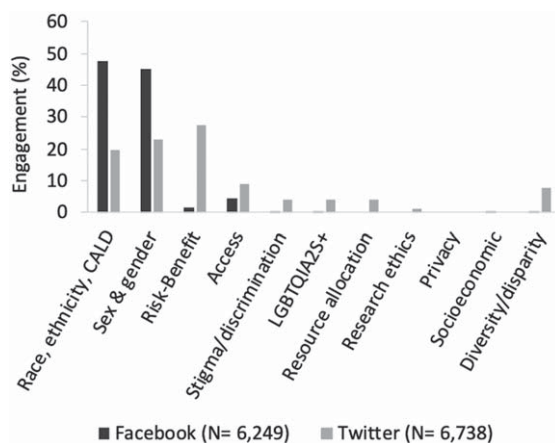

Fig. 6. Engagement of ELSI sub-themes. Percentage of social media engagement for ethical, legal, and social issues (ELSI) in dementia research content. Facebook engagement is a sum of reactions, shares, and comments. Twitter engagement is a sum of likes, retweets, replies, and quote tweets. Percentages for each sub-theme are of a total of the N codes indicated for each platform. CALD, cultural and linguistic diversity.

Figure 5 shows the engagement of dementia research topics excluding posts by academics or researchers. On Facebook, diagnostics (30%) had the highest engagement, followed by treatment (26%) and prevention/risk (18%). On Twitter, treatment (34%) had the highest engagement, with many posts discussing the recent Food and Drug Administration's approval of aducanumab. Second was prevention/risk (27%) followed by COVID-19 effects (9%).

The principles of justice were the primary ELSI sub-themes discussed on social media. These discussions centered around the social determinants of health and inequities in dementia research. Specific themes included: dementia risk and diagnosis, quality of care, treatment delivery, quality of life, and the experiences of individuals impacted by dementia or those working in dementia research. On Facebook, the most frequent specific ELSI sub-themes ($N=65$) were: race, ethnicity, and cultural and linguistic diversity (CALD; 50%), sex and gender (31%), LGBTQIA2S+(3%), access (3%), and socioeconomic disparities (3%). On Twitter, these were ($N=88$) were: race, ethnicity, and CALD (24%), sex and gender (20%), risk-benefit (17%), access (12%), and LGBTQIA2S+ (5%). Sex and gender discussions mostly revolved around health disparities and risk profiles between men and women.

Social media engagement of ELSI sub-themes differed slightly from their coding frequency rankings (Fig. 6). General diversity/disparity had much less Facebook engagement compared to access, espe-

cially for likes and shares. Twitter engagement was the highest (28%) for risk-benefit posts which centered around decision-making for dementia treatments. Regarding the drug aducanumab, mentions of risk-benefit overlapped with health equity concerns over its high cost compared to the limited evidence of benefit. One health organization commented on Twitter: "For many, this price will pose an insurmountable barrier to access..." Another post described a lack of racial and ethnic diversity in the clinical trial of aducanumab as failing to serve communities more heavily burdened by the disease. Outside of risk-benefit, the subtheme of sex and gender (23%) was second on Twitter, followed closely by race, ethnicity, and CALD (20%).

Type of post

The second coding dimension characterized the form of content exchange in each post. It included three major themes describing the purpose of the post: sharing knowledge, sharing personal experiences, and sharing opportunities (Fig. 7). We defined 'sharing' as an exchange or request to exchange. Most social media posts enabled the sharing of knowledge related to dementia research (Facebook 63%; Twitter 80%). Sharing knowledge was primarily in the form of research findings, followed by general information for both platforms. Sharing opportunities (Facebook 28%; Twitter 18%) or sharing personal experiences (Facebook 10%; Twitter 2%) were less frequent.
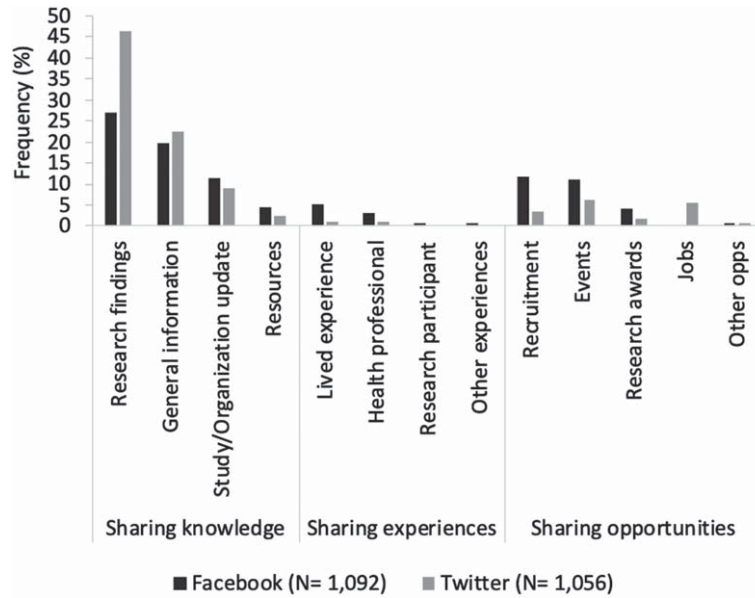
Fig. 7. Purpose of dementia research posts. Percentage of Facebook and Twitter dementia research content by post type. Percentages for each post type are of a total of the N codes indicated for each platform.

Media types on dementia research. Overall, there was a large percentage of external links relative to total posts (Facebook > 72%; Twitter > 79%). Some posts contained multiple links. On Facebook, 45% of users shared links to content created by them or their organization. On Twitter, 37% of users shared links to content created by them or their organization. There were also multimedia components linked or embedded in the posts themselves (i.e., videos, gifs, infographics). On Facebook, the most frequently coded media types were: science news (40%), multimedia (30%), document/webpage (10%), study materials (7%), and form/application (5%). On Twitter, these were: science news (39%), multimedia (28%), journal article (7%), document/webpage (8%), form/application (5%).

Science news was the major media type for both platforms. However, there was a greater percentage of posts sharing journal articles on Twitter ($N = 192/1000$; 19%) than Facebook ($N = 34/904$; 4%). See Fig. 8. Most journal articles were peer-reviewed (Facebook 91%, Twitter 89%) and open access (Facebook 69%, Twitter 78%). A minority of the articles were preprints or working papers. Publication year ranged from 2012 to 2021 (median = 2020) on Facebook. On Twitter, publication year ranged from 2008 to 2021 (median = 2021).
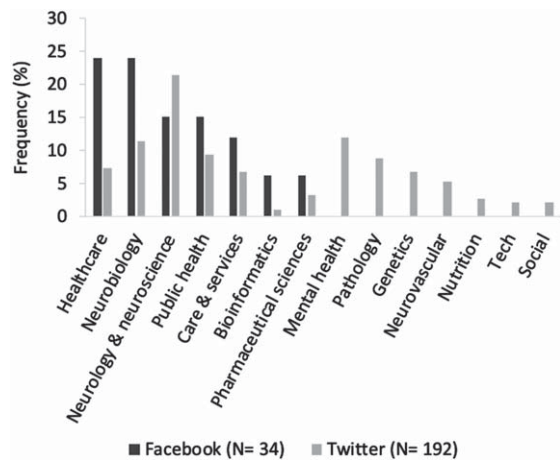

Fig. 8. Dementia journal articles. Percentage of dementia research fields for journal articles on Facebook and Twitter. Percentages for each field are of a total of the N codes indicated for each platform.

Sentiment analysis

Facebook sentiment analysis revealed that 48% of all posts expressed a positive emotional tone versus 21% expressing a negative emotional tone (Fig. 9). Fourteen percent of posts were neutral in tone. On Twitter, emotional tone was more evenly split between positive (34%) and negative (26%) posts. Strongly negative Twitter posts (20%) more
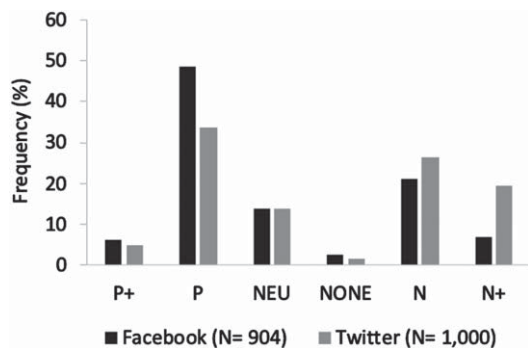
Fig. 9. Polarity of dementia research on social media. Sentiment of dementia research content on Facebook and Twitter. Percentages for each polarity are of a total of the N posts indicated for each platform. P, positive; N, Negative; Neu, Neutral; None, No sentiment;+indicates strong sentiment.

than doubled the percentage of strongly negative Facebook posts (7%).

DISCUSSION

Social media enables the convergence of individuals from various backgrounds to exchange dementia research content. Our aim was to obtain a programmatic capture of the current dementia research landscape on the popular social media sites Facebook and Twitter. This evidence-based summary can inform dementia research practices to better harness social media as an engagement tool and support the imperative of reflexivity by contextualizing dementia research online.

We performed content analysis of dementia research-related posts on social media, revealing the key dementia research themes shared online. The findings suggest that prevention is a dementia research area of major focus in the online content exchange, largely facilitated by advocacy or health organizations on Facebook and by academics or researchers on Twitter. Prevention was a varied theme capturing a range of understandings of dementia risk factors, from biological to environmental and social. Even so, recommendations to protect brain health typically encouraged individuals to make lifestyle changes. Although coded separately from prevention, the large Facebook engagement of diagnostics is consistent with online interest oriented towards the antecedents of dementia. These results parallel the paradigmatic shift in focus to prevention in dementia research more broadly [14, 40]. Earlier studies of general dementia content on Twitter identified other

major themes over prevention, such as prediction [34], stigmatization, and advocacy and awareness [33, 41]. These thematic differences could indicate a progression in online discussions towards active prevention. Our results demonstrate the importance of understanding how contextual spaces foster unique online patterns or perspectives even between overlapping topics, such as dementia research versus broader dementia discourse.

As with prevention, we find that the social determinants of health are salient ethics considerations in dementia research on social media–especially fairness and equity in relation to socio-demographic identity. In these posts, several socio-cultural factors contributed to greater dementia risk and systemic exclusion of certain groups at various levels of research and healthcare. Some social media posts focused on a single aspect of identity and its impact on brain health. One example was the difference in dementia risk between men and women. Other investigative posts highlighted the link between health disparities in dementia and intersecting modes of identity and marginalization (race, ethnicity, CALD, LGBTQIA2S+) [42, 43]. The notable presence of social justice posts on social media are in alignment with burgeoning calls for intersectional [43, 44] and situated [45] approaches to aging and dementia research. The pattern of social awareness in our data is consistent with other research demonstrating collective action on social media. One example is the involvement of people living with dementia in political activism and advocacy on Twitter [11].

The contrast between individual prevention strategies and social justice in our results is relevant to current ethics discussions of personal vs public responsibility. There are criticisms of hyper-individualized responsibility to prevent dementia [46], as this view fails to highlight the social or historical factors interfering with individual efforts to engage in prevention activities [47–49]. Moralizing individual prevention efforts may contribute to the stigmatization of persons who later develop dementia. The influence of societal discourse and its impact on individual views of aging and dementia is documented in areas of personhood and technology adoption [50, 51]. This may be especially true given the wide reach of social media. Future research could analyze how users interpret prevention posts on social media and how this affects ascriptions of responsibility. Furthermore, messaging is an indicator of information quality. An earlier study of online Alzheimer resources found that low quality preven-

tion information focused on nutrition whereas higher quality sources included a balanced assessment of modifiable risk factors [52]. Thus, how prevention messaging is delivered by researchers is of critical importance to avoid confusion, and to encourage constructive engagement of research that involves risk reduction or therapy.

Treatment is still a topic of major interest for users interacting with dementia research content, as evidenced by its relatively competitive engagement with prevention on both Facebook and Twitter. High engagement for treatment posts in our results could be partially explained by events surrounding the recent approval of aducanumab by the FDA [53], sparking much online debate. Aducanumab news contributed to the high engagement of posts weighing risk and benefit on Twitter. We attribute the close association between treatment and risk-benefit in our results with the differing ethics profiles of dementia research on Twitter and Facebook. Ethics concerns surrounding aducanumab included barriers to treatment access (i.e., cost) weighed against uncertain benefit, and limited diversity in the clinical trial participants.

Regarding the types of posts and sentiment analysis, there was some overlap and distinction between platforms. Consistent with previous literature, the primary purpose of most posts was for sharing knowledge in the form of science news [34, 54]. In the dementia research context, Twitter users skewed towards academic and research backgrounds, whereas previous studies of general dementia content found greater numbers of health professionals and the general public [33, 34]. With a higher percentage of academic users in our Twitter data, it follows that there are greater numbers of journal articles, varied research areas, and references to research findings shared on that platform over Facebook. The high percentage of peer-reviewed and open access articles on Twitter suggests that while access to academic data is improved by its availability, it may be diminished from a readability standpoint [55]. Sentiment analysis revealed that Facebook posts had an overall positive emotional tone, whereas Twitter was more divided between positive and negative emotions. This might be explained by differences in platform conventions, such as the polarized activity on Twitter [56].

Comparison with other studies

Our study is different from previous social media work [11, 12, 33, 34, 41] as it is the first overview of its kind for dementia research-specific content exchange on Facebook and Twitter. Previous studies sampled general or limited dementia content on social media and typically from a single platform [11, 12, 33, 34, 41]. We firmly situated our data collection in a dementia research context across two social media platforms. We iteratively created a definition for dementia research content to identify posts. By excluding posts not related to dementia research, our results provide a focused depiction of dementia research trends on social media. Posts were retrieved from a variety of Facebook communities, rather than a single page, forum, or thread. Finally, our study included an analysis of key ethical, social, and legal issues in the dementia research content exchange.

Limitations

We acknowledge the limitations of our study. Given the dynamic nature of social media, our results represent a snapshot of content exchange during a specific period. We accessed publicly available data, and therefore it is possible that private content exchange may exhibit different thematic patterns (e.g., more personal experiences). Facebook data collection occurred over a two-year period whereas Twitter data collection occurred over one year. On Facebook we sampled from a variety of high and low subscriber communities, whereas we focused our Twitter sample on the most retweeted posts. The differences in data collection and sampling may affect the patterns in the data. Our data includes posts from researchers sharing their own work, which may affect engagement numbers. Data analysis did not include an evaluation of the reputation of the source. All the above limit the generalizability of our results in different social media contexts.

Conclusions

Understanding and contextualizing current content exchange practices is critical to guide future social media engagement for dementia research. By summarizing dementia research-specific content on Facebook and Twitter, this study uncovered similarities and differences between platforms, with implications for their potential as tools in dementia research recruitment and engagement. On Facebook, advocacy and health organizations largely facilitated the exchange of dementia research, as opposed to the academic or research-focused users on Twitter. Prevention was a major topic of interest for both platforms. Dementia research posts on the

social determinants of health largely discussed ethics themes of social justice and identity. The focus on promoting brain health supports the relevance of existing social media content to engage healthy individuals in research. This suggests that Facebook and Twitter content reflects current topics in dementia research which may be better harnessed to drive engagement. Future studies of dementia research on social media can investigate online spaces in different languages, how user identity drives interaction, and the qualitative nature of online comments. The uses, patterns, and challenges uncovered in this study will inform a larger examination involving interested parties to develop ethical and practical guidance of social media in dementia research.

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