

Analyzing Twitter-Based Social Networks of Support Communities for Hispanic and African American Family Caregivers of Persons with Dementia

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Abstract. We applied social network analysis to compare Hispanic and Black dementia caregiving networks on Twitter that were established as part of a clinical trial from January 12, 2022, to October 31, 2022. We extracted Twitter data from our caregiver support communities (N=1980 followers, 811 enrollees) via the Twitter API and used social network analysis software to compare friend/follower interactions within each Hispanic and Black caregiving network. Analysis of the social networks revealed that enrolled family caregivers without prior social media competency had overall low connectedness compared to both enrolled and non-enrolled caregivers with social media competency, who were more integrated into the communities that developed through the clinical trial, partly due to their ties to external dementia caregiving groups. These observed dynamics will help to guide further social media-based interventions and also support the observation that our recruitment strategies effectively enrolled family caregivers with various levels of social media competency.

Keywords. social network, Hispanic, African American, Twitter, dementia caregiver

1. Introduction

The prevalence of Alzheimer's disease and related dementia is disproportionately higher for Hispanics and African Americans than non-Hispanic Whites [1]. This identifies an

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outstanding need to forge relationships and networks with Hispanic and Black communities to meet the demands of the dementia caregiving population. Social exchange theory emphasizes the important role of friendship relations in behavioral science [2]. Twitter can improve the delivery of health interventions and increase social engagement and connectedness [2]. However, the “digital divide” could intensify the disparities that caregivers already experience. Despite the enormous potential benefits of technology, caregivers who are not competent in technology may be at risk of digital exclusion and consequently face further health and social inequalities. The purpose of this study is therefore to apply social network analysis of Twitter friend and follower relations to Hispanic and Black dementia caregiving networks in a clinical trial to gain insights regarding levels of social media competency that may be applicable to the recruitment practices and implementation of further studies.

2. Methods

We recruited 811 African American and Hispanic family members of a person with memory issues or dementia using traditional and innovative recruitment strategies, including Twitter advertisements, for a clinical trial from January 12, 2022 to October 31, 2022. We then extracted Twitter data from these caregiver support communities (N=1980 followers, 811 enrollees) via the Twitter API.

We applied social network analysis to quantify community social network effects in the Twitter data using Python [2] and the Python NetworkX module, gathering statistics on the overall degree (number of connections) of each Twitter user and their in-degree and out-degree (number of incoming and outgoing links) to represent the connectedness of the individual to his/her communities [2,3].

Next, we counted the number of isolates in the network (people with no or just a single connection). Last, we applied the Cytoscape network visualization module to this sociodemographic data to facilitate a visual mapping of the analytics [3]. The study was approved by the Institutional Review Board (IRB). Resources and analytic codes are available on GitHub and OSF.io (<https://osf.io/qruf3>).

3. Results

Using the Twitter API to query friend and follower data for the 1980 followers (including 811 enrollees in the clinical trial) of our African American and Hispanic dementia caregiving social support accounts found approximately 4.3 million links among 1.9 million nodes (Twitter users) within the African American caregiver community and 97,076 nodes and 145,618 links within the Hispanic community. The majority of links and nodes derived from a small number of prolific “celebrity” or “super friend” accounts, which tended to be peripheral to the caregiving social support networks (Figure 1) [4].

Considering only the connections between direct followers (both enrolled and not enrolled in the clinical trial) of the social support accounts and augmenting these with data about the total Twitter friends and followers of each member of the caregiver networks proved more effective in evaluating the caregivers’ levels of social media competency. Table 1 provides empirical measurements of the network characteristics illustrated by the visualizations in Figure 1. The African American and Hispanic networks both exhibit significantly higher numbers of connections per participant among

the non-enrolled followers compared to the enrolled, as measured in the numbers of neighbors and incoming (“follower”) and outgoing (“friend”) connections. The non-enrolled participants also have much higher numbers of connections across all of Twitter. These degrees of connectivity can be considered as proxies for social media competency, as can the proportions of isolates in the groups (those whose only connection is to the community account). It is also possible to find small sub-communities in both core networks that contain nodes with large numbers of external connections; on further investigation, these tend to be the accounts of other dementia caregiving organizations who have been connected to the clinical trial through shared interests and participants.

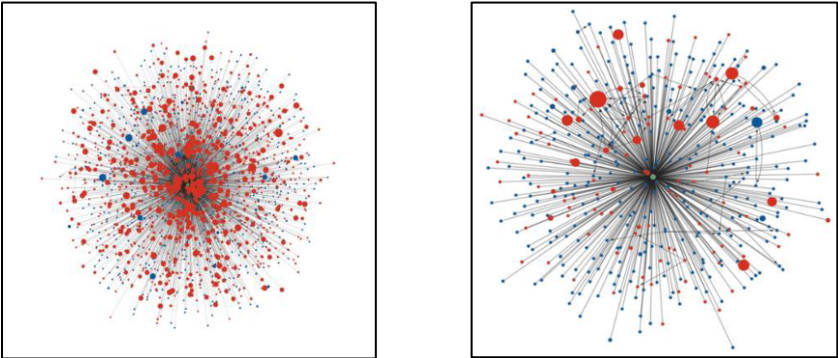


Figure 1. Visualizations of the social networks of our social support communities on Twitter for African American (left) and Hispanic (right) family dementia caregivers (red: non-enrolled followers, blue: enrolled participants, green: the community account; nodes are scaled to indicate their relative numbers of friends/followers on Twitter)

Table 1. Network statistics of the African American and Hispanic social support communities for dementia caregivers on Twitter, including followers of the community accounts who are not enrolled in the clinical trial. Counts of nodes (Twitter accounts) and edges (friend/follower relationships), average node degree (neighbors) and counts of isolates are provided, presenting numbers and proportions in the context of the entire Twitter social network as well as a context that is strictly limited to the caregiver support communities.

		African American		Hispanic	
		Twitter	Caregiver Network	Twitter	Caregiver Network
# edges	Total	4,306,437	747	145,618	47
# nodes	Enrolled	475	475	318	318
	Non-enrolled	1,908,684	1,034	96,758	113
node degree mean (median)	Enrolled	223 (4)	0.116	76.6 (5)	0.09
	Non-enrolled	3,382 (1,498)	1.39	1,024 (86)	0.584
# isolates (%)	Enrolled	11 (2.3%)	440 (92.6%)	3 (0.015%)	296 (93.1%)
	Non-enrolled	93 (4.8e-5)	721 (69.7%)	10 (0.01%)	94 (83.2%)

4. Discussion and Conclusion

This study provides useful insights into the composition of Twitter social support communities that were established as part of a clinical trial recruitment. Other interventions seeking to reach underserved caregiver groups on Twitter or on other social network platforms such Mastodon, a federated, open-source Twitter alternative, are likely to encounter similar levels of social media competency among the enrolled participants and others who may interact with the communities due to their membership

in related groups, or because they are ineligible for the study but nevertheless would benefit from access to the community as a “compassionate care” service. It is important also to note that the findings of our study align with previous research regarding the uneven reach of Twitter and other social media platforms, especially among caregivers of persons with dementia: Twitter use is slightly higher among those with a college education, and although approximately 24% of all online adults use Twitter, younger Americans are more likely than older Americans to use the platform [2,4].

These findings shed light on how to optimize recruitment strategies, highlighting the correlation between digital literacy deficiencies, indicated by a lack of engagement with the larger social media network community, and the ability of the participants to comprehensively access, engage and benefit from the full menu of resources made available through caregiver-targeted online community interventions, [2,5]. Our work not only pinpointed the social media competency gap among the enrolled family caregivers, it exhaustively identified the caregivers who lack social media competency and introduced opportunities to mitigate the gap. Typical caregivers of a person with dementia in the Hispanic or African American communities may have culturally unique barriers to developing social media competency, such as language barriers, low health literacy, low technological literacy, disability, low income, and/or limited access to electronic devices. Surprisingly, device access, language, or trust were not significant issues during recruitment. We have observed that most of our enrollees carried newly released phone devices with up-to-date features, often obtained through a U.S. social program. Further, Hispanics/Latinx were the first group to reach our recruitment goals (N=400). Most participants demonstrated trust of the researchers by waiting in line for 2-3 hours and voluntarily handing over their phones to our team to receive assistance when enrolling. However, the largest challenge was very low digital literacy. Our enrollees with low social media literacy required 10-90 minutes of assistance per person. Innovative strategies are urgently needed to train participants in basic smartphone skills such as downloading apps, recovering login credentials, navigating Captcha “bot” tests, scrolling, and connecting to Wi-Fi or hotspots. The network visualization was useful in elucidating and warning about the digital divide among minority family caregivers who are already disadvantaged.

In conclusion, social network analysis confirms that our recruitment strategies using traditional and innovative methods effectively enrolled family caregivers with various levels of social media competency among African American and Hispanic family caregivers of persons with dementia. Social network analysis and visualization further highlighted digital literacy as a challenge to implementing social media-based interventions among these groups.

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