Recruitment of Caregivers of Dementia Patients: A Research Study Utilizing Social Media

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Purpose

The goal of this feasibility pilot study was to determine effectiveness of online social media recruitment with a goal N of 20 to then extrapolate for a larger advertisement effort for the post-pilot study.

Introduction

Recruitment is an important part of investigative research. Gaining enrollees in research and retaining them can be one of the most time intensive and costly parts of research studies. The recruitment process challenges researchers by necessitating them to cast a large net to obtain a large sample size but also make sure costs in recruitment remain manageable. A large sample size is needed to overcome non-significant findings or underpowered studies, therefore recruitment of an even larger pool of individuals is needed. These challenges emphasize that recruitment should not be discounted when planning a research project as it can affect the statistical analysis of the results and be a laborious process without proper planning.

Social media has considerable reach in getting to the general populace as well as smaller populations with more rare conditions, in large part due to the sheer volume of use of social media by the population at large. Internet accessibility has grown, and access continues to become available to an ever-increasing number of people within the United States – not only through personal computers but also phones. The biggest use of internet browsing has become social media and social media has become ubiquitous in daily life of the American zeitgeist with Facebook, YouTube, and Instagram being large portions. This provides a tempting pool from which research could fish out research participants especially for reaching those niche populations.

Dementia is an umbrella term, covering chronic neurodegenerative diseases, that affects a large population in the United States, with Alzheimer's being the largest portion. Being a chronic process that slowly degrades neurocognitive function over time, dementia slowly incapacitates the afflicted, necessitating custodial care by family members, professional caregivers, or nursing homes. That care can cost up to $1 trillion by 2050 with middle-aged to elderly family members providing the lion's share of that care. These caregivers often use social media as a support mechanism.

Methods

Recruitment of caregivers with dementia through social media was done by making advertisements. These advertisements were run on Facebook utilizing their proprietary "algorithm" to reach the intended audience. The advertisements led to a Facebook Group named, "Patient Centered Injury Prevention" which itself had links to the website created by the research group entitled "Patient-Centered Injury Prevention" at patientcenteredinjuryprevention.org. The site was where potential research participants could find information on safety in dementia concerning general safety, home safety, and firearms safety. The advertisements were built using Canva, which is a site that allows for ease of building flyers, posters, advertisements, etc. Facebook's algorithm keeps track of data which was utilized in determining advertisement efficacy in recruitment of research participants. There were 4 advertisements total in the final running decision and are named as follows: "Your Care, Their Safety", "Staying Safe in Dementia", "Firearm Safety in Dementia", "Staying Safe in Dementia" (Research Version).

Once a potential enrollee saw the ad on their Facebook advertisement side bars, they could click on the advertisement which would take them to the Facebook page. From there they could go to the research website., which had a subpage where they could fill out a questionnaire and email it to the team to determine eligibility.
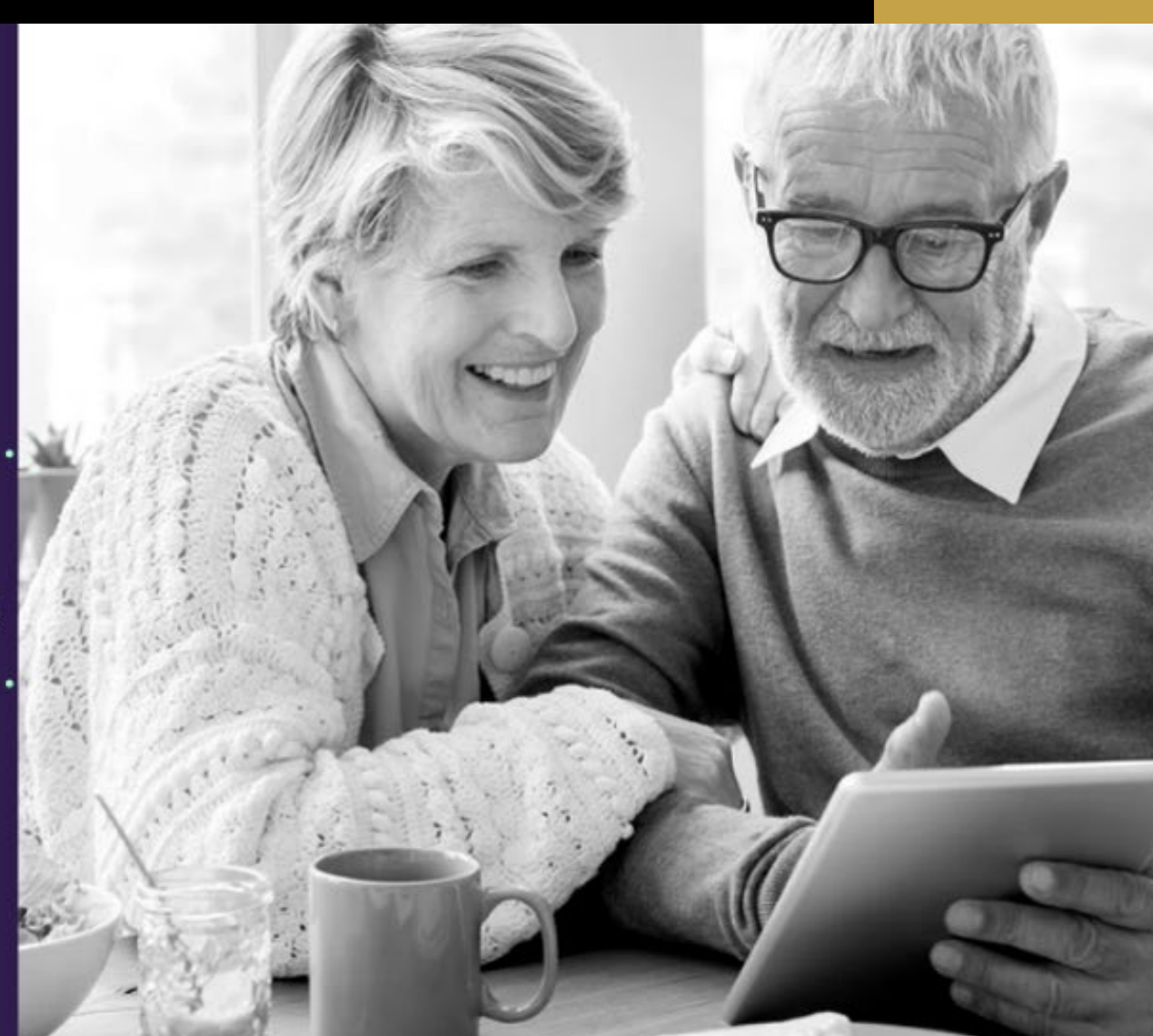
Exclusion Criteria

Eligible participants will be adults (≥18 years) living in the United States who speak English, are not in legal custody or institutionalized, and who are informal caregivers for a community dwelling person with ADRD and firearm access. Participants must have internet access but do not need to live in the same home (or state) as the person with ADRD, but the person with ADRD cannot live in any type of facility because facilities often have regulations prohibiting firearm possession.

Results

Advertising ran on Facebook from March 19th to April 21st reaching 312,682 individuals. From those people 3,188 navigated to the Facebook landing page then 252 to the study website. 16 were able to complete the screening form of which 2 was successfully enrolled.

Figure 1: This figure is the advertisement that was run under the title, "Your care, Their Safety."

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Conclusion

While enrollment during this pilot study was low and lower than contemporary standards this can be attributed to a variety of extenuating factors. Should these be addressed prior to full study then potentially there can be a greater number of enrollees versus the pilot study. Therefore, it can be stated that recruitment via Facebook potentially can be a useful tool if there is simplified navigation from advertisement to screening submission for the potential enrollee.

Table 1: Analytic data regrading specific advertisements (see figures 1-4) including dates run clicks, and enrollments

FB ad version	Date range posted	Amount of time "live"	# of FB ad views	# of FB ad clicks	click rate	$ spent on ad	# clicks per $1 spent on ad	# of clicks to landing page (note: approx. ranges due to limitation w/ analytics)	# of clicks to "study-info" landing page	# completed screening form	# enrolled
"Your Care, Their Safety" version	3/19/21 at 1pm -- 3/24/21 at 2pm	121 hours (5 days 1 hr)	67,294	404	0.60 %	$338.32	1.19	213 - 421	12 - 22	1	0
"Staying Safe in Dementia" version	3/24/21 at 2pm -- 3/30/21 at 5am	135 hours (5 days 15 hr)	64,479	1561	2.42 %	$462.59	3.37	1500 - 1757	108 - 122	12	2
"Firearm Safety in Dementia" version	3/30/21 at 5am -- 4/1/21 at 7am	50 hours (2 days 2 hr)	52,910	480	0.91 %	$197.09	2.44	436 - 663	25 - 46	0	0
"Staying Safe in Dementia" (Research) version	4/1/21 at 7am -- 4/6/21 at 2pm	127 hours (5 days 7 hr)	127,999	1152	0.90 %	$475.84	2.42	952 - 1035	99 - 107	3	0

Table 2: Daily analytic data regarding all advertisements views including clicks to specific pages and enrollments

Date	# of FB ad views	# of FB ad clicks	# of clicks to landing page	# of clicks to "study-info" landing page	# completed screening form	# enrolled
3.19.2021	1969	18	37	5	1	0
3.20.2021	12476	66	18	1	0	0
3.21.2021	20769	99	44	3	0	0
3.22.2021	31376	155	58	2	0	0
3.23.2021	52727	297	56	1	0	0
3.24.2021	71025	440	208	10	0	0
3.25.2021	81044	804	343	30	2	1
3.26.2021	86918	1087	284	17	0	0
3.27.2021	93725	1381	231	16	2	1
3.28.2021	105185	1561	239	17	1	0
3.29.2021	123453	1780	195	18	6	0
3.30.2021	146642	2073	257	14	1	0
3.31.2021	170105	2312	179	11	0	0
4.1.2021	204836	2495	227	21	0	0
4.2.2021	235204	2839	203	22	0	0
4.3.2021	257988	3063	201	21	0	0
4.4.2021	280922	3246	132	17	0	0
4.5.2021	295579	3424	189	18	3	0
4.6.2021	312556	3593	83	8	0	0
4.7.2021	312682	3597	1	0	0	0
4.8.2021	312682	3597	2	0	0	0
4.9.2021	312682	3597	1	0	0	0
4.10 - 4.12	312682	3597	0	0	0	0
4.13 - 4.19	312682	3597	0	0	0	0
4.20 - 4.21 (as of 1pm)	312682	3597	0	0	0	0
TOTAL	--	--	3188	252	16	2

Figure 2: This figure is the advertisement that was run under the title, "Staying Safe in Dementia."

Figure 3: This figure is the advertisement that was run under the title. "Firearm Safety in Dementia."

Figure 4: This figure shows the analytics suite data for the ad version "Staying Safe in dementia (Research)."

Discussion

The purpose of this study was to determine the efficacy of recruitment of caregivers of those with dementia into a research study through social media outreach. In that, the data shows that utilizing social media advertisements is an effective means with which to reach an intended audience. However, this does not necessarily translate to successful enrollments.

Advertisements were run from mid-March to late April which were successful in bringing end users to the Facebook group page. However, as by design, the advertisements led to the Facebook group page, a separate entity from the research website designed by the research team. This multi-step process could lead to loss of potential enrollees through loss of interest, poor clarity of navigation, a feeling of the effort not being worth the time/compensation, and distrust of navigating off Facebook to a 3rd party site.

This data shows that reaching a desired audience through social media advertisements is effective but there is significant drop off before enrollment if there is further navigation required from the social media site. Each step of the process allows for loss of interest or simply end-user error to translate to a lost potential enrollee due to all the "moving parts. Design philosophy emphasizes making the process as simple and streamlined as possible for the end-user to successfully complete a task. Thus, therein lies the rub of gaining sufficient enrollment.

Limitations

This brings to attention the next steps of enrollment research: there should be a simple and streamlined enrollment process from the end-user perspective, there should be attempts to further incentivize enrollment beyond monetary compensation, and there should be diversity in social media platforms used to advertise.

A simpler process for enrollment from the enrollee's point of view can allow for more enrollment because of ease of use. A new process of enrollment can be designed and studied versus this study's results to determine the difference in clickthrough and successful enrollment numbers.

Further incentivization beyond monetary compensation can lead to more enrollment as it would be deemed worth the effort from the enrollee's perspective. This can be done with diversification of enrollment methods most likely done through peers. These can be such methods as social club engagement, peer testimony, or an open forum between peers and researchers. As mentioned in the body of literature there is more success in enrollment with peer involvement adding weight to the potential enrollee's decision for their own involvement. There is a sense of purpose that can be added when a common group is able to work together on a goal that cannot be replicated through dollar amounts.

As well, it is important to stress that reaching large quantities of people itself is important, but there exist limits when using a single platform for advertisement. Facebook, while the most used social media platform and furthermore most used by the potential caregiver population of those with dementia, is a single platform. The body of research shows that when more platforms are used or even when other advertisement avenues are used such as print or radio there is more population reached which tends to end with more successful enrollments.

While social media advertisements can reach a large audience of people there is variance in that population reached. Utilizing Facebook's proprietary "algorithm", which employs users' personal computer web surfing data, leads to more targeted advertising. This necessitates those users be searching for dementia/dementia caregiving/caregiving in their web browsing, which can limit who is reached. In this study, the majority of those reached were middle aged to elderly and female. This correlates to the body of literature showing most caregivers being in those age groups and of that sex. Yet, there is little control of the diversity of that population reached through social media as it entirely depends on end-user involvement in that social media platform. This can translate to a large but more monolithic pool of study participants rather than a more accurate reflection of the intended population.

Further limitations were driven by time and expenses. As aforementioned studies have addressed, there comes a point where recruitment ends, and the study period must begin. A longer run length of advertisements could have potentially led to more enrollments albeit this necessitates more financial support.

Future Directions

Addressing limitations will likely drive more successful enrollment. As this is a feasibility pilot study it is appropriate to look at these limitations carefully and address them for further research endeavors to become more successful in achieving the stated goals. 2 enrollments from roughly 2.5 weeks of advertisements relative to the audience reached is likely caused by the poor ease-of-use which led to significant drop off from the numbers of people reached via advertisement. More enrollment numbers would likely be reached once limitations are addressed and a longer advertisement period is feasible.

Figure 5: This figure is a line graph showing the daily interactions of Facebook users with the advertisements during a period of time in days. The line graph shows the daily interactions on a 10,000 person Y-scale and the time in days on the X-axis. The title number of 273,954 is the total number of people reached from February 28th to August 17th, 2021. Keeping in mind that advertisements were only running from March 19th to April 21th 2021, this shows that during advertising is when the page saw the most traffic.

References

1. Lane, T. S., Armin, J. P., & Gordon, J. S. (2015). Online Recruitment Methods for Web-Based and Mobile Health. *JOURNAL OF MEDICAL INTERNET RESEARCH*, 1-13.
2. Hansen, D., Stephenson, P., & Sheehan, D. (2016). Family caregiver recruitment via social media: Challenges, opportunities and. *International Journal of Palliative Nursing*, 1-6.
3. Kristin L. Corey, M. K. (2019). Utilizing Internet-based Recruitment and Data Collection to Access Different Age Groups of Former Family Caregivers. *PMC*, 1-14.
4. Lynn Huynh, B. J.-H. (2014). Cost-effectiveness of health research study participant recruitment strategies: A systematic review. *Clinical Trials*, 576-583.
5. Dana Hansen, A. A., Amy Petrinec, R. P., Mona Hebesby, P., & Denice Sheehan, R. (2019). Advancing the Science of Recruitment for Family Caregivers. *JMIR NURSING*, 1-11.
6. Karen Morrison, L. W. (2014). Recruiting Community-Based Dementia Patients and Caregivers in a Nonpharmacoloic Randomized Trial: What Works and How Much Does it Cost? *Journal of Applied Gerontology*, 788-800.
7. Ida Darmawan, M., Caitlin Bakker, M. A., Tabetha A Brockman, M., PhD, C. A., & PhD, M. E. (2020). The Role of Social Media in Enhancing Clinical Trial Recruitment: Scoping Review. *JOURNAL OF MEDICAL INTERNET RESEARCH*, 1-15.
8. Jacqueline Lorene Bender, P., Alaina B Cyr, B., Luk Arbuckle, B., & Lorraine E Ferris, L. P. (2017). Ethics and Privacy Implications of Using the Internet and Social Media to Recruit Participants for Health Research: A Privacy-by-Design Framework for Online Recruitment. *JOURNAL OF MEDICAL INTERNET RESEARCH*, 1-14.
9. Jane Topolovec-Vranic, P., & Karthik Natarajan, H. (2016). The Use of Social Media in Recruitment for Medical Research Studies: A Scoping Review. *JOURNAL OF MEDICAL INTERNET RESEARCH*, 1-13.
10. Kayla Herbell, P. C., & Jaclene A. Zauszniewski, P R.-B. (2018). Facebook or Twitter?: Effective recruitment strategies for family caregivers. *Applied Nursing Research*, 1-14.
11. Lattie, E. G., Kaiser, S. M., Alam, N., Tomasino, K. N., Sargent, E., Rubanovich, C. K., . . . Mohr, D. C. (2018). A Practical Do-It-Yourself Recruitment Framework for Concurrent eHealth Clinical Trials: Identification of Efficient and Cost-Effective Methods for Decision Making (Part 2). *Journal of Medical Internet Research*.
12. Antoun, C., Zhang, C., Conrad, F. & Schober, M. F. (2015). Comparisons of Online Recruitment Strategies for Convenience Samples: Craigslist, Google AdWords, Facebook, and Amazon Mechanical Turk. *Field Methods*, 1-16.
13. Whitaker, C., Stevelink, S., & Fear, N. (2017). The Use of Facebook in Recruiting Participants for Health Research Purposes: A Systematic Review. *Journal of Medical Internet Research*.
14. Alzheimer's Association. (2021, November). *Facts and Figures*. Retrieved from Alzheimer's Association:
15. Dementia.org. (2021, November). *Dementia*. Retrieved from dementia.org: https://www.dementia.org/
16. Alieske E. H. Dam, M. P. (2017). Development and feasibility of Inlife: A pilot study of an online social support intervention for informal caregivers of people with dementia. *PLOS ON*, 1-14.
17. Daniel Robert Bateman, M., Erin Brady, M. P., David Wilkerson, L. P., MSW, E.-H. Y., Yamini Karanam, B., & Christopher M Callahan, M. (2017). Comparing Crowdsourcing and Friendsourcing: A Social Media-Based Feasibility Study to Support Alzheimer Disease Caregivers. *JMIR RESEARCH PROTOCOLS*, 1-16.
18. Elizabeth Bartlett, P. K., Elaine Fielding, P., Maria O'Reilly, P. D., Margaret MacAndrew, P. R., & Judy McCrow, P. R. (2018). Recruitment of Individuals With Dementia and Their Carers for Social Research: Lessons Learned From Nine Studies. *Research in Gerontological Nursing*, 119-128.
19. Caryn D. Etkin, C. J. (2012). Recruitment and Enrollment of Caregivers for a Lifestyle Physical Activity Clinical Trial. *Research in Nursing & Health*, 70-81.
20. Leslie, M., Khayatzadeh-Mahani, A., & MacKean, G. (2019). Recruitment of caregivers into health services research: lessons from a user-centred design study. *Research Involvement and Engagement*, 5-7.