

Using Informatics to Engage Vulnerable Populations in Research: Lessons Learned from the COVID-19 Pandemic

George Demiris^a, Jane Chung^b, Anne M. Turner^{c,d}

^a Department of Biostatistics, Epidemiology and Informatics, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA

^b Department of Family and Community Health Nursing, School of Nursing, Virginia Commonwealth University, Richmond, VA, USA

^c Department of Health Services, University of Washington, Seattle, WA, USA

^d Department of Biomedical Informatics and Medical Education, University of Washington, Seattle, WA, USA

Abstract

Social distancing and “lockdown” measures introduced by the COVID-19 pandemic created barriers to recruitment and engagement of community members in research activities. Information technology tools were quickly introduced to allow for virtual participation of stakeholders in research. Vulnerable populations, namely communities with limited access to resources or at a higher risk to experience bias or discrimination, were less likely to engage in such virtual research initiatives. Informatics tools have the potential to support these populations, but existing disparities require a careful consideration of engagement strategies. We discuss three case studies of ongoing research projects targeting vulnerable populations and highlight the role of informatics in facilitating engagement. Target populations include family caregivers of hospice patients, low-income older adults and patients with dementia and their families. We describe strategies to overcome unique challenges introduced by the pandemic, and ways to build a more resilient future.

Keywords:

Vulnerable populations, COVID-19, stakeholder engagement

Introduction

The COVID-19 pandemic introduced many challenges for health care delivery and biomedical research globally. Social distancing and “lockdown” measures introduced barriers to recruitment and engagement of community members in research activities. Information technology tools were quickly introduced to bridge geographic gaps and allow for virtual participation of stakeholders in the research enterprise. This new reality also led to the introduction of “virtual” clinical trials and the proliferation of digital health tools. The ability for individual citizens to participate in these meaningful opportunities was however impacted by inequities both in existing health systems and community infrastructures. Vulnerable populations, namely communities with limited access to resources or at a higher risk to experience bias or discrimination, were less likely to engage in virtual research initiatives. Examples of vulnerable populations in this context include individuals and communities with limited access to digital tools that were found necessary for communication and data collection during the pandemic, those with lack of trust in formal systems of care and academic research, or likely to

experience bias, individuals with limited literacy and/or health literacy.

Informatics tools have the potential to support vulnerable populations but existing inequities and disparities as well as diverse infrastructures require a careful consideration of strategies to engage stakeholders in research in a variety of settings. Our current experiences can help us prepare for a more resilient future where health care crises, whether minor or as major as a global pandemic, do not lead to isolation and exclusion of segments of the population from research.

The purpose of this paper is to discuss case studies of ongoing research projects targeting vulnerable populations and highlight challenges introduced by the pandemic as well as the role of informatics in facilitating engagement for these populations.

Methods

Three case studies involving ongoing research projects targeting vulnerable populations are identified and summarized. For each of the case studies presented here, we describe the overall study purpose, the population served (and why it constitutes a vulnerable population), challenges introduced by the COVID-19 pandemic, strategies to overcome these challenges, and ways to build a more resilient future using informatics tools.

Results

The PISCES Project

Hospice care is conceptualized as quality compassionate care for people facing a life-limiting illness, with services that cover clinical care, pain management, and emotional and spiritual support tailored to patients’ and families’ needs and preferences. Hospice has experienced significant growth in the US in recent years. Family members, spouses, friends or others who assume the unpaid or informal caregiving role are essential to the delivery of hospice services; however, stress and caregiver burden can negatively affect their morbidity and mortality. The emotional needs of individuals caring for dying persons at home are not well attended, and interventions aiming to support hospice caregivers are notably lacking. We designed an intervention called PISCES (Problem Solving Intervention to Support Caregivers in End-of-Life Care Settings) which is a

problem-solving therapy intervention designed specifically for family caregivers of hospice patients. The aim of the project is to examine the effectiveness of PISCES on caregivers' anxiety, depression and overall quality of life.

Recent scientific evidence highlights the importance of understanding the risks and unmet needs of informal caregivers who care for patients at the end of life [1]. The presence of a caregiver in the home is required for admission to many US hospices, because professional caregiving is not available 24 hours a day or designed to replace family caregiving for patients with terminal illness who choose to die at home. In an average day, the primary caregiver of an elderly person will spend more than 6 hours assisting with personal hygiene, medication, household chores, shopping, and transportation [2]. The challenges intensify as patients approach death. Caregivers are at greater risk for depression, deteriorating physical health, financial difficulties, and premature death compared to non-caregivers [3]. These health risks are compounded by the fact that caregivers are less likely to engage in preventive health behaviors, or otherwise attend to their own health needs. In many instances, hospice agencies struggle to provide adequate or frequent support to caregivers as they are faced with a series of challenges. Nearly 25% of hospice patients and families report the need for improved communication and additional emotional support [4]. Translatable interventions that are effective in supporting coping and improving the caregiving experience are greatly needed and hospice caregivers have been traditionally underrepresented in behavioral research.

Social distancing rules imposed by the COVID-19 pandemic had detrimental effects on hospice care as hospice agencies struggled to maintain high quality services while reducing or even eliminating in-person interactions. Additionally, family caregivers were often concerned about additional visitors in their residence and several of the original study protocol procedures (in person consent visit, in person sessions etc.) were no longer possible.

We converted all in-person sessions to virtual ones using commercially available video-conferencing solutions. In order to facilitate this shift, we had to provide flexibility in the selection of hardware and software platforms but also increase the amount of technical support and guidance provided to participants, recognizing that many caregivers did not have access to computer technology or great experience with it. We introduced the use of the regular phone to ensure that participants were not excluded from the study because of their existing residential infrastructure. This required a careful redesign of the intervention sessions, the training protocol and corresponding treatment fidelity checklists. Our interventionists underwent additional training to convert the therapy session procedures to ones that can remain effective and convey empathy even when delivered online or over the phone. We made technical support staff available to ensure that participants could call ahead of sessions to prepare as well as receive information about the best ways to use videoconferencing software and have technical questions answered. Emphasis was placed on facilitating effective communication with participants of varying degrees of literacy, health literacy and computer experience.

The challenges introduced by the pandemic highlighted options to help us build a more resilient future. Hospice agency staff who normally enter people's homes regularly, can include issues of accessibility and preparedness in their regular environmental scan protocol to ensure all their participants have some means to maintain engagement in their existing and potentially new social networks, and be included in activities that will ensure access to digital tools. Ensuring support,

training and infrastructure needs are met for participation in virtual research endeavors can become part of a proactive approach to improving health care processes, and to maximizing inclusiveness and accessibility of current and emerging digital health tools.

The Voice2Connect Project

Staying connected in older adulthood is crucial to healthy longevity and overall well-being [5]. The issue of social isolation and loneliness is particularly important for older adults living in urban, low-income senior housing who often have multiple chronic health conditions, physical disabilities, lack of transportation and limited social capital. Smart speakers and embedded artificial intelligence-based assistants can help older adults in such environment feel less lonely and engage in meaningful social interactions, for example, by providing easy access to communication with others, or sending a reminder about social and leisure activities in the building. We designed a Voice2Connect study, a user-centered design study to examine how smart speakers can support the needs for social connectedness among older adults living alone in low-income senior housing who are primarily African American and to develop prototypes of a smart speaker-based system that can help older adults stay connected and feel less lonely.

Widespread technology access has created new opportunities for social connectedness in older adults. However, traditionally underserved populations, such as low-income senior housing residents who have racial disparities, still face an unequal distribution of technology access due to multiple barriers, including the cost of the technology, low literacy, lack of self-efficacy, and mistrust of the technology [6]. There is a need to explore innovative approaches to help low-income senior housing residents fulfill their social roles and feel less lonely.

The issue of social isolation and loneliness is prevalent in low-income senior housing residents, which has been more exacerbated by the COVID-19 pandemic. In order to protect the senior housing community, social distancing rules have been applied by the property management company, such as a no visitor policy and cancellation of all onsite activities and programs. This has impacted the conduct of the original study protocol and procedures, such as in-person recruitment, screening, baseline health assessment, and focus group interviews. For example, the inability to meet residents and hold information sessions on site has become a critical barrier to subject recruitment. The team had to change the mode of eligibility screening and baseline health assessment from in-person visits to phone-based meetings. Most of the participants do not have access to the Internet or information and communication technology (e.g., computer, smart phone), which did not allow us to use a conferencing technology (e.g., Zoom) to talk to potential participants. Limited cell plans many low-income senior housing residents have is another barrier to phone-based eligibility screening and questionnaire administration. In addition, we had to change our venue for focus group interviews from an on-site community room to a certain location on the university campus. This change in the protocol resulted in additional costs due to the need for providing participants with transportation means and increased research staff time for coordination and preparation (e.g., safe driving training for van rentals). Last but not least, due to the limited ability or inability to meet housing residents in person, it was hard to explain the smart speaker technology, one of the core pieces of information that needed to be shared with potential participants.

A strong academic-community partnership has been noted as a key strategy for the successful conduct of research. During the

study conceptualization and at the beginning of the project, the research team had meetings with the representative of the property management company to get buy-in. The research team's established relationship between the property management company and housing residents was helpful to overcome the recruitment challenges. Specifically, housing representatives identified several residents as potential participants and made referrals to the study team. A resident coordinator from another building actively mobilized an information session outside the building when the COVID-19 cases were decreasing and encouraged their residents to attend the session by providing prizes. She also recommended another senior housing facility as a recruitment site. Housing staff's awareness of what is going on with their residents informed the choice of recruitment strategies (e.g., avoiding "cold calls"). Also, training a resident in each building to be an "ambassador" has been identified as a new strategy to access this hard-to-reach population during the pandemic. The ambassadors were willing to share study information with others and assist with participant identification and recruitment.

The research team needs to understand the sociocultural context of users (e.g., technology experience, health literacy, and disability) and environmental infrastructure (e.g., Internet, cellular services, available technology at the building) where an intended technology will be implemented. Additionally, there is a need to discuss both academic-community partnership and technology sustainability prior to and throughout the informatics research project. Expectations for the potential to deploy technology platforms in the housing building after a community needs assessment and conceptualization project ends should be discussed. Funds for resident ambassador involvement in research activities need to be included in future grant applications. The academic partner should provide an opportunity to community members or intended users to learn about the technology being considered for deployment. This includes group or individual information sessions where target users share concerns about privacy and security and the research team identifies barriers to adoption and use of the technology among the potential users.

The DMAR project

An estimated 6.2 million adults over the age of 65 have Alzheimer's Disease [7]. As their disease progresses, older adults with Alzheimer's Disease and Related Dementia (ADRD) frequently require increased home care, or must transition from independent living to a more supportive environment. Decisions around receiving more supportive care are often difficult and stressful for both the older adult with ADRD and the caregiver. Such decisions require weighing multiple factors such as autonomy, cost, and safety that are influenced by personal values, preferences, and constraints.

Allowing older adults with ADRD to be involved in decision-making has been associated with higher quality of life for the ADRD/caregiver dyad and is important for maintaining personhood [8]. Yet, older adults with ADRD are often excluded from the decision-making process as their disease progresses. Caregivers frequently take on more responsibility for decisions however, studies have shown that caregivers' decisions become less aligned with those of the older adult with ADRD as their disease progresses. Better mechanisms are needed to allow older adults with ADRD to remain involved in decisions about their own care.

The Decision Making in Alzheimer's Research (DMAR) is a 5-year National Institute on Aging (NIA) - funded project investigating how and why decisions are made by individuals with Alzheimer's Disease and Related Dementia (ADRD) and

their caregivers regarding transitions to more supportive care. The goal of the DMAR project is to develop novel strategies for understanding of decision-making processes, and the preferences that influence decision-making, for older adults with ADRD and their caregivers to keep individuals with ADRD meaningfully involved in the decision-making process, even as their cognitive status declines. This research project involves: 1) qualitative interviews with older adults with ADRD, caregivers and providers to gain a detailed understanding of the decision-making processes and key attributes involved in preferences about transitions in care; 2) developing and testing of a dementia care preference tool which can be used for assessing and differentiating preferences of older adults with ADRD and their caregivers; 3) a longitudinal study using the tool will allow for initial comparisons of preferences between older adults with ADRD and caregivers as well as assess consistency in preferences among individuals with ADRD over time.

Funding for this project began in the spring of 2020, when "work from home" orders and social distancing restrictions were being put in place. The original research protocol involved in home or in clinic interviews with an ethnically/ racially diverse group of individuals with ADRD, their caregivers and staff. Participant recruitment was planned to take place through the University of Washington (UW) Alzheimer's Disease Registry, senior centers and community agencies serving older adults. Concern for participant and researcher safety, as well as social distancing and work from home policies, imposed by UW as a result of the COVID-19 pandemic barred in-person access to study participants including individuals with dementia, their caregivers, and staff that work with individuals with dementia. Many of the protocols and methodological aspects the origin study (in-person consent, in person interview sessions, focus groups etc.) required immediate modification to conduct remote interviews. Prioritization of health and safety for loved ones, the increased burden to caregivers and occupation of health care staff with COVID-19 care all presented challenges to recruitment and in conducting interviews. Safety concerns, increased community concerns and competing issues made recruitment of minority ADRD and caregivers particularly challenging. In addition, many potential participants were not familiar and did not possess the necessary experience with remote technologies required to reliably perform online interviews.

All aspects of the recruitment and subsequent interviews with older adults with dementia and their caregivers were affected by the COVID 19 pandemic restrictions. Moving to an online remote (Zoom) format was doable with many participants, but the lack of experience, technology and adequate internet access was an ongoing issue for both participants and research staff. *Screening and Informed Consent:* The choice of screening tests and methods to ensure adequate informed consent were modified for remote administration. *Study Design:* The original intention was to begin interviews with dementia participants, however because of difficulty with access, the decision was made to start remote interviews with staff members, who were more consistently available due to work reductions and had greater experience and comfort with the research process and online platforms. *Privacy and Technical Support:* Arrangements were made for providing the option to have the caregiver present or not, and to move to the telephone, if internet access became problematic either on the researcher or participant end. Added flexibility for rescheduling interviews for another time was necessary. *Minority Recruitment:* Trusted relationships and clearly demonstrated benefits of the research for minority communities were critical to recruitment. The community partners representing vulnerable communities were

themselves under resourced and under-staffed. Additional challenges created by national and local social and political issues to address inequities among racial and ethnic groups were acknowledged and respected.

Discussion

Digital equity refers to whether individuals and communities can readily access and effectively use the technological infrastructure necessary to participate in activities of modern society. As information technology and automation are becoming increasingly pervasive in healthcare delivery and research, digital equity is critical for inclusion of individuals and communities both in high quality health care services and participation in biomedical research. Most deliberations addressing digital equity focus on infrastructure (which may affect rural areas to a greater extent as it relates to the availability of broadband) and on financial means to acquire hardware or digital services to utilize digital tools available for a given infrastructure. The work we describe in this paper confirms these challenges but also highlights an additional one when it comes to digital inclusion of vulnerable populations in research activities, namely the systematic exclusion of these communities from digital inclusion efforts that is exacerbated by potential functional, cognitive or emotional barriers to adoption of just-in-time conversions of traditional services to digital ones. The current pandemic highlighted the responsibility of the informatics community to raise awareness about digital inequities and the impact on vulnerable communities both for daily living and health care access but also for inclusion in research activities. This calls for funding for digital inclusion programs but more importantly a prioritization of digital inclusion when designing informatics systems and tools.

Conclusions

Informatics can play a significant role in building a resilient future for digital inclusion even in times of a health care crisis. This calls for a proactive emphasis on vulnerable populations and a commitment to include representatives of these communities in the design, implementation and evaluation of informatics tools and the reflection of the digital inclusion priority in system design specifications. Additionally, policy initiatives are required; universal broadband, education and training can significantly advance digital inclusion in health care delivery and research.

Acknowledgements

The PISCES project is supported by the National Institute of Nursing Institute (NINR) of the National Institutes of Health under award nr. 2R01NR012213. The Voice2Connect project is supported by the National Institute on Aging (NIA) of the National Institutes of Health under award nr. R03AG069816. The DMAR project is supported by the National Institute on Aging (NIA) of the National Institutes of Health under award nr. R01AG066957. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References

- [1] M. Pinquart, and S. Sorensen, Differences between caregivers and non-caregivers in psychological health: a meta-analysis. *Psychol Aging* **18** (2003), 250-267.
- [2] M. Pilisuk, and S.H. Parks, Caregiving: Where Families Need Help. *Social Work* **33** (2001), 436-440.
- [3] R. Pruchno, M. Kleban, J. Michaels, and N. Dempsey, Mental and Physical Health of Caregiving Spouses: Development of a Causal Model. *Journal of Gerontological Psychological Sciences* **45** (1990), 192-199.
- [4] J.M. Teno, B.R. Clarridge, V. Casey, L.C. Welch, T. Wetle, and R. Shield, Family perspectives on end-of-life care at the last place of care. *JAMA* **291** (2004), 88-93.
- [5] J. Holt-Lunstad, T.B. Smith, and J.B. Layton. Social relationships and mortality risk: A meta-analytic review. *PLoS Med* **7** (2010)
- [6] J.D. Jensen, A.J. King, L.A. Davis, and L.M. Guntzviller. Utilization of internet technology by low-income adults: The role of health literacy, health numeracy, and computer assistance. *Journal of Aging & Health* **22** (2010), 804-826.
- [7] 2021 Alzheimer's disease facts and figures. *Alzheimers Dement* **17** (2021), 327-406.
- [8] C.J. Whitlatch, L.F. Feinberg, and S.S. Tucke. Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *Gerontologist* **45** (2005), 370-80.

Address for correspondence

Corresponding author:
George Demiris PhD, FACMI
418 Curie Blvd
Fagin Hall, University of Pennsylvania
Philadelphia PA 19104
USA
gdemiris@upenn.edu