Assistive and Interactive Technology to Enhance Quality of Life and Independence for Persons with Dementia and Their Caregivers (IRB# 497-20-EP)
Application for 2020-2021 Graduate Research and Creative Activity (GRACA) Grant
Doctoral Student: Sarah Hubner; Faculty Mentor: Dr. Julie Blaskewicz Boron
College of Public Affairs and Community Service; Department of Gerontology

PROJECT DESCRIPTION

The purpose of this study is to investigate the utilization of assistive and interactive technologies (AITs) in persons with dementia and mild cognitive impairment (PWD/MCI) and their caregivers. Additionally, this study seeks to explore the relationship between AIT use and adoption, quality of life (QOL), and caregiving burden. AITs are items, equipment, and product systems which may be used to increase, maintain, or improve functioning capabilities of persons with a disability or modifiable need. These technologies are especially relevant to the cognitively impaired community, as they may improve persons' ability to remain community-dwelling and independent-living longer, a goal for most aging adults. Additionally, use of these AITs may serve to reduce time to care dependency and caregiving burden. Autonomy and independence for the impaired adult, and reduced burden on the caregiver may help to sustain or even enhance QOL for both populations.

For PWD/MCI and their caregivers, remaining community-dwelling with high levels of function is an important goal in disease management. As the number of Americans living with Alzheimer's disease continues to increase (5.8 million people in 2019) this goal also becomes an essential national and worldwide priority (Alzheimer's Association, 2019). It has been estimated that approximately 80% of PWD/MCI receive daily assistance with personal care, a large portion of which comes from unpaid family and friend caregivers (Alzheimer's Association, 2019). This reliance on unpaid assistance may be somewhat alleviated by improving overall independence of PWD/MCI, reducing the length of time that PWD/MCI are in need of assistance, and mitigating the caregiver burden experienced during times of unavoidable care.

The demand for caregivers is growing, while, by 2030, the number of available informal caregivers is expected to decline by approximately 42% (Centers for Disease Control, 2019; Vespa, 2018). This imbalance of care availability to need contributes to caregiver burden, the chronic stress associated with caregiving (Bevans & Sternberg, 2012). The significant burden of dementia may result in financial, psychological, social, physical, and emotional stress for PWD/MCI and their caregivers, influencing QOL (Bevans & Sternberg, 2012). However, AITs may serve as a reasonable intervention to improve PWD/MCI's independence and decrease caregiver burden, bolstering QOL for these individuals. In recent years, there has been a large push to integrate technologies into the lives of PWD/MCI to improve independence and caregiving (Golant, 2017; Hattink et al., 2016). AITs may be especially useful in supporting health and non-health related challenges, instrumental activities of daily living, social integration and connection, and reduction of loneliness (Khosravi et al., 2016).

Given the potential of AITs to positively impact the lives of impaired individuals and their caregivers, this study aims to investigate the needs, preferences, and usability (ease of use and usefulness) of AITs in community-dwelling dementia populations and their caregivers. This is especially useful as it may highlight differences between the needs, use, and preferences between the dyadic caregiver and care recipient populations. Results may reveal evidence regarding the relationships between technology and physical health, mental health, social wellbeing, and personal relationships. The proposed study additionally aims to explore the individual characteristics that may differentially impact needs and technology preferences. The interrelationships between these characteristics and QOL (psychosocial and physical wellness, ability to enjoy life/activities, acceptable standard of health, comfort, and happiness) will be considered. The results of this study will contribute to a greater understanding of how AITs can be utilized to improve autonomy of impaired populations, support adult and caregiver QOL, and improve access to tools to simplify life particularly during the progression of a debilitating disease.

Research Questions and Contributions

This investigation will broaden the larger study's understanding of the relationship between individual characteristics, AITs, and QOL by contributing qualitative data via focus groups and one on one interviews. Additionally, this investigation will diversify the study by contributing additional perspective from non-white populations. Qualitative data and diversification are necessary to provide a more comprehensive scope of research. The research questions for this project are as follows:

1.) What are participants' individual needs, preferences, and opinions of various AITs? Moreover, how do these vary across populations (male/female, white/non-white, PWD/MCI/caregiver, etc.)?
2.) What needs and services remain unmet or inaccessible across populations of interest?
3.) How do individual characteristics affect the caregivers' and PWD/MCIs' life experiences (ability, AIT use, QOL, burden, etc.)?

These questions emphasize the relationships between AIT needs, use, and preferences, as well as their impact on QOL, caregiver burden, and independence. They appropriately give space for sub-analyses on diverse populations to investigate a varied experience. These research questions support the aims of the larger study and will contribute meaningful qualitative and diverse data and interpretations. This research is timely and innovative as it reiterates the value of technology, especially during the COVID-19 pandemic, during which more individuals are relying on AITs to remain connected. Additionally, this study acknowledges the need for increased research on diverse populations and vulnerable groups, such as those with cognitive impairment. Further, this research aims to increase the scope of understanding regarding the experience of PWD/MCI and their caregivers and inform how interventions may be improved for future implementation.

The findings from this research will be presented at the UNO Student Research and Creative Activity Fair in poster form. Additionally, results from this research will contribute to poster submissions for *The Gerontological Society of America Conference* and the *Cognitive Aging Conference*. Goals of this research include manuscript development for submission to a journal for publication. Potential journals include but are not limited to *Innovation in Aging, The Gerontologist, The Journals of Gerontology: Psychological Sciences,* and the *Journal of Alzheimer's Disease.*

Research Methodology

Focus Groups and Interviews. In light of the ongoing COVID-19 pandemic, qualitative data collection will occur virtually via Zoom. For this project, I will conduct caregiver focus groups and one on one interviews with PWD/MCI. A total of three caregiver focus groups, consisting of approximately five individuals in each group will be conducted; ten one on one PWD/MCI structured interviews will be collected. These qualitative data collections are proposed as part of an ongoing needs assessment, partially funded by a 2019/2020 Nebraska Collaboration Planning Grant. PWD/MCI participants will be aged 65+, living independently in the community, and fluent English speakers. These persons will self-identify as having dementia or cognitive impairment and will be assessed and deemed capable of consenting for themselves. Caregivers will be aged 19+, fluent English speakers, and will be providing regular/daily assistance to a PWD/MCI aged 65+.

Virtual sessions will be guided and will explore participant AIT familiarity, interest, and adoption; AIT trust, concerns, dislikes, and likes; daily activity ability and disability; functionality of AITs for sustaining independence; and QOL in relation to daily activity and AIT use. Questions will be aimed at participants themselves and/or care recipients as appropriate. This methodology is supported by Miller et al. (2018) and previous methodology used in a complimentary study from our lab (IRB#115-20-EP). Technologies discussed may include but are not limited to in-home devices (i.e., smartphones and tablets), transportation, and medical technology.

Subsequent to focus group and interview collection, all audio will be transcribed and qualitative analysis will occur. For example, themes from the interviews will be identified, and relevant quotes will be extracted. Data analysis will occur in R. Participants will be compensated $30 for participation.

Additional Data Collection. As of January 21st, 2021, the currently collected data pool of caregivers is 93% white and female. To access a more diverse sample, it is necessary to expand the reach of the study beyond our immediately accessible area (Nebraska and Iowa). To achieve this goal, we will

conduct additional needs assessment surveys via Amazon Mechanical Turk (MTurk). Amazon Mechanical Turk is a crowdsourcing marketplace that allows for matching participants with surveys. MTurk gives researchers access to a "diverse, on-demand, scalable workforce" (Amazon Mechanical Turk Inc., 2018). MTurk eliminates the need to collect participant information for compensation, as surveys are pre-purchased, and 'workers' are compensated anonymously (Amazon Mechanical Turk Inc., 2018). To diversify the study, we will collect an additional round of samples with targeted oversampling of non-white populations. Female and male groups from white, Black, Hispanic, and American Indian/Asian populations will be targeted independently with a goal of n=30 per population.

Project Timeline

Month (in 2020)	Project Phase	Research Activities
March – April	Data Collection	Recruiting focus group participants and conducting surveys as part of larger study
May– July	Qualitative Data and Additional Data Collection	Conducting focus groups and interviews, conducting additional surveys (via Amazon MTturk)
June – July	Data Digitization	Qualitative data will be transcribed; surveys will be digitized and cleaned
July – August	Data Analysis	Complete analysis of project data
Fall Semester	Deliverables	Drafting of manuscripts; conference and journal submissions

Student/Faculty Mentor Roles

Doctoral Student: Sarah Hubner, College of Public Affairs and Community Service, Department of Gerontology. As the researcher for this project, I will be responsible for 1) recruitment and data collection, 2) applying for IRB change request/approval as necessary, 3) transcribing focus groups/interviews and digitizing data, and 5) analyzing all data. Subsequently, in the 2021 fall semester, I will conduct work on products and deliverables via an independent study/dissertation credit.

Faculty Member: Dr. Julie Blaskewicz Boron, College of Public Affairs and Community Service, Department of Gerontology. Dr. Boron is my advisor, the chair of my doctoral committee, and one of the Principal Investigators for the larger study. Dr. Boron will provide advice and guidance in the aforementioned student responsibilities. Dr. Boron will also assist in identifying research participants, will monitor/moderate data collection and analysis, and provide feedback on deliverables.

Previous Internal Funding.

I have not received any previous funding for this research project. I did receive a GRACA for the 2019-2020 funding year for a complimentary project (IRB# 115-20-EP). Although the research goals are similar, this project is distinct from my previous GRACA as it targets PWD/MCI age 65+ and their caregivers as opposed to adults age 60+ and their caregivers. Additionally, this project seeks to include supplemental focus on diverse populations, targeting non-white participants. PWD/MCI and their caregivers face specific challenges in aging, disease progression and maintenance of autonomy; these challenges are exacerbated in non-white groups. PWD/MCI in general are a difficult population to access and require a higher level of assistance in order to remain community-dwelling longer. These factors necessitate an independent investigation into how AITs may mediate the aforementioned challenges, with special attention given to non-white participants. The implications of this investigation may inform interventions and technologies to improve PWD/MCI and their caregivers' QOL. Results from this study may also be generalized to other individuals living with disabilities, ultimately informing interventions and technologies for a variety of populations aimed at improving autonomy and reducing dependency.

BUDGET JUSTIFICATION

The total amount requested for this grant is $5000. The proposed stipend budget reflects the time allotment at a standard graduate student pay rate of $10 per hour.

Project Phase	Details and Justification	Time/Pay Allotment	Budget
Data Collection (March-April 2021)	Recruiting focus group participants and conducting surveys as part of larger study	40 hours	$400
Qualitative Data (May-July 2021)	Conducting focus groups and interviews	20 hours	$200
Data Digitization (June-July 2020)	Qualitative data will be transcribed; surveys will be digitized and cleaned	110 hours	$1,100
Data Analysis (July-August 2020)	Complete analysis of all project data	75 hours	$750
STIPEND SUBTOTAL			**$2,450**
Qualitative Data (May-July 2021)	Participant pay for focus groups and interviews	$30/participant, 25 participants	$750
Additional Data Collection (May-July 2021)	Conducting additional surveys targeted at non-white populations and white males (via Amazon MTturk)	Approximately $7.50/survey, 240 surveys	$1,800
SUBTOTAL DIRECT COSTS			**$2,550**
TOTAL COST FOR PROJECT			**$5000**

Associated Sources of Income

I have been a Graduate Research Assistant (GRA) for the Department of Gerontology (12-month appointment) since July of 2020 and am under the current guidance of Dr. Julie Blaskewicz Boron. I engage in a variety of departmental tasks, and my time is devoted to research. My current research responsibilities include manuscript development and project management for multiple projects including two technology and aging projects and two technology and COVID-19 projects. Through this funding, I am able to devote 20 hours per week to research, during which I dominantly spend my time working on short-term goals, immediate deadlines, and coordinating with other students on the project(s).

Funding for this project would allow for important additional data collection. This added data would contribute relevant qualitative data and would also serve to diversify our dataset. Personal stipend for this project would allow me to devote additional time to this specific project. This would also allow me to conduct the labor and time-intensive focus group/interview process. Devoted time would also allow for increased time for development of deliverables. This is to the benefit of Dr. Boron and her co-PIs. This is also to my academic benefit and will provide significant data for future publications and dissertation work in the fall.

Additional Expenses

Access to journals is available through the University of Nebraska Omaha's library at no additional cost. Additionally, the College of Public Affairs and Community Service has a variety of statistical software programs available for data analysis. R Linux, a free statistical software, is also available for data analysis.

References

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February 4, 2021

TO: GRACA Award Committee
FR: Julie Blaskewicz Boron
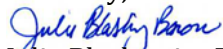RE: Letter of Mentor Support, Sarah Hubner

I write this letter in strong support of Ms. Sarah Hubner's GRACA application. Ms. Hubner is pursuing her Doctoral Degree in Gerontology. I am the Doctoral Program Chair and serve as chair of Sarah's dissertation committee. As her primary research mentor, Sarah has been my graduate assistant (GA) for the past three years, focusing on how cognition and cognitive change affects daily life, functioning, and independence. She has been involved in projects investigating dementia risk, and the impact of technology on quality of life (QOL) in aging individuals and caregivers. This includes ways technology can be used to support aging individuals with varying cognitive, psychological, and/or physical needs. In her time as a GA, Sarah has learned how to collect and process the data, construct hypotheses, and conduct analyses to test the hypotheses. She has gained experience preparing IRB applications, writing abstracts, presenting at conferences, and developing her skills to contribute to peer-reviewed manuscripts. She currently has two full manuscripts drafted from prior work ready for peer-review. Ms. Hubner has been very thorough in reviewing literature to have an interdisciplinary understanding of cognitive aging. She has devoted copious amounts of time to learn how to be a researcher and writer, contributing to the necessary skill set for success on her proposed GRACA project. My experience with Sarah as a researcher and student in my courses shows that she is motivated, reliable, organized, and strives to manage multiple tasks and commitments successfully. I believe Sarah's experiences make her well prepared to achieve her goals in her GRACA proposal.

In regards to collaboration, Sarah's GRACA application has the goal of specifically focusing on supporting aging individuals with mild cognitive impairment (MCI) and/or dementia as well as caregivers to these individuals. An additional note is her interest in recruiting minority populations, which is essential to understanding the needs of all aging individuals. The purpose of this research will be to focus on technology in the home that can be used to assist aging individuals with dementia or MCI and/or caregivers with the overarching goals of improving QOL and maintaining independence. Adults aged 65+ with a diagnosis of MCI or dementia as well as informal caregivers represent steadily increasing segments of the population, thus supporting these individuals' needs is imperative. Understanding how technological advancements may help meet these needs is timely, particularly in light of the increased need to utilize technology to communicate during the ongoing pandemic. As Sarah's faculty mentor, I have provided her with constructive feedback on her proposal. We will meet weekly throughout the duration of the project, setting goals for the upcoming week to ensure that progress is being made, challenges are addressed, and that she is developing the necessary skills and abilities to be a published researcher. Sarah's knowledge and skills are noteworthy, as she has taken great strides to develop hypotheses of her own, as is evident with this proposal.

The project to be used in Sarah's GRACA application has been approved by the IRB and would require minor modifications. The requested money will help support Sarah over the summer months, and contribute to additional data collection, particularly for obtaining a more diverse sample. Ensuring that Sarah can focus on her research will help her further her research, analytic, and writing skills, all of which will contribute to her dissertation work.

In closing, I strongly recommend that Sarah Hubner be a GRACA recipient. I am enthusiastic regarding this recommendation, and look forward to helping Sarah continue to develop as a researcher, scientist and professional in the field of Gerontology. I hope that she will earn this award to help support her development. If I can provide you and your colleagues with any additional information, please do not hesitate to contact me.

Sincerely,

Julie Blaskewicz Boron, Ph.D.
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