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## Remote Monitoring Technologies in Dementia Care: An Interpretative Phenomenological Analysis of Family Caregivers' Experiences

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## Remote Monitoring Technologies in Dementia Care: An Interpretative Phenomenological Analysis of Family Caregivers' Experiences

### Abstract

The desire to maintain an independent lifestyle is one shared by an increasing number of older adults. Adult children, spouses, siblings, and other relatives, also known as family caregivers, play an integral role in helping their loved ones maintain independence. Remote monitoring technologies (RMTs) such as wearable sensors, mobile emergency devices, smartphone apps, and webcams can be used to monitor, sense, record, and communicate a person's daily activities. However, understanding is limited of the family caregiver's needs and perceptions of RMTs used in a home-based setting. The purpose was to explore how family caregivers perceive RMTs and their use for monitoring and supporting their care recipients who choose to live independently. We used a survey to capture some basic characteristics of family caregivers, what they know about RMTs, and to recruit interview participants. We conducted semi-structured interviews with four participants who shared the commonality of caring for a relative with dementia. We reported the survey data using descriptive statistics and we applied interpretative phenomenological analysis (IPA) to analyze and report results from the interviews. Four themes emerged including the unique relationships that exist in family care, the risk-benefit conundrum that accompanies benefits and tradeoffs of RMT use, human-technology interaction and usability, and the importance of creating tailored solutions to facilitate RMT adoption and use. Our findings provide insight into factors impacting adoption and use.

### Keywords

Remote Monitoring Technology, Family Caregivers, Aging, Dementia, Interpretative Phenomenological Analysis

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# Remote Monitoring Technologies in Dementia Care: An Interpretative Phenomenological Analysis of Family Caregivers' Experiences

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*The desire to maintain an independent lifestyle is one shared by an increasing number of older adults. Adult children, spouses, siblings, and other relatives, also known as family caregivers, play an integral role in helping their loved ones maintain independence. Remote monitoring technologies (RMTs) such as wearable sensors, mobile emergency devices, smartphone apps, and webcams can be used to monitor, sense, record, and communicate a person's daily activities. However, understanding is limited of the family caregiver's needs and perceptions of RMTs used in a home-based setting. The purpose was to explore how family caregivers perceive RMTs and their use for monitoring and supporting their care recipients who choose to live independently. We used a survey to capture some basic characteristics of family caregivers, what they know about RMTs, and to recruit interview participants. We conducted semi-structured interviews with four participants who shared the commonality of caring for a relative with dementia. We reported the survey data using descriptive statistics and we applied interpretative phenomenological analysis (IPA) to analyze and report results from the interviews. Four themes emerged including the unique relationships that exist in family care, the risk-benefit conundrum that accompanies benefits and tradeoffs of RMT use, human-technology interaction and usability, and the importance of creating tailored solutions to facilitate RMT adoption and use. Our findings provide insight into factors impacting adoption and use. Keywords: Remote Monitoring Technology, Family Caregivers, Aging, Dementia, Interpretative Phenomenological Analysis*

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## Introduction

The desire to maintain an independent lifestyle is one shared by an increasing number of a special population of older adults recognized as individuals who desire to “age in place” (Jaschinski, & Allouch, 2019). Referred to as family caregivers, family members often play an integral role in helping their loved ones live independently (Hwang, Truong, & Mihalidis, 2016; Mynatt, Melenhorst, Fisk, & Rogers, 2004; Waseem, 2013). Family caregiving is a type of informal caregiving. Family caregivers are usually unpaid to provide support ranging from regular phone calls to check in on their loved ones to a more hands-on role of providing assistance with activities of daily living. Examples of activities of daily living include bathing, dressing, shopping, managing money, providing transportation, and administering medication. Informal caregivers often play an integral role in helping their loved ones age in place.

Advances in ambient and remote monitoring technologies (RMTs) facilitate the ability for older adults wanting to age in place, to have personalized, patient-centered, and preventative care. Using a socio-technical model known as smart and connected health (SCH), software and hardware solutions are being designed to manage chronic illness, monitor symptoms, and improve quality of life (Carroll, 2016; Gutierrez & Ochoa, 2017).

RMTs that sense, record, and communicate various activities of older adults who are living in their homes can benefit family caregivers and care recipients alike (Hwang, et al., 2016). Digital health tracking is being recognized as a new wave of preventive care (Harvard Health Letter, 2018). Developments persist to bring to the consumer market products of a new generation of sensor technologies that monitor and transmit data in remote and in physical ways, for example, smart tattoos detecting vital signs, orthopedic clothing with heat sensors, and ingestible digital pills to record and send information when a drug is taken, and many other healthcare-context product solutions (Harvard Health Letter, 2018).

There are more questions about benefits and concerns about RMTs and digital health tracking than there is research about how RMTs actually are beneficial. Some of the early RMTs have been noted for their utility. For example, Rowe, Kairalla, and McCrae (2010) found the use of a nighttime home monitoring system to track movements of a care recipient who had dementia decreased the caregivers’ worry and improved “peace of mind” and perceived sleep quality. The digital family portrait in-home monitoring system supports connection and awareness by informing “family members about a relative’s daily activities, health status, and potential problems” (Mynatt, et al., 2004, p. 38). There are several RMTs currently on the market. For example, Alarm.com ([www.alarm.com](http://www.alarm.com)) offers a wellness service that enables family caregivers to monitor their loved ones remotely through a smartphone app. GreatCall’s ([www.greatcall.com](http://www.greatcall.com)) *Lively Mobile Plus* and *Lively Wearable*, enable the user to connect with professionals with a touch of a button. Finally, while initially designed for healthcare institutions and used for telehealth, telepresence robots have entered the home environment. These robots can be used for a variety of activities such as cleaning, transporting objects, and monitoring (Michaud, et al., 2007; Sefcik, Johnson, Yim, Vivio, & Cacchione, 2018). As the market for RMTs continues to expand, there is also the need to understand and explore evidence of the “complex and diverse living experiences and care needs of older adults” (Gutierrez & Ochoa, 2017, p. 1618). In turn, from exploring those experiences and needs of older adults, and their caregivers, there is a need to impart requisite user experience requirements into technology design solutions.

We focus on understanding the socio-technical solutions used by family caregivers. An understanding of how family caregivers can use RMTs to monitor and support the health, safety, and well-being of their care recipients in an in-home setting is limited (Jaschinski & Allouch, 2017; 2019). Gutierrez and Ochoa (2017) indicate informal caregiving is complex, dynamic, and cooperative in nature. The need increases for coordinated efforts made by

caregiving networks (e.g., family members, practitioners, caregiving service providers, other) that also increases the demand for cooperative “technology-based caregiving services” (p. 1619) to support the needs of the older adult and those of their caregivers.

Family caregivers play an important role in the care of older adults. It is important to understand their unique context including their needs and perceptions regarding the use of RMTs. This study adds to the body of knowledge on family caregiving and more specifically, serves as the basis for developing awareness and training programs that will support the decision making of family caregivers and their care recipients relative to the adoption and use of existing RMTs.

We sought to answer the following research question:

How do family caregivers perceive RMTs and experience their use for monitoring and supporting their care recipients who are living at home?

### **Role of the Researchers**

The first author, Martha Snyder, has 25+ years combined experience in learning technologies, user-centered design, and project management. Her interest in technology and design solutions for the elderly started in 2002 with her doctoral dissertation, which focused on the design of online learning communities for older adults. Since 2005, she has cared for multiple adult family members in her home. These experiences, in particular, inspired this research.

The second author, Laurie Dringus, has 25+ years in research, teaching, and practice in human-computer interaction (HCI). Her background in information systems (IS) and psychology enables her to study the impacts of the use of technology in various contexts. Her research blends HCI, IS, and computer-mediated communication (CMC), focusing on understanding the complex nature of human interaction in technology. Her interest in this study focuses on usability and human-centered design of RMTs.

The third, fourth, and fifth authors supported Martha and Laurie by reviewing the qualitative analysis, providing suggestions for presenting results, and assisting in manuscript development. All of us have experience in qualitative research and value the interpretive phenomenological approach afforded by IPA.

### **Literature Review**

The number of studies investigating the technologies that can be used to support older adults who desire to live at home has grown substantially over the last 10 years (Vines, Pritchard, Wright, Oliver, & Brittain, 2015). Much of the literature reviewed from 2002 to 2015 has focused on acceptance and use of technology in general (Barnard, Bradley, Hodgson, & Lloyd, 2013; Burnett, Mitzner, Charness, & Rogers, 2011; Leung et al., 2012; Mitzner et al., 2010) to support persons with dementia and their caregivers (Hwang et al., 2015; Rosenberg, Kottorp, & Nygård, 2012; Topo, 2009) and to support independence, specifically (Lee & Dey, 2014; Mynatt & Rogers, 2002). Other studies have focused on healthcare providers' perceptions of technologies for monitoring older adults within an institutional setting (Lee & Dey, 2014; Thompson & Thielke, 2009; Tiberio, Rogers, Mitzner, & Kemp, 2013), how to measure use of assistive technology in relation to caregiver burden (Mortenson, Sixsmith, & Woolrych, 2015), and on the design of the specific technologies used to care for the elderly (Michaud et al., 2007; Wada, Ikeda, Inoue, & Uehara, 2010; Zsiga et al., 2013).

Research in the past 5 years has taken a deeper dive into how monitoring and other assistive technologies are perceived by older adults and by professionals and family members

who care for them (Berridge, 2016; Caldeira, Bietz, Vidauri, & Chen, 2017; Haken, Allouch, & van Harten, 2018). Berridge (2016) conducted 49 semi-structured interviews with residents, their family emergency contacts, and staff of six low-income independent living apartments to understand the implications of privacy when using passive sensor-based remote monitoring systems. Using grounded theory methods to analyze the data, Berridge reported themes about what privacy means to actual users of monitoring systems and that residents should have control over boundary management to protect their privacy if they agree to be monitored in the home. Themes of boundary management included, for example, who accesses monitoring data and how monitoring is being used. Caldeira and colleagues (2017) conducted a qualitative study, which included interviews and observations designed to understand how independent residents of a continuing care retirement community manage their health through various self-care and collaborative care (i.e., with staff, healthcare providers, peers, and family members) activities such as external monitoring and self-tracking. Their study revealed seniors perceive there needs to be a balance between collaborative care activities (involving assistance) and independence and that “tensions arise from seniors’ desire for independence” (p. 1605). Haken, Allouch, and van Harten (2018) conducted a literature review on research that focused on the use of advanced medical technologies in home settings, with an emphasis on quality and safety. Haken and colleagues reviewed literature published from the period 2011-2015 on the use of advanced medical technologies at home. Findings from the review show that only little more than a third of studies in the home involve patient/caregiver experiences and professionals’ experiences in the home are also understudied. These results would suggest that deployment of health technology in the home environment itself is understudied.

Research on perspectives on surveillance and monitoring technologies appear to be gaining traction in studies related to RMTs as well. For example, Mortenson, Sixsmith, and Woolrych (2015) presented theoretical perspectives relating to how home-based surveillance technologies have been implemented and how they are experienced by older adults. Mortenson and colleagues warn against the potential of technology encroachment on the “private lived space of the individual” (p. 512) and the need to consider how technology used in the caregiving process may have a pervasive impact on how the power dynamics of informal and formal caring relationships will be affected.

Finally, research focusing specifically on the needs of persons with dementia and their caregivers has focused on how RMTs can be used to support everyday life, improve quality of care, and reduce caregiver burden. For example, Hirt, Burgstaller, Zeller, and Beer (2019) identified a gap in the literature pertaining to “the development and implementation of assistive technologies” (p. 296) for persons with dementia. Hirt and colleagues defined assistive technologies as technologies used *by* people with dementia (e.g., navigation and communication aids and alerts), technologies used *with* people with dementia (e.g., telepresence systems, reminiscence books, and games), and technologies used *on* people with dementia or “applied without their direct participation. . .to ensure safety, to monitor, alert and prevent the risk of harm” (p. 296). They conducted a scoping review to provide an overview of the studies that focus specifically on the needs of people with dementia and their informal caregivers with regard to assistive technologies and found that most of the needs fell into the category of activities of daily living and customization of assistive technologies developed specifically for persons with dementia. Berridge (2019) pointed out some of the ethical issues related to passive remote monitoring technologies, which are monitoring systems that collect data without the person needing to take any action or even be aware that data are being collected (e.g., location tracking and sensor-based monitoring, and webcams). Within the context of dementia care, Alzheimer Europe (2010) identified several ethical issues related to these types of technologies including concerns about dignity, privacy, reduced social interaction, and impositions on a person’s “daily rhythm.” Obtaining informed consent or assent to use assistive

technology with persons with dementia can also be difficult due to the progressive nature of the disease and the threat of the person's capacity to consent deteriorating over time. Berridge (2019) argued that these are critical issues that need to be explored by practitioners and researchers in order to inform policies and practices that guide how these technologies are integrated into health plans such as Medicaid and home and community-based services.

The works summarized collectively provide insights into the concept of aging in place while they also characterize the prospects and challenges of technologies that play an increasing vital assistive role in providing care support and enabling independence of older adults, and persons with dementia more specifically. Research offers some insights into the use and utility of RMTs such as wearable sensors, mobile emergency devices, smartphone apps, and webcams that can be used to monitor, sense, record, and communicate a person's daily activities. However, research offers a limited understanding of the family caregiver's needs and perceptions of RMTs used in a home-based setting.

### **Methodology and Design**

This is primarily a qualitative, phenomenological study (Finlay, 2011) in which we explored how family caregivers perceive and experience RMTs and their use for monitoring and supporting their care recipients who choose to live independently. Carroll (2016) suggested qualitative techniques to uncover the needs and learn about the experiences of end users. He conducted a series of semi-structured interviews with experts to understand the key success factors in the design of Smart and Connected Health (SCH) software innovations. Hwang et al. (2016) emphasized the need to approach design problems relating to gerontechnological innovations from a qualitative and interpretive stance. We used a short survey to gather preliminary data regarding the population of family caregivers and their current perceptions and use of RMTs. The results of the survey were used to support our qualitative methods including describing the current context, recruiting those who were interested in participating in a follow up interview, and developing an interview guide that was used for an in-depth analysis of the family caregivers' perceptions and lived experiences.

### **Participants and Setting**

Participants included family caregivers (e.g., adult children, spouses, partners, and siblings) of one or more older adults who live at home. We used snowball sampling (Gay, Mills, & Airaisian, 2009) and recruited participants by first sending email requests for participation to acquaintances. To increase the number of survey responses, we followed up by sending requests for participation through our personal networks on LinkedIn and Facebook.

### **Data Collection**

Prior to data collection we received approval from Nova Southeastern University's Institutional Review Board (IRB), and we obtained informed consent from participants.

#### **Online survey.**

Prior to distributing a survey to participants, it is important to conduct a pilot study as a way to find deficiencies and areas that can be improved (Gay et al., 2009). We pilot tested the instructions and the survey with a group of six people including a marketing professional from a healthcare company, an academic research methodologist, a hospice care doctor, and four persons who represented the target population. This blend of pilot participants provided

useful feedback on various elements of the survey including the design, clarity of questions, ease of completing the survey, completion time, items that might have been left out and items that were irrelevant (Gay, et al., 2009). After pilot test feedback was collected and analyzed, modifications to the survey were made such as simplifying the presentation of information, updating the categories related to gender and ethnicity, increasing the age range for the care recipient from 70 to 100, and adding an “other” category to the question about types of caregiving performed on a regular basis.

Results of the survey also informed the questions that we asked during follow up semi-structured interviews. For example, the survey informed us of the specific RMTs that were being used so we were able to follow up and ask questions specific to those technologies. We distributed the survey electronically via Opinio (ObjectPlanet, 2019), an online survey software tool. At the end of the survey, participants were asked if they would be willing to participate in a follow up interview about their perceptions of RMTs. If checked “yes,” participants were asked to provide their name and contact information. Thirty-eight participants completed the survey. Of the 38 respondents, 16 expressed interest in participating in a follow-up interview. Of those 16, we were able to connect with 10. After explaining the purpose of the study in more detail, 3 participants expressed that they did not know enough about RMTs to participate. Therefore, we made arrangements with the remaining 7 participants to conduct the follow up interview.

### **Semi-structured interviews.**

Six of the seven semi-structured interviews were conducted by phone and one via Skype, a web conferencing tool. Prior to the interview, we asked participants to complete a verbal informed consent. Each interview ran 45 minutes to one hour. We used an interview guide consisting of a series of open-ended questions to ask for specific stories that were intended to help participants share their unique caregiving experiences and tasks they perform, their perceived use of existing RMTs, perceived benefits and risks of using RMTs, and their concerns about adoption and use of RMTs. Examples of these open-ended interview questions included the following:

- What is a day-in-the-life as a caregiver like?
- What problems do you encounter when it comes to caring for your care recipient?
- How do you feel about using RMTs to help you monitor and care for your care recipient?
- What do you perceive as benefits and risks of using RMTs in your particular situation?
- What difficulties might you have helping your loved one adopt RMTs?

We audio recorded each interview and sent the recording to a professional transcription service. Once we received the transcriptions back from the service, we assigned codes to the files and replaced real names with pseudonyms. Converting the interviews into a digital format facilitated coding of the data (Gibbs, 2007). To show appreciation for their time, we mailed a \$20 Target® gift card to each participant at the conclusion of the interview. Smith, Flowers, and Larkin (2009) suggested that interpretative phenomenological analysis is best done with a homogenous group. Of the seven interviews we conducted, four interviews were done with persons who were caring for someone who had some degree of loss of cognitive functioning. We chose to analyze those four interview transcripts because we felt that they represented the most homogenous group. Hirt et al. (2019) implied that persons with dementia and their

caregivers have different needs with regard to assistive technologies from the broader population of older adults. Alzheimer Europe (2010) identified ethical issues regarding assistive technology that are specifically focused on persons with dementia. The following sections focus on our data analysis methods for these four interviews with the family caregivers.

## **Data Analysis Methods**

We used interpretative phenomenological analysis (IPA) to analyze the interview data. Smith et al. (2009) stated “IPA is concerned with the detailed examination of human lived experience” (p. 32). IPA is useful when the goal is to understand the process and the meaning within a specific context as opposed to specific or concrete outcomes, causes, and consequences. Here the purpose was to explore how family caregivers perceive and experience their use of RMTs for monitoring and supporting their care recipients. Analysis of data was a recursive process involving a transition of focus from “the particular to shared and from the descriptive to interpretative” (Smith et al., p. 78).

Following is a brief description of how we analyzed the data. A more detailed explanation of these analysis methods can be found in Snyder and Dringus (2019). First, we immersed ourselves in the data by listening to the audio recordings and reading transcripts over and over. Then we made initial notes and exploratory comments. We used a combination of making notes by hand and noting comments within the electronic document using Microsoft Word’s review (i.e., making comments in the margins). In the electronic version of our notes, we could more easily distinguish the descriptive (i.e., key words and phrases), linguistic (i.e., use of repetitive words, pronouns, metaphors, and pauses), and conceptual comments (i.e., comments that might prompt future questions) using different font styles, namely normal, italics, and underline respectively. We found that the combination of the hand-written notes and electronic notes and going back and forth between the two styles were useful in our analysis. Examples of descriptive comments included phrases such as “caregiver says voice recognition when texting is fabulous” and “caregiver senses webcam would be too invasive.” We coded the word, “carer,” as a linguistic comment in one of the transcripts because in one participant’s case, there was an issue with constantly changing paid caregivers. When discussing with a participant the desire of the care recipient to have her independence, we noted the following conceptual comment: “Could wearing some kind of visible monitoring device make people feel like they are helpless?”

We developed emergent themes by going back and reading through the coded transcripts over and over again and looking at the exploratory comments. Through this process, we were able to better organize and interpret the transcriptions. We created a table in Microsoft Word to help us organize these initial themes and the key words and phrases that described those themes. For example, one of the initial themes was remote monitoring technology risks. Key words and phrases that we associated with that theme included invasion of privacy, security of information, false sense of security, confusion with technology, and distraction. After we identified key themes in each case, we looked for patterns across cases. Through this process, we identified common themes across all four participants. For each theme we identified, we noted exemplary quotes that represented that theme, as well as, our own interpretation of the theme. In addition to this recursive process of data analysis, we used the data from the surveys and interviews to create a composite description of each of the participants. We feel these composites help the reader get a sense of the context of the analysis.

## **Trustworthiness**

We employed the following methods to ensure trustworthiness: (a) referential adequacy of materials, (b) transcription checking, and (c) code cross-checking (Erlandson, Harris, Skipper, & Allen, 1993; Gibbs, 2007). Referential adequacy of materials refers to how the context of the case is presented so that enough information is communicated to the reader to ensure an understanding of the findings within the context. We paid careful attention to how the analysis and interpretations of the data were presented within the broader context. Given an outside transcription service was used (i.e., Rev.com), we reviewed each transcript prior to analysis to ensure there were no mistakes. This process was also a first step in helping us become familiar with the data (Gibbs, 2007). Finally, Gibbs suggested in addition to the application of the constant comparison technique and writing detailed memos about codes during the coding process, seeking outside assistance from colleagues to cross-check codes and prevent definitional drift is also helpful. For our study, we sought the assistance of two other researchers to help in the crosschecking of codes.

We also referred to Yardley's (as cited in Smith, et al., 2009) principles for assessing quality to guide our analysis. These four principles include (a) sensitivity to context, (b) commitment and rigor, (c) transparency and coherence, and (d) impact and importance. For sensitivity to context, we became more sensitive to the topic being investigated by reviewing the pertinent literature, discussing the contexts of the interviewees, making investigators' biases overt through ongoing journaling, and by immersing ourselves in the data analysis process. For commitment and rigor, we maintained attentiveness to the interviewees by focusing on questions asked and responses given and going beyond superficial results to develop sufficiently interpretive findings in the analytical process. For transparency and coherence, we maintained a research notebook that detailed the procedures used the study and reflections on the process. Procedures are also outlined here along with evidence in the form of direct quotes from the interviews to support interpretive results of the IPA. For impact and importance, our goal was to present something "interesting, important or useful" (p. 183) to our readers.

## **Results**

As mentioned, the purpose of the survey was to obtain a basic description of participants' perception and use of RMTs, inform the questions that were asked during follow up interviews, and recruit participants for follow-up interviews so we chose not to report survey results herein. This section focuses on the interpretative phenomenological analysis of the interviews. Interview findings are organized by theme and presented through a descriptive and interpretive summary. Exemplar quotes are used to illustrate the essence of each theme's qualities.

### **Participant composites**

Participants included Lucy, Cara, Samantha, and Devon (pseudonyms). We constructed the following participant composites from the survey responses and interview data.

#### **Lucy.**

Lucy is a white female in her 40s. She is employed full-time and cares for her parents and her husband. She also cares for her 10-year-old son. Her husband is in his 60s and her parents are between the ages of 70 and 89. She lives in the same residence as her husband and

her parents live less than five miles away. The focus of the interview was on her husband, who was diagnosed with Alzheimer's disease at an early age. While Lucy is at work, a paid caregiver is with her husband. Although Lucy is familiar with various types of RMTs including medical alert devices, pendants, wrist-worn sensors, and smartphone apps, she does not currently use any type of remote monitoring technology other than the cell phone.

### **Cara.**

Cara is a white female in her 60s. She is employed part-time and cares for her brother, who is in his 70s and has been diagnosed with Alzheimer's disease. She lives less than five miles from her brother. A paid caregiver lives with her brother in his home. However, Cara checks in about three times per week to offer companionship, general keeping tabs, and some supervision of the paid caregiver. Cara is both familiar with various RMTs and has also used in-home and mobile medical/emergency alert devices, a sensor mat, and remote cameras.

### **Samantha.**

Samantha is a white female in her 50s. She is employed full-time and cares for her mother who is in her 80s and has been diagnosed with dementia. She lives 6-15 miles from her mother. A paid caregiver provides most of her mother's care. However, Samantha interacts with her mother daily providing care and assistance such as check-in phone calls, assistance with shopping, food preparation and bathing, serving as a healthcare advocate, and general keeping tabs on her mother. She is familiar with RMTs including the in-home and mobile medical/emergency alert devices. She has also used the in-home medical/emergency device that plugs into a land-line telephone jack.

### **Devon.**

Devon is a white trans-male in his 60s. He is not employed and cares for his wife who is in her fifties. Devon indicated that his wife experiences difficulty with mobility and cognitive processing abilities. He lives in the same residence as his wife and is the primary caregiver. He provides daily assistance with activities such as shopping, and bathing, offers companionship, and does all the cooking and meal prep. He is familiar with RMTs such as mobile medical/emergency alert pendants, wrist-worn sensors, smartphone apps, apps that integrate with wearable wristbands, and smartwatch features. He uses smartphone apps (i.e., Find My Friends) to help him monitor and guide his wife when she is out of the house.

## **Interpretation of interview results**

The following themes represent patterns that cut across all cases. These themes include (a) family caregiver connection, (b) risk-benefit conundrum, (c) human-technology interaction and usability, and (d) tailored solutions. A description of the theme along with exemplar quotes are provided.

### **Family caregiver connection.**

The connections family caregivers feel are unique and different from the broader caregiving context because of the personal relationships. Participants expressed feelings of frustration, isolation, and being overwhelmed, while at the same time emphasizing love,

compassion, and empathy towards their relative. This intense love can also bring emotional pain and distress.

Lucy described her frustration with trying to find programs for her husband and herself. She noted,

I have actually had my husband turned away from programs because he's not old enough. Then I went to a couple of these support groups and there were people my age but they were caring for parents. When I said that I was caring for my spouse, all they could do was to show pity, and I don't want pity. I want help.

Samantha expressed feelings of frustration and isolation as the only one in her family who has taken on the caregiving role. "I think what's challenging is the frustration of just being the only one of my family that does this, or supports this. There isn't someone to relieve me as much."

Family caregivers are juggling many roles and oftentimes caring for more than one person, which can cause them to feel overwhelmed. Lucy said, "Between the 10 calls a day I get from my husband and then my parents, it can be a little overwhelming. . . I am the true sandwich generation." Caring for a person with dementia can be "tricky" as described by Cara:

To care for someone with Alzheimer's in your own home, you really need to know what you're taking on board. Number one, when are you, yourself, going to get some rest? How on earth are you going to constantly deal with them either wandering around, or talking, or sitting silently and you're not quite sure they can verbalize what they need?

Although participants freely expressed their struggles, they also described their experience as a unique and special connection with their loved one. For example, Samantha stated,

I'm very keenly aware of the limited time that we have remaining together, so I appreciate and try to listen to her, and just be in the moment, much more than any other time in my life, I think. So that's something very special.

The unique situations that family caregivers experience also result in a strong desire to protect their loved ones from harm. They are concerned about how their relatives are treated by hired help, the community, and the healthcare system. For example, Lucy expressed concern about the part-time hired caregiver:

She is very condescending to him, and he doesn't need that. He doesn't need that at all. He doesn't need somebody to say, "See, look, you forgot." An Alzheimer's patient doesn't need that. I mean, it's hard enough for me not to say, "I told you that already."

She wished the person could "just be kinder."

### **Risk-benefit conundrum.**

Regarding the perceived risks and benefits of RMTs, there is a conundrum between the benefits of having peace of mind, a sense of self-efficacy, and greater independence versus

perceiving RMTs as an invasion of privacy, a security risk, a false sense of security, and a distraction.

Some participants reported that RMTs are used to facilitate communication and support between the caregiver and care recipient. This benefit enables the caregiver peace of mind. Devon uses the app Find My Friends to provide verbal turn-by-turn directions to his wife when she takes the bus by herself. He noted,

Her sense of direction is very good, but when she gets very tired, I have to guide her block by block. Having Find My Friends on the phone means that she doesn't have to try to read the street sign and tell me where she is when she's downtown, in the middle of a crowd of people, it's noisy, and it really affects her brain functioning.

Cara feels at ease when she is able to use the webcams in her brother's home to make sure he's okay and noted, "I was able to look at my brother at 12:00 at night to see if he is getting out of bed, or if he is not. I can look at him sitting. . .and laughing."

Use of RMTs can give caregivers confidence in their ability to care for their loved one. Using a webcam, Cara was able to supervise the caregiver from a distance. She explained:

When my brother was having difficulties getting in and out of the car, I would say to the carer, "When you're taking him out today text me and I will watch." I was able to see, because he was having great difficulty of sitting into the car.

When referring to potential benefits of RMTs, Devon also discussed the value of independence for the care recipient noting,

The more they can do on their own and feel like, "I'm an independent person and I'm functioning on my own." That is really an important piece. Feeling like people are checking up on you, and keeping track of you, and keeping tabs on you, whether you want them or not, it takes away independence and it makes people feel like they are lesser in some way.

Contrarily, participants expressed concerns regarding privacy and security, false sense of security, and distraction associated with RMT use. When discussing potential use of remote cameras, Samantha stated,

I think from her perspective, she more recently, over the past year or so, has been much more into a sense of "I want my privacy," and I think that she might have trouble with the idea of someone watching, to the extent that she would remember that it was in place.

Regarding security, Devon mentioned privacy and security are important to his wife because "...she understands just how easily those systems can be hacked."

RMTs were perceived as offering a false sense of security. When discussing the use of emergency response pendants, Samantha noted: "My reluctance is that it doesn't seem. . .It can't stop something from happening to her. It just alerts you maybe if something does." When discussing the use of a webcam, Devon had reservations: "If I'm not there, it doesn't do a lot of good if she's fallen in the shower, if she manages to get ahold of me and I'm across town. And she wouldn't want anyone else to come help her."

RMTs were also perceived by some as a distraction. Samantha noted a downside to be able to monitor her mom stating, “if I had access, that I’d be spending more time than I really can afford, at work, or something like that to access information.” Lucy expressed similar concerns when discussing webcams stating,

part of me doesn’t want to worry myself. Also, how often do you check it? What do you check? What do you do if you see something you don’t like? It’s kind of like, the pros and cons and it seems like the cons outweigh the pros.

### **Human-technology interaction and usability.**

Participants were asked about the features and applications of existing RMTs for monitoring and supporting their relatives. Issues pertaining to the way they interact with the technology as well as its usability were mentioned.

Participants expressed concerns about their care recipients’ ability to use or continue to use technology. For example, Samantha talked about her mom’s use of a wrist life alert that was given to her by the local hospital.

I think the challenge has been for me, and for her, in that she, to my knowledge, that she doesn’t have any technical ability, so I don’t know if there are things that don’t require her to have technology, Internet, or what have you.

Lucy was concerned about how long her husband would be able to use technology noting inconsistencies in using text messages on his cellphone. “Sometimes he reads them and can respond to them, and sometimes he goes, No, I never got your texts, so I don’t know that he hears it ding or knows even to check it.”

Usability issues relating to appearance, function, and features were also mentioned. For example, Lucy mentioned that monitoring devices that look like jewelry would be appealing. When referring to medical bracelets, she described that she could never get her husband to wear a medical alert bracelet that had a medical sign on the front and on the back it read, “I have epilepsy” or “I have diabetes.” She explained, “But if something were to look like a Fitbit, a Lokai bracelet, or even one of those rubber bracelets that you wear when you are raising money for something, he would wear that.” Regarding functionality, Devon mentioned, “the most useful technology by far is the ability to text on our phone [and] use the voice recognition technology. . .we can use that out and about if we get separated in a store.”

### **Tailored solutions.**

The fourth theme emphasizes the need for solutions that are tailored for the family caregiver and his or her loved one. Participants discussed needs relating to adoption and use of RMTs. These needs included availability, function, cost, informed consent, and the carer as educator.

Participants had a difficult time understanding what types of RMTs were available and what problems they could solve. Technology is changing so rapidly, it’s hard to keep up.

For example, Samantha mentioned, “I just think that there is so much information, but sometimes, it’s a question of making it easy to digest and access.”

Lucy expressed how difficult it is finding the information she needs.

I wish that there was easily accessible information. The [Alzheimer’s websites] are unbelievably confusing in how to find resources. The same with the drug

companies, plow the doctors with samples and brochures and that sort of thing, I wish that some of the technology companies did the exact same thing so that when you get your diagnosis of Alzheimer's or you go back a year later and there's been a decline, such as our situation, they can hand you a packet.

Samantha also expressed preference for brochures in doctors' offices stating,

So probably for me, the easiest place to receive information would be from, for example, if we had an emergency room visit, and someone would have given me a resource, or a tool, and said, "Here are some things that are available. Here are some things that we participate in." That might have been helpful. Maybe the doctor's office having brochures.

Cost is another factor that concerns participants as it relates to RMT adoption and use. Samantha asked, "Are any of them [RMTs] supported or sponsored. Or is there a testing? You know how sometimes you could go to, I don't know, a hairdresser in training, and it's cheaper?"

Participants expressed worry and concern about what to expect as their loved one continues to experience cognitive decline. Will they even be able to know how to use any type of RMT? Lucy described it as "terrifying" to think that her husband will wander off one day. She struggles between the thought of locking him up in the house (like he's in jail) and giving him the freedom to open doors without setting off alarms and instead, carry his cell phone while he takes a walk around the block. Lucy described her husband's loss of memory related to the cell phone,

I know he can't text anymore. He can still send email, and he can use the phone-phone. That part he's got down. But some of the more recent learnings, if using text messaging and things like that are not as solid.

Participants expressed the need to normalize the use of RMTs so that they will be accepted not only by the care recipient but also the carer. In Cara's case, she described her situation with the paid, live-in carer. Carers feel like, "Why don't you trust me? They miss it completely that my brother is a vulnerable person and vulnerable people need to be monitored."

Finally, sometimes caregivers need to educate other people about their loved one's disability. Devon noted, "We need to educate the caregiver on how to educate other people." Cara noted the need to educate paid caregivers on the reasons why she is using a webcam so that they feel comfortable having it in the house.

## Discussion

We sought to understand how family caregivers perceive RMTs and their use for monitoring and supporting their care recipients who choose to live independently. Through interviews with four family caregivers, we identified four themes including: (a) family caregiver connection, (b) risk-benefit conundrum, (c) human-technology interaction and usability, and (d) tailored solutions. The following discussion considers the themes described in relation to the extant literature.

### Family Caregiver Connection

We learned that the relationship between the family caregiver and the care recipient who has dementia presents a unique caregiving connection. While caregivers expressed a

strong bond with their care recipients, represented through love, compassion, and empathy, they also expressed strong feelings of frustration, isolation, and being overwhelmed. These negative feelings are exacerbated due to the behavioral and psychological symptoms of dementia (BPSD) such as hiding, wandering, visual hallucinations, and inappropriate eating and toileting behaviors (Song, Park, Park, Cheon, & Lee, 2018). This may be a different kind of relationship from, for example, paid caregivers who are caring for people with dementia, as they might not have the same emotional connection. Perhaps this finding implies the need for a unique approach to supporting and educating these family caregiving dyads that focuses on their emotional needs as well as their educational and physical needs. Supporting these family caregivers by developing user-centered training opportunities could be beneficial as the quality of the care received by persons with dementia is positively correlated with the length of time they remain being cared for at home (Christie et al., 2018).

### **Risk-benefit Conundrum**

We learned that family caregivers found RMTs beneficial noting caregiver peace of mind, better communication between the caregiver and the care recipient, caregiver confidence, and caregiver and care recipient independence. These findings are consistent with Mitchell and colleagues (2018) who found the use of RMTs by family caregivers and their care recipients offered “useful information, promoted peace of mind, was easy to use, prevented health crisis. . . , and promoted independent living” (p. 16). We also learned that some family caregivers perceived risks to using RMTs, notably privacy and security related to the technology, false sense of security as a result of device output, and distraction. Mitchell et al. (2018) also found that RMTs were perceived by some as an invasion of privacy, provided too much information resulting in distraction, and feedback from RMTs was confusing to interpret. Mortenson and colleagues (2015) warned of the inherent dangers of using RMTs with the older population, especially the impact on their relationship with their caregivers. They noted two key areas to consider with regard to surveillance technology (e.g., webcams), in particular. First, we need to consider the extent to which this technology is used in the home. Unlike public spaces where surveillance technologies are used to monitor larger groups of people, used at home, they monitor a *specific* person. This attention could become an encroachment “upon the lived space of the individual” (p. 525) and thus cause conflict between the caregiver and care recipient (Yamashita et al., 2017). Bradford, Van Kasteren, Zhang, and Karunanithi (2017) referred to this perception that someone was watching over the care recipient all of the time as “the silent watcher.” Second, power relations between the caregiver and care recipient need to be considered. Mortenson and colleagues (2015) suggested future studies need to focus on the pervasiveness of these technologies and the power relations between the caregiver and care recipient in order to fully realize how they impact the everyday lives of older adult care recipients and not inadvertently disempower them.

Regarding privacy and security, Alami, Benhlina, and Bah (2018) identified threats to privacy and security in wireless sensor networks (WSNs) including threats to information in transit (e.g., interception and modification of data), attacks against routing protocols, eavesdropping, and traffic analysis. It is important that the RMT project design teams are aware of and address these types of threats by, for example, incorporating privacy and security protocols into user requirements.

### **Human-technology Interaction and Usability**

We learned that there were issues pertaining to acceptance and use of RMTs by both the caregivers and care recipients. These issues related to the care recipients’ technical abilities,

the way both the caregiver and care recipient interact with the technology, how they use it, and the potential stigma that might come with wearable RMTs. Mitchell et al. (2018) also found that family caregivers perceived RMTs as “confusing and unclear” (p. 18) when it came to interpreting the data generated by the RMT and also needed more help in learning how to use RMTs.

Wearable sensors are common RMTs among family caregivers of persons with neurodegenerative diseases such as Alzheimer’s. Wearables are most frequently used to locate the care recipient, monitor vital signs, and prevent falls (Kolasinska, Quadrio, Gaggi, & Palazzi, 2018). Kolasinska and colleagues (2018) reported that while health practitioners preferred the use of wrist worn sensors, family caregivers and their care recipients preferred sensors that are sewn into clothing. They concluded that wearables should be as invisible and inobtrusive as possible noting that a solution could be sensors sewn into clothing.

### **Tailored Solutions**

We learned that family caregivers who are caring for persons with dementia, need tailored solutions that are easily accessed, presented in a format that is easy to use, and address a variety of issues related to RMT adoption and use such as features and benefits, privacy, security, and cost. In addition, it is important to also acknowledge the behavioral and psychological symptoms of persons with dementia and design appropriate education that aligns with cognitive decline and the progression of the disease. Berridge (2018) identified the need for ways to support ethical decision-making when it comes to the use of RMTs to monitor persons with cognitive impairment and asked the question, “what constitutes appropriate use” (p. 7). She stated, “researchers are just beginning to learn what privacy means in relation to in-home monitoring and how to talk about it with older adults” (p. 7).

Song and colleagues (2018) suggested customized and proactive education focused on managing the behavioral and psychological symptoms of persons with dementia early in the caregiving journey would help caregivers manage these symptoms and potentially reduce the negative feelings, noting “How and with which attitudes caregivers communicate in attempting to change a patient’s behavior can determine how successful they will be” (p. 26). They suggested the need to “develop family-caregiver guidelines and empowerment programs to improve interaction skills in effectively coping with [behavioral and psychological symptoms] and thereby reducing their psychological distress” (p. 28). The need to tailor solutions based on the user’s needs was also reported by Mitchell and colleagues (2018) who found reasons for a mismatch included the care recipient’s stage or progression of disease and whether the caregiver lived with the care recipient.

It is possible that eHealth interventions such as online courses, smartphone or tablet applications designed to support the family caregiver, could not only facilitate the adoption of RMTs but also provide support to a broader population of caregivers. These types of solutions have proven to be beneficial in helping caregivers manage problems such as depression, stress, and anxiety, as well as improve their sense of self-efficacy, and confidence. They are also low-cost solutions that can be tailor-made and implemented widely due to their low-threshold access (Christie et al., 2018). Another suggestion is to create virtual local community support groups. These groups are similar to the physical support groups that are formed within local communities but instead, the communication would take place virtually through web-conferencing tools or smartphone apps like GroupMe or WhatsApp. Although larger virtual communities exist online, knowing that there are people in one’s local community who may be experiencing similar issues could create a more relevant and just-in-time network given the resources are more focused on a particular neighborhood, town, or city. In addition, it is often difficult for caregivers to physically travel to a local support group. This type of virtual local

support network is similar to apps such as Nextdoor's private social network for neighborhoods, OLIO food-sharing app, and the Freecycle app designed to give and receive items for free within their local communities.

### **Limitations**

The focus of this study was to understand the unique lived experiences of a specific population of informal caregivers. In this instance, Smith et al. (2009) recommend a small, homogenous group. The focus on the ideography and the particulars of a small number of cases is most important. However, this study was limited by time and resources. Given the uniqueness of each caregiving experience, we felt that we could have dug deeper into the transcripts or perhaps interviewed a few more people, which might have enabled us to produce a richer interpretation of the caregivers' experiences.

### **Implications**

Family caregivers play an important role in the care of older adults. It is important to understand their unique context including their needs and perceptions regarding the use of RMTs to support the health, safety, privacy, security, and well-being of their care recipients. This study not only serves as the basis for future research into each of these issues more deeply, it can also provide a foundation for developing awareness and training programs that will assist family caregivers and their care recipients in adoption and use of existing RMTs. For example, as Berridge (2019) pointed out, while serious ethical issues relating to passive RMTs, in particular, have been identified such as privacy, autonomy, and consent, there is a need for future research that identifies evidence associated with positive outcomes of RMTs and investigates how to best implement and use these technologies in a way that genuinely improves older care recipient's quality of life. This type of research could inform both practice and policy.

With regard to training and awareness programs, we provide the following three recommendations. First, awareness programs that focus specifically on the ethical implications of RMTs when they are used to care for and support persons with dementia who are living at home are needed. These types of programs would benefit a variety of stakeholders including the caregivers, care recipients, care providers, policy makers, and others. A clear understanding of the risks and benefits of various RMTs will help decision-makers make an informed choice about whether and how to use them. Although RMTs might make it easier for caregivers to monitor and care for their care recipient, their decisions to use RMTs might not be what their care recipient wants. Second, awareness programs that present the different types of RMTs and their benefits and drawbacks could also be beneficial to both caregivers and care recipients alike. Third, training programs that teach caregivers how to use the RMTs where they experience demonstrations and hands-on practice in using various RMTs would help facilitate RMT adoption and use. Finally, in each of these recommendations, future research should consider the voices not only of the informal caregivers but their care recipients as well.

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