Supporting Caregivers in Complex Home Care: Towards Designing a Voice User Interface

by

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Author's Declaration

This thesis consists of material all of which I authored or co-authored. Please see Statement of Contributions included in the thesis.

This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Statement of Contributions

Ryan Tennant was the sole author of Chapters 1, 2, 3, and 7 which were written under the supervision of Dr. Catherine Burns and Dr. Kate Mercer and were not written for publication.

This thesis consists in part of three manuscripts written for publication. Exceptions to sole authorship of material are as follows:

Research presented in Chapters 4, 5, and 6:

This research was conducted at the University of Waterloo by Ryan Tennant under the supervision of Dr. Catherine Burns and Dr. Kate Mercer. Ryan Tennant, Dr. Catherine Burns, and Dr. Kate Mercer contributed to study design. Ryan Tennant and Dr. Kate Mercer contributed to participant recruitment and conducted the interviews. Ryan Tennant and Sana Allana were the primary coders and analyzed each interview. Ryan Tennant wrote the draft manuscripts and was the lead author for these three submitted chapters, which all co-authors contributed intellectual input on.

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Abstract

Despite significant advancements in the development of digital health tools and the rising provision of health care services in the home, information management and communication has yet to be standardized through digitization across caregiver teams in complex home care. With the increased risks of adverse events in dynamic and unpredictable home environments, there is a critical need to improve care inconsistencies and prevent communication breakdowns. An opportunity exists for digital health tools to support the standardization of information sharing processes in the home. However, designing digital tools to support complex home care is challenging when considering the uniqueness of patient conditions, the home environment, and caregiving team diversity. Adopting digital health tools in unregulated environments also induces a challenge for standardizing digitization in this complex domain. With advancements in natural language processing and speech recognition, the development of digital health interfaces that provide a natural interaction with information by voice has shown promise to support information management and communication and facilitate engagement with home care technology.

The objective of this research is to build a foundation for the future development of a voice user interface or Voice Assistant (VA) to support caregivers in complex home care. The objectives are two-fold: (1) to understand the diverse caregiving experiences related to health information management and communication in complex home care and (2) evaluate the diverse perspectives of caregivers on the design of a VA to support these identified processes. Using a mixed-methods approach of semi-structured interviews and questionnaires with 22 caregivers across North America, this research contributes to understanding both the information and communication processes as well as the design considerations for integrating VA technology in complex home care by potential primary users.

This thesis consists of three papers that describe the partial results of one study. One paper focuses on the semi-structured interviews with family caregivers of Children With Special Health Care Needs (CSHCN) to understand the processes involved with managing care in their home. The second paper focuses on the semi-structured interviews with family caregivers and hired caregivers of older adults in the same context. The third paper focuses on the semi-structured interviews and questionnaires with all participants about their expectations for the design of VAs in complex home care.

This thesis captures the rich experiences of caregivers who are managing the coordination of care in complex home environments and the considerations for designing VA technology in this domain. The principal findings highlight similarities in caregiving processes and the nuanced complexities among caregiver populations that can inform the design and usability considerations of future digital health tools. There is also the potential for VA technology to provide utility for health information management and communication. However, considerations for functionality and the context of use may impact this innovation's diffusion. Future research should collectively examine home care from caregiving teams' perspectives and objectively measure human-information interaction with this technology in context-specific scenarios.

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Dedication

To Aiti and Grandma.

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List of Abbreviations

CSHCN Children With Special Health Care Needs v

CUI Conversational User Interface 28

ISO International Organization for Standardization 29

SUS System Usability Scale 30

TAM Technology Acceptance Model 3

VA Voice Assistant iv

Chapter 1

Introduction

Over the past 20 years, our healthcare system has experienced a significant shift towards care being provided in the home, resulting in increased responsibilities for caregivers to provide and coordinate care services in environments that are not directly designed to support healthcare tasks [3, 4]. The aging population, along with advancements in medicine and technology to treat medical complexities, are major contributors to rises in life expectancy and the increased reliance on home care, which requires the newly combined efforts of diverse teams to support care effectively [1, 5, 6]. A critically important aspect of supporting safety in complex home environments involves health information sharing, where a lack of communication can result in serious consequences for patient health [7]. Communication among caregivers in complex home care includes the human and social aspects of human-information interaction, and in the present-day, increasingly involves human-information interaction through technology [7]. However, despite the world's shift to the Information Age where access to timely data has become more prominent in many domains, including healthcare, the challenge of adopting health information digitization to support care services provided in the home among caregivers remains unsolved [8]. There is potential for the design of novel methods of technology interactions to improve human-information interaction with health data and positively influence healthcare digitization for the home environment.

On average, family members in Ontario spend 20-hours per week for four years supplementing health care services in the home and purchase approximately 20 million extra visits or service hours, including nursing, personal support, therapy, supplies, equipment, or other services [4]. In 2015, there was a total of over 29 million hours of personal support care provided to over 700 thousand individuals [4]. The Community Care Access Centre defines complex care as medical, physical, cognitive and social conditions at risk for hospitalization, chronic conditions, unpredictable care needs, and the need for a support network. Of the 700 thousand receivers of home care in 2015, 70% were categorized as complex, compared to less than 40% in 2010 [9].

There is significant literature that in-home electronic health record could support standardizing communication and providing efficient access to information in the home [8, 10, 11, 12]. However, there are currently no substantial technologies used in this domain, and annual adoption rates for systems such as online portals have been reported to range from 5-12.4% [13, 14]. Some of the previously identified adoption and usability challenges result from the design of the interface and the burden to physically interact with a system to record and retrieve data, which prevents caregivers from experiencing the value that many systems could offer in supporting safety and coordination [8].

VAs such as Amazon's Alexa, Apple's Siri, or Google's Assistant have been previously shown to engage a user's interaction with information in fundamental use cases such as accessing the news, music, or the weather [15]. While VAs have not been deployed in a regulated health care environment, to the best of the author's knowledge, research has shown potential for VAs to provide substantial support for effectively interacting with health information in specific contexts, both for care professionals and patients [8, 10, 12, 16, 17]. While the literature has proposed using VAs in complex home care, there is limited understanding of the human factors involved to engineer this method of interaction for the complex work domain of home care.

To address the gap in designing effective digital health tools for complex home care that meet the needs of caregivers and support engagement, the objectives of the research for this thesis are two-fold:

1. To evaluate the current complex work domains of caregivers to formulate an in-depth understanding of their diverse experiences with information management and health communication, and
2. To provide an initial evaluation for the adoption, design, and usability considerations of VAs to support the identified information and communication processes of complex home care.

To achieve each research objective, we designed a mixed-method study to explore caregivers' perspectives from diverse backgrounds and experiences. The methods included semi-structured interviews and questionnaires. The purpose of the interviews was to capture caregivers' unique experiences qualitatively and better understand the reasons behind their experiences and beliefs about using VAs in complex home care. We used both an inductive and theoretical thematic analysis for the qualitative results. The theoretical analysis was guided by the Technology Acceptance Model (TAM), a systems theory that enables a better understanding of the key aspects of user acceptance of a new system and how design decisions may impact the successful integration of information systems in a work domain. The questionnaire used in this study consisted of Likert-scale questions to quantitatively evaluate caregivers' perspectives. These questions were designed based on existing literature about the potential uses of VAs in complex home care and triangulated with the qualitative data [8].

Primary findings on caregivers' diverse experiences show that there are overlapping processes among caregivers of CSHCN, caregivers of older adults, and professionally trained hired caregivers to manage and communicate health information in complex home care. However, the complexities within these processes remain distinct across caregiver groups due to the medical complexity, which directly impacts the home care dynamic and the degree of responsibility required by caregivers. Concerning perspectives on VAs, primary findings suggest potential utility for supporting complex home care communication and information management. The application of the TAM identifies that caregivers specifically perceive usefulness and ease of use for VAs in complex home care to interact with health information. Caregivers also express that utility for the care receiver would provide peace-of-mind. However, concerns about the provided value of VAs compared to current methods for managing health information and issues regarding the influence of personality and intelligent support on effective use may impact wide-spread adoption.

While this research provides a foundation for understanding the information complexities involved with complex home care and the potential for the design and adoption of VA technology that supports information interaction, future research should continue to explore this critically important domain. The focus should be directed towards research that explores contextual interactions with VA technology by caregiver teams to inform the human factor considerations further influencing the adoption of digital health technology in complex caregiving environments.

1.1 Primary Research Contributions

This thesis's main contributions are to provide empirical insights into complex home care information processes and inform the design of digital health technology for information management and communication to support patient safety. The contributions to the field of human factors research in healthcare can be specifically described three-fold:

1. To provide empirical insights into the work domains of family caregivers of CSHCN with respect to the management and communication of health information in their home.
2. To provide empirical insights into the work domains of family caregivers and hired caregivers of older adults with complex health conditions with respect to the management and communication of health information in their home.
3. To provide empirical insights into the design and usability considerations influencing the adoption of VA technology to support caregivers' information management and communication in complex home care.

1.2 Thesis Organization

The thesis is organized as follows:

Chapter 1 provides an introduction to the thesis and an overview of the research topic, the gap in the current literature, the importance of the research, a statement of the objectives, primary results and next steps.

Chapter 2 describes the necessary background required to understand this research, including the model of home care, human factors, principles of innovation adoption, and prior literature on the use of digital health technology as well as designing and evaluating novel interfaces in a health care domain.

Chapter 3 describes the mixed-methods study design and the specific methodologies used for data collection and analysis.

Chapter 4 focuses on the interview and survey results from family caregivers of children with special health care needs. This chapter has been submitted for publication to JMIR Human Factors (doi: 10.2196/preprints.28895)

Chapter 5 focuses on the interview and survey results from family caregivers and hired caregivers of older adults. This chapter is being submitted for publication.

Chapter 6 describes the results from caregivers' perspectives on the usability, design and acceptance of voice assistants in complex home care. This chapter is being submitted for publication.

Chapter 7 discusses the connections between information management and communication processes to the design and adoption of voice assistants in complex home care, and provides concluding remarks and suggestions for future research in this domain.

Chapter 2

Background

2.1 Information Interaction & Human Factors

In the context of this research, an understanding of human factors for human-information interaction is critically important. Access to information and the user experience with an information system can play an essential role in influencing human behaviour [18, 19]. Understanding human factors in the context of human-information interaction provides a foundation for studying complex systems.

In the mid-20th century, the world experienced a significant shift into the Information Age, which broke down communication barriers and the limits constrained by the human capacity for information processing and decision-making [20]. The rapid development of information technology and the inception of the internet provided access to a library of knowledge in the palm of one's hand. As information accumulated and cloud storage supported ubiquitous computing applications, the type and the form factor of technologies that enabled access to increasing volumes of data also evolved. One can now retrieve the world's stored data from a 1.5-inch screen on their wrist, an 86-inch screen hanging on their wall, or from a device that has no screen at all. As information exponentially accumulates beyond orders of magnitude that are challenging to comprehend, where 90% of today's data was only created in the last two years [21], the world has reached the precipice of an important shift towards human-information interaction: the Experience Age [22].

The Experience Age focuses on the interaction with information [22]. Today's technologies enable some of the simplest of gestures, motions, and sounds to make the relationships between humans and information more intuitive than they have ever been before. As explained by Raya [23], the discipline of human-information interaction encompasses various research domains today. It can be explored through the application of methods and principles from human-computer interaction, computer-supported cooperative work, and human factors [23]. Human-computer interaction studies how information is presented to a user to encourage effective interaction, while computer-supported cooperative work involves studying information sharing and interpretation among individuals [23]. While also focused on the tools for information interaction, human factors is a multidisciplinary field that covers various challenges in the field of human-information interaction [23].

Raya [23] defines human factors as the study of how human performance and safety can be improved by understanding how humans relate to the world around them. For human-information systems, this refers to understanding the information required for a system to operate [23]. Systems thinking, which was initially proposed by Ludwig von Bertalanffy in the 1930s and later published as a theory in 1968, in general terms, aims to understand sets of elements, their relationships and how they work together to achieve a desired goal [23]. The engineering component of human factors further focuses on the mechanisms of system design. The designed controls and displays of a system provide a user with information about its state in the physical environment, subsequently influencing decision-making processes that alter their future behaviours and interactions [23]. In the context of this research, the system under investigation is complex home care.

2.2 Complex Home Care

According to the National Research Council of the United States, the proposed home care model involves four factors: the individuals, their tasks, the technologies used, and the working environment. The individuals of home care are the people receiving care, who may also care for themselves and those who are providing care, which may include professionally trained hired caregivers and family caregivers [1]. Often, the family caregivers must train their hired caregivers about their home environment and the specifics of the caregiving situation [24]. The diversity of individuals results in caregivers with a wide range of personal and health literacy skills, social needs, economic and social resources, and perceptions or preferences for care [25]. The majority of family caregivers providing home care vary widely in their training compared to professionally trained hired caregivers [26]. However, caregivers are most likely to be older and female [27, 28].

Home care tasks typically involve health maintenance, activities associated with episodic or chronic care, and palliative care [1]. With the nature of these tasks being provided in the home, there is significant risks for hazards and challenges to emerge for caregivers [29]. The conditions being supported may be simple and require little time and no medical equipment such as coaching in self-help skills or helping with medication management [1, 29]. At the other end of the spectrum, home care tasks may be complex and consume several hours every day using complicated devices for wound care, dialysis, chemotherapy, and respiratory therapy, which are tasks that used to be limited to inpatient environments [1, 29].

Home care devices range from simple first aid tools to respiratory equipment, including

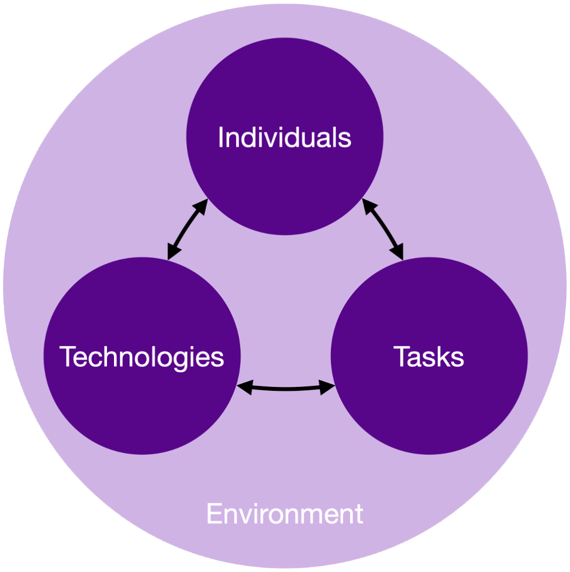

Figure 2.1: Model of home care as described in human factors terms [1]

the monitors and computer programs associated with them [1]. Technologies also include methods for documentation and record-keeping [25]. Although some of this equipment was designed for professional use, it is finding its way into the home environment with non-professional users [1].

Finally, encompassing home care is the environment in which care is provided [1]. The environment where care is provided can either impede or facilitate patient safety and the quality of care that they received [29]. With few exceptions, homes are not designed to support health service interactions and healthcare tasks optimally, and they exist within unique social atmospheres [29]. Overall, health care that occurs in the home is a very complex experience for caregivers. This model's factors affect the safety and quality of care that occurs in this dynamic and often unpredictable environment [1].

However, the home is often argued as an ideal setting for complex care [25, 26]. It supports aspects such as comfort through familiarity, directed care, and affords care recipients like older adults the opportunity to age-in-place [29]. The diversity in the elements and interconnections of this model and the culture of health care in a home environment only heightens the importance of the human factors involved.

2.3 Information Management in Home Care

2.3.1 Introduction

Providing care in a home environment for patients requiring in-home health care services has been extensively studied in particular patient populations. The body of caregiving literature focuses on older adults who have conditions including dementia or complicated medication regimens and includes improving the overall safety of care in the home [30, 31]. Some research focuses on the caregivers of CSHCN, and the unique challenges and consequences that this group of caregivers experience when navigating care coordination [32, 33, 34]. With respect to information management and communication, a significant body of literature focuses on the processes involved with care handoffs between caregivers and caregivers' information needs to perform health-related tasks in a home environment.

2.3.2 Caregivers of CSHCN

One of the most critical moments of information sharing for caregivers is when patients with complex health needs transfer from the hospital to their home. In this context, the exchange and translation of health information from health care professionals to family caregivers and other caregivers on a patient's caregiving team is critical for maintaining safety and quality of care [35, 36, 37, 38]. From the perspectives of caregivers of CSHCN, Desai et al's [35] qualitative study identified the need for health care professionals to provide family caregivers with comprehensive written instructions regarding contingency plans and their child's medications [35]. They also identified the need to provide family caregivers with the opportunity to ask questions to health care professionals who are familiar with their child to better understand their child's condition(s) [35]. Caregivers explicitly described the need for this information to be easily retrievable by printing it on brightly coloured paper so that they could find it in an emergency [35]. With the increasing amount of paperwork that families of CSHCN collect, this unique perspective may result from prior experiences of caregivers struggling to find specific health information among increasing amounts of data promptly [11].

2.3.3 Caregivers of Older Adults

Arbaje et al [38] analyzed the information processes for health care professionals and caregivers involved with transitioning an older adult from hospital to home care. They identified four failure modes influencing the transition's safety: managing too much information, not having enough information, having wrong information, and requiring data from multiple sources [38]. Their results highlighted the need for digital health technology to standardize information processes for transitions to home care [38], which was also supported by the results of Nasarwanji et al's [36] study. Nasarwanji et al [36] performed contextual inquiry of patient discharges for older adults to map information processes and flow, specifically with healthcare professionals. Their principal findings identified the lack of standardized workflows for exchanging information and the order of tasks to transition an older adult's care, where home care coordinators described creating guidebooks and manuals for personal use [36]. Current methods of collecting small paper notes, printed emails, and other documents in a binder did not support shared situation awareness among stakeholders during this transition [36]. Having accurate, updated, and concisely presented information is critical to promote a seamless transition to home care [36].

While Nasarwanji et al's [36] study focused on health care professionals because of the impact that their involvement has on their workflow, Carnahan et al [37] captured perspectives on information sharing by older adult patients and their caregivers during hospital discharge to home care. They identified that caregivers' and older adults' information needs were variably met [37]. One of the most significant challenges many of their participants faced resulted from locating relevant information within a plethora of papers that were provided to them [37], as similarly identified in the study mentioned above by Desai et al [35]. Also, the necessary information was not initially provided to individuals on their caregiver teams [37]. In one of their participants' experiences, this resulted in a nurse arriving without knowledge that the patient required wound care and was physically unprepared to provide proper treatment [37].

2.3.4 Information for Medication Management

Despite handoffs being recognized as an essential factor for improving safe care transitions among caregivers [39, 40, 41], gaps within inter-professional communication remain a challenge that hinders transitions to home care, which specifically influences safety in the context of medication management [31]. Carnahan et al [37] further identified the need for medication information support for older adult patients and their caregivers to be personalized towards their health literacy and cognitive capabilities. This finding was supported by the results of a contextual inquiry performed by Keller et al [42]. Keller et al's [42] study explored the task of outpatient parenteral antimicrobial therapy, where patients or their caregivers infused antimicrobial fluids through venous catheters in the patient's home.

Their principal findings highlighted the need to apply human factors engineering principles to present clear instructional information to caregivers to reduce task ambiguity [42]. Especially for medication administration tasks, reminding caregivers about the sequence of steps and sub-steps and providing clear information to support device troubleshooting should be effectively and efficiently supported [42].

Currently, medication management and the systems used to support medication adherence in the home vary in their effectiveness due to non-existent benchmarks for evaluating usability and workload [43, 44]. Lang et al's [31] interview study with older adults, their caregivers, and their providers captured the striking variations in medication management that occurred in the home. They discovered that many older adults and caregivers devised unique tracking systems which might work well for their unique home environment but raised safety concerns with providers on their reliability [31]. Other caregivers and patients had non-exist tracking methods, which equally concerned providers [31].

2.3.5 Conclusion

During the critical period of care transition from a hospital to the patient's home environment, information management and communication sets the initial standard (or lack of one) for care coordination in the home. While current research identifies that technologies and other systems fail to consider the human factors involved in this transition of care, there is a promising opportunity to develop innovations for this space that enhance patient safety and the caregiving experience. Further understanding caregiving characteristics in complex home care will provide a means for developing tools that establish high-quality health information management and communication in the home.

2.4 Technology Adoption in the Information Age

Understanding the factors influencing the adoption of innovations into society is essential for the exploration of novel technologies in a work domain that employs non-standardized processes resulting in makeshift methods which might be resistant to change. While innovation may provide significant benefit to its users, users' perceptions about integration may directly impact wide-spread use. It is critically important to understand the foundation of innovation diffusion for research that aims to design novel innovations for complex systems.

Fortunately, the adoption of innovation in society is a widely studied field that ranges from domains such as the environment, operations research, education, finance and health care. For example, in environmental research, the diffusion of innovation theory has been recently used to examine consumer attitudes towards purchasing sustainable products [45]. In operations research, it has been used to study the impact of agent-based simulations, which consider individuals' behaviours and interactions, to teach junior managers about technology management [46]. Principles of innovation diffusion have also been recently applied to improve the inclusiveness and culture of STEM education [47] and to study the relationships between financial information and communication tools and their adoption in society [48]. In health care, the study of digital health technology use by genetic counsellors with characteristics of diffusion theory has also identified perceived challenges of adoption [49]. Most recently, attitudes toward the use of automation to support the development of health guidelines by synthesizing health evidence have been evaluated using an innovation diffusion framework developed by Everett M. Rogers to identify the need for transparency in automation technologies [50].

Rogers' Diffusion of Innovation framework [51] combines five important factors that can be used to describe and predict the rate of adoption for an innovation into society: (1) *Relative Advantage*, (2) *Compatibility*, (3) *Complexity*, (4) *Trialability*, and (5) *Observability* . It is critical to point out that these factors describe the perceptions of users, rather than experts of a system, and that these factors exist among others as the most important characteristics describing adoption [51].

Rogers describes the *Relative Advantage* of innovation as *"the degree to which an innovation is perceived as being better than the idea it supersedes,"* and one of the most significant drivers is the economic advantage relative to prior innovations. However, even when the economic advantage of innovation is highly influential, it is often coupled with another predictive characteristic [51]. Rogers explains that in some cases, this characteristic's economic aspect can overpower other factors and result in the over-adoption of an innovation, which may result in a reduced overall value. In other cases, it may be difficult to perceive the benefits of innovation if it requires long-term use or acts as a preventative measure against an adverse experience [51]. He explains that the benefit of the innovation is the lack of a negative consequence. The uncertainty in knowing the consequences for future events may slow the rate of adoption. Furthermore, when incentives are immediate and finite, long-term use might dwindle if the immediate advantage outweighs any perceived future benefit [51].

The *Compatibility* of innovation is *"the degree to which an innovation is perceived as consistent with the existing values, past experiences, and need of potential adopters,"* which is highly related to the concept of familiarity [51]. Rogers explains that the more an innovation can seamlessly integrate into existing lifestyles, the less likely it will change a user's behaviour, resulting in increased adoption. However, he cautions towards innovations that maintain consistency with prior practices. They may come with the risk of over-adoption or miss-adoption. Innovations should focus on meeting user needs [51].

The *Complexity* of innovation is what Rogers describes as *“the degree to understand and use.”* This definition could be synonymous with the learning curve, which was first described by psychologist Hermann Ebbinghaus in 1885 [52]. While Rogers explains that innovations that are difficult to use negatively impact adoption, this pressure influences the development of more user-friendly innovations, such as the evolution of the home computer.

Rogers describes the *Trialability* of innovation as *“the degree to which an innovation may be experimented with on a limited basis.”*, which is often more important for early adopters than latecomers. The more flexibility provided to a user to test the innovation positively impacts adoption [51]. Rogers explains that after potential users perceive the positive interaction of early adopters, the impact of their trial of the innovation holds little weight and they more rapidly advance to using innovation to its capacity.

Finally, the fifth factor of Rogers’ framework on the Diffusion of Innovation is *Observability*, which he describes as *“the degree to which the results of an innovation are visible to others,”* and positively influences adoption. This factor is closely related to the *Relative Advantage* of an innovation where the ability for users to experience value influences the likeliness of adoption [51]. The challenge in this relationship, as Rogers previously mentioned, is the ability to directly or immediately experience value for preventative innovations. The economic advantage may be delayed or only perceived after long-term use. The connection between *Observability* and *Relative Advantage* for preventative innovations may require other factors in this framework to drive adoption.

2.4.1 The Technology Acceptance Model

The TAM draws similarities to the concepts described in Rogers’ Diffusion of Innovation framework. Developed by Dr. Fred Davis and described in his 1986 Ph.D. dissertation, the TAM combines the concepts of user motivation, which includes *Perceived Usefulness*, *Perceived Ease of Use* and *Attitudes Toward Use* to predict the actual use of a system, or the behavioural response (Figure 2.2). The usefulness and ease of using a system are considered cognitive responses based on the design features of a system that influence a user's attitudes, which is considered an affective response [2]. Davis also describes that the *Perceived Ease of Use* of a system influences the *Perceived Usefulness* because it directly impacts a user's performance.

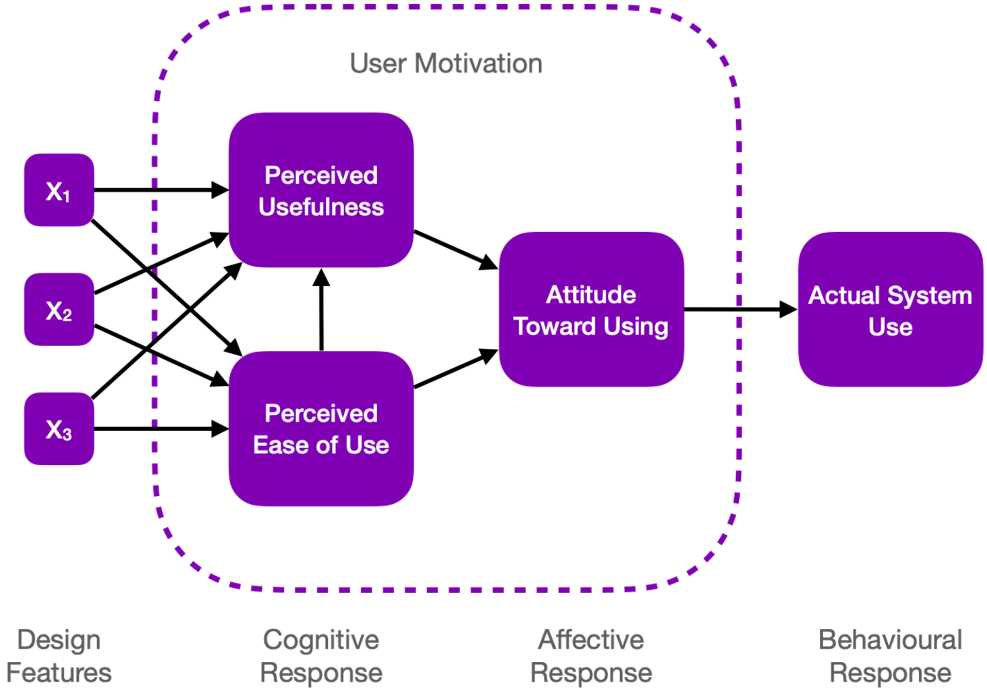

Figure 2.2: Technology Acceptance Model [2]

In the context of the adoption of information communication technology in healthcare, the TAM has been widely used to evaluate the factors that influence user acceptance. For example, elements of the TAM have been used to build questionnaires that measure perceived usefulness and perceived ease of use of a mobile application for collecting family health history [53], as well as for understanding the factors influencing the acceptance of telemedicine services [54]. Theoretical thematic evaluations using the TAM have also been used to inform the design of mobile health applications for use by caregivers to manage health information [55] and encourage patient self-management of chronic disease [56]. The TAM has also been used to evaluate wearable devices' acceptance successfully [57], and the adoption of intelligent health monitoring systems [58].

Despite the wide-spread use and robustness of the TAM [59], there are concerns with its applicability to this domain. Regardless of the beneficial components of an information system concerning its usefulness and ease of use, detractors to adoption for healthcare professionals include information privacy, and the potential use of the information, which the TAM does not directly capture [60]. Factors such as the cost, system training, user characteristics, and the organization's size also influence adoption, where these factors are more salient in smaller organizations [60]. Handy et al [60] suggests that for information systems in healthcare, the TAM is not complete without considering individual and organizational characteristics.

For intelligent information systems in healthcare, the TAM has been extended to evaluate acceptance by healthcare professionals, which has also revealed limitations to the model's original factors. In a study by Sohn et al [61], the TAM identifies the importance of enjoyment over usefulness for adopting intelligent systems. This disagrees with prior research and the framework developed by Rogers, which suggests aspects of usefulness are an essential factor in adoption in the context of these systems [61]. Sohn et al [61] suggest that the hedonic aspects of the interaction and user curiosity about intelligent systems significantly impact adoption.

The TAM's application to VAs is currently limited. The current body of literature focuses on adopting the technology by general consumers for the primary use of these systems to support simple interactions like checking the weather. To the best of the author's knowledge, there is no significant research on using the TAM to evaluate the adoption of VAs in healthcare or complex home care. The current literature on TAM applied to VAs is further described in Section 6.3.1.

2.5 Digital Health Tools in Complex Home Care

2.5.1 Introduction

The vast literature and evidence supporting the need to adopt digital health technology in a home environment stem from the inherent collaboration required among caregivers to ensure safe and quality care [11, 31, 35, 36, 62]. Studies have been conducted to identify the latent needs of stakeholders for the design of technologies that support information management in home care and the coordination of tasks among individuals and evaluated the use of these innovations within the home environment. However, there has yet to be a developed system that captures the needs for effectively supporting information management, health communication, and ultimately adopting these systems in complex home care [63]. Many solutions have explored graphical user interfaces for mobile applications to support health care in the home. More recently, advances in voice user interfaces in the form of VAs like Amazon's Alexa or Google's Assistant support research into this natural mode of information interaction as a tool for performing tasks in the home, some of which is related to a person's health. However, issues with technology development that do not involve user-centred design methods or integrate caregivers' perspectives into the final product may contribute to barriers for usability and the ultimate adoption of such technologies in the home [64, 65, 63]. The literature review for this section provides background information on the current research conducted on digital health technologies involving graphical user interfaces and the emerging research on VAs used in the home and health care context.

2.5.2 Graphical User Interfaces

Smartphone and computer use has become ubiquitous as a technology to enhance communication and information sharing. With the ease of downloading a software application onto a device, access to new software tools is much easier than before. Current technologies to support information management and communication are centered around certain diseases and patient conditions, and do not encompass general information management and communication needs. For example, for older adults with diseases such as dementia, there are various applications currently in development or available to support caregivers and their home care [63].

Koumakis et al [63] has categorized many of the currently known and in-development applications for dementia in 2019 as one or more of the following: disease detection, diagnosis and assessment; management assistance and support; and interventions. Despite research that has shown how digital health technology can improve shared situation awareness with patient care teams in hospital settings [66, 67], very few applications identified in Koumakis et al's [63] study support integrated care or efficient communication between caregivers. However, caregivers are positively inclined towards having an application that supports this functionality [63]. While Koumakis et al [63] describes that there are mixed results about the positive adoption of internet-based and mobile health technologies by caregivers, they expect that the cost-effectiveness of integrated solutions will play an important role in adoption. However, there are a lack of studies that investigate this adoption factor [63].

Guidsado-Fernandez et al [68] evaluated a new care delivery model called Connected Health, designed to improve care for patients with dementia by enabling continuity and information flow among stakeholders using a health portal in the home. Through personalized information and functionality that provided a means to record vitals, write notes, and view training information, the Connected Health model has been shown to improve caregiving confidence, depression and self-efficacy, and interaction by caregivers with health care professionals [68, 69]. The design of information sharing technologies to support care coordination among stakeholders has also been shown to improve home care for caregivers of other patient conditions, such as depression [70]. Yamashita et al's [70] digital tracking tool specifically identified the benefits of an indirect sharing tool to support opening the discussion for sensitive topics in the home. They also identified that family caregivers became the primary users of their solution, through tracking their loved ones health [70]. The design features of their digital tracking tool may influence future adoption as interactions were somewhat consistent throughout the six-week study period and the solution provided significant social benefits to their participants [70]. However, Yamashita et al [70] did not directly evaluate or report the potential adoption of this novel tool beyond the study period. Guisado-Fernandez et al's [68] evaluation demonstrated promising results towards improving caregivers' involvement in managing health care at home and using online portals as a preventative measure against adverse events by including caregiver perspectives, their needs, and their attitudes into the initial stages of the design process. However, while the literature supports the connection between user-centered design and increased adoption of developed technologies, Guisada-Fernandez et al [68] identify that many technologies do not consider the perspectives of patients with dementia. Their qualitative approach to understand the needs and attitudes of patients with dementia provides a foundation for developing future technologies for this user population [68].

Other applications have been developed for caregivers of persons living with cancer, which may be seen as more favourable than web-based portals, potentially due to interface design and ease of access [71, 72]. Heynsbergh et al's [71] development of a smartphone application was guided by user-centred design through focus groups and phone interviews. The evaluation of their mobile application for caregivers of people living with cancer illustrated the importance of providing care-specific information about cancer in their application, such as medical terminology [71]. However, functionality supporting social interactions among caregivers and financial or legal information was least valuable [71]. While participants assessed the application in this study as acceptable for use by caregivers of cancer patients and provided positive reports overall, application usage greatly varied [71]. The application does not support information needs as a patient's condition evolves [71], which suggests that user adoption beyond the evaluated study period may be limited. However, as with the development of other applications, Heynsbergh et al [71] did not directly evaluate the potential adoption of their application beyond the study period. Similar to the cancer-specific application developed and evaluated by Heynsbergh et al [71], Wang et al [72] evaluated a mobile application for caregivers of children with acute lymphoblastic leukemia. This application provided functionality through treatment tracking, reminders, a social platform, financial assistance, and a knowledge centre, which resulted in decreased caregiver anxiety and increased knowledge [72]. It is important to note that Wang et al [72] also included communication with health care professionals in their application. Their participants mentioned that having access to information sharing functionality with health care professionals eased their access to scientific knowledge about their child's care [72]. However, despite the user-centered approach their participants expressed unmet needs for the application to be available on other mobile operating systems, that it does not provide long-term support, and does not support anxiety related to their child's disease progression [72]. While Wang et al [72] did not directly evaluate the potential adoption of their application, it is expected that these factors would play a role in the attrition rates of such a solution if it were deployed.

In summary, while caregivers provide insight on the designs of mobile applications [73, 74], they primarily focus on providing a breadth and depth of general information needed to care for someone with a specific condition, while also providing a means for unstructured data input [71, 72]. The current state of developed applications and recent short-term deployment studies highlights the impact of the novelty factor, which may lead to increased uptake on adopting a new solution in the short term. However, there exist critical factors influencing adoption in the long term which have yet to be discovered. There is an opportunity for a qualitative approach to understand the experiences of caregivers on their current methods and technologies, to provide insight into the domain of adopting digital health tools that support information management and communication in the general context of home care.

2.5.3 Voice User Interfaces

There is an identified need to develop digital health technologies in the home that can provide functionality through tracking symptoms, flexibility for free text fields, contacting a health care provider, and the ability to upload images [75]. There is an additional desire for easy input of data through preset menus or voice interaction [75]. Voice interaction with health information in the home as well as the health care context is an emerging method of human-computer interaction that has also been proposed [8, 10, 11, 76]. The current body of literature identifies the use of VA technology for patients to more effectively interface with mobile applications, for physicians to support medical dictation, and to enable diagnoses of diseases such as Alzheimer's or Parkinson's [10]. There is significant potential for VAs to improve access to timely information in a health care context. For example, one recent study examined integrating a single voice command into a mobile application to provide hands-free blood glucose monitoring [76]. They found that 80% (28,725/34,572) of their participants interacted with their system at least once to check their blood glucose levels over a one-month period [76].

A significant body of literature focuses on using VAs for older adults and their perceptions on interacting with this technology in their home to support cognitive processes. For example, Kim captured the initial perceptions of a group of older adults using a VA. Responses to the voice interaction were favourable for their first commands but unfavourable for a conversational interaction [77]. Other literature focuses on older adult interactions with VAs in the health care domain, specifically in providing medication timing and dosage reminders [78]. Jesus-Azabal et al's [78] study on developing a VA to support medication management has been successfully tested in a lab setting. Still, it has not been evaluated for in-home patient use [78]. However, Jesus-Azabal et al [78] foresee older adults interacting with the VA to understand their medication schedule and store information about medication issues for other caregivers to see. In general, older adults perceive the potential for VAs to improve their access to health information and to improve their experiences for searching for information [77, 79]. However, concerns about privacy, financial burdens, and the accuracy of information may act as barriers to adoption for personal use [79]. Despite the development of VAs for patients and the natural method of voice interaction, in the context of persons with dementia, it has been suggested that the required learning curve for understanding how to interact with VAs may require additional assistance from a caregiver [80].

Furthermore, with respect to the context of persons living with dementia, approximately one-third of dementia caregivers are older adults above the age of 65 [81]. Research has shown potential for VAs to support more senior adult caregivers [81]. Li et al [81] specifically designed a VA to help caregivers manage the diet of someone diagnosed with dementia. Their VA provides guidance and personalized recommendations on nutrition, cooking and eating behaviours for someone with dementia, using a detailed ontology-based information model [81]. Li et al's [81] in-lab testing showed high dialogue understanding success rates (86%) and perfect recommendation accuracy (100%). However, the usability of the system in a home environment is unknown. Their VA has not been tested by caregivers in this setting [81].

One recent study by Corbett et al [82] evaluated the long-term use of VAs in the general home environment by older adults and their caregivers. Their primary findings were positive towards the use of VAs to support aging in place in finding information and entertainment [82]. With current device capabilities, older adults also used their VAs as a conversational partner [82]. Caregivers mentioned their desire to use the VA beyond entertainment, to check-in on medication events [82]. However, the required learning curve and changing to new habits were challenges associated with successful integration [82]. For example, one of the problematic practices that the participants in Corbett et al's [82] study could not let go of, was writing information down in paper notebooks.

For caregivers of CSHCN, there is limited literature on the potential for VAs to support health care tasks in the home. However, Sezgin et al [11] has proposed a spectrum of contexts for VAs to provide increasing value at home for children with medical complexity, ranging from the following: (1) general information retrieval, (2) instructions for health care tasks and reminders, (3) assessment of therapies and risk and identifying health conditions through bio-markers, and (3) prescribing therapy, medications or other treatments [11]. They also propose that VAs could provide more autonomy to the child as they become teenagers and take more responsibility for their health [11]. However, critical considerations and limitations preventing integration remain. For example, current limitations include access to raw health care data from mainstream vendors, Health Insurance Portability and Accountability Act compliance, the relative market demand, caregivers' social and economic status, language support, and translating current services to permit voice interaction [11].

2.5.4 Conclusion

The literature identifies a gap in the development of digital health technology to support caregivers in complex home care. Research has shown significant promise for digital health technology to support patients. However, while caregiver perspectives have been considered for the design of some software applications for home care, they are often an afterthought or minimally considered during the design and development of emerging innovations for home care. The challenge towards including caregivers may be grounded in diverse needs of patients compared to their caregivers. With the mixed challenges associated with graphical interfaces, there is potential for the design and integration of a alternative interface modes such as voice interaction, to provide both meaningful access and an improved experience with health information by all stakeholders.

2.6 Evaluating Voice User Interfaces in Healthcare

2.6.1 Introduction

VAs are considered one category of interaction with Conversational User Interfaces (CUIs), growing in prevalence as a more effective way to access information in a natural way, inherent with human communication. Text-based CUIs are used on company web-pages to help potential customers learn about available products and services, on smartphones to act as a personal assistant, and by governmental organizations to teach users about specific topics. One topical example of a text-based CUI is the COVID-19 chatbot launched by the city of Toronto in May 2020 [83]. Unlike traditional graphical user interfaces that require users to know where to look for information and perform a sequence of actions to access it, CUIs make information more accessible through natural human language. Many CUIs achieve this by understanding the aspects of human language regarding intents and entities. Intents are the reason for the interaction [84]. For example, in a health care context an intent could be to record a medication intake, or retrieve medication interactions. Entities are the details that are extracted to capture a complete understanding of the input [84]. Following the previous examples, an entity could be the amount of medication being recorded, and the type of medication.

Some of the most common voice user interfaces are known as Apple's Siri, Amazon's Alexa, and Google's Assistant, which help users with tasks such as searching the web, playing music, and creating reminders. Human interaction with CUIs has been an increasingly studied topic in several domains. With its growing diffusion into society to support everyday tasks, it is essential to study the factors for the effective design of CUIs. This literature review lays the foundation for how CUIs developed for healthcare are currently evaluated concerning usability and the opportunities for filling those gaps with future research.

2.6.2 Usability Standards

The National Standard of Canada defines usability in the International Organization for Standardization (ISO) 9241 as the following: "Usability relates to the outcome of interacting with a system, product or service, a more comprehensive concept that is commonly understood by ease-of-use or user-friendliness" [85]. This standard also emphasizes that usability needs to be considered within the context of use. This includes the potential users of the system, the environment in which they interact with the system, the goals and tasks to be performed with the system, and the available resources [85]. For example, in the healthcare domain, the context of use could consider a paediatric nurse who works in the intensive care unit of a large hospital. At a certain point in their shift, their primary objective is to document the status of their patient's health condition using an electronic health record and the patient's physical medical chart. In this example, within the context of the ISO description, designers would consider the nurse's usability to record the required information into the electronic health record.

As defined by ISO 9241, usability outcomes are the effectiveness of use, efficiency, and satisfaction. Additionally, it is recommended that usability is measured with respect to the outcomes related to the accessibility of the system, the user experience, and the ability for the system to avoid causing harm [85]. For the example with the paediatric intensive care unit nurse, usability measures could identify how accurately they can record the required information into an electronic health record. Usability measures could further evaluate how timely and enjoyable the interaction is. These factors may ultimately indicate a user's willingness to interact with the system in the future.

The ISO standard for usability does not identify specific usability measures that can be implemented, nor are there specific measures for evaluating CUIs identified in this standard. However, ISO 9241 identifies that usability can be evaluated through observable outcomes (i.e. objective measures) and the user's perception of the outcome (i.e. subjective measures), ultimately depending on the system and domain of use.

2.6.3 Subjective Usability Measures

The most common subjective usability measure used to evaluate CUIs in the literature were questionnaires that included Likert-based questions and interviews and feedback from participants both during and after their interaction with the CUI. Some research articles reported using customized questions to measure usability that were unfortunately not included in the article by the researchers [86]. A study that used a custom questionnaire did include their questions for evaluating a medication reminder VA, which consists of a seven-point Likert scale [87]. A total of eight questions were used in this study [87]. The questions directly asked participants about ease of use, accuracy, usefulness, the naturalness of the interaction, and the participants' comfort with the system [87].

Many studies subjectively reported usability with the System Usability Scale (SUS). The SUS is one of the most widely used scales to measure system usability and authors often cite it as a quick and reliable measurement tool that provides a global usability score [88]. Studies that used the SUS often adapt the wording of the SUS questions to be specific to CUIs [89]. For example, the word 'system' in the statement "I think that I would like to use this system frequently" is replaced with the word 'Chatbot' [90]. In all cases where the SUS was used for CUI usability testing, the resulting scores were above the accepted average of 68 [89, 90, 91, 92].

Other scales described in studies include the User Experience Questionnaire, which is a scale that measures usability and aspects of user experience, and the IBM Computer System Usability Questionnaire. Chatzimina et al [93] used the User Experience Questionnaire to measure efficiency, dependability, perspicuity, originality, and CUI stimulation. The authors cited the User Experience Questionnaire as a quick measure of user experience [93]. Based on the ISO definition of usability, this questionnaire may cover some of the essential usability aspects described in the ISO standard. Interestingly, this scale also provided a measure of goal aspects (i.e. efficiency, dependability, and perspicuity) and non-goal aspects (i.e. originality and stimulation) of the CUI under investigation [93]. Chatzimina et al [93] did not include other usability testing measures and only relied on a single quantitative User Experience Questionnaire as a quick and valid measure of user experience. The IBM Computer System Usability Questionnaire was used by Valtolina et al [92] to evaluate a healthcare knowledge CUI. This questionnaire focused on satisfaction and only used positive wording, unlike the SUS and User Experience Questionnaire, which has a balance of positive and negatively worded questions [92]. The four outcomes of the IBM Computer System Usability Questionnaire are the following: system usefulness, information quality, interface quality, and overall satisfaction [92].

While some studies used a single questionnaire in their experiments to subjectively measure usability, other researchers chose to combine questionnaires. Holmes et al [94] used three questionnaires to evaluate the usability of a WeightMentor chatbot. Their study aimed to determine if the traditional measures and questionnaires could be used to evaluate the usability of health-related CUIs [94]. The authors used two previously discussed questionnaires, the SUS and User Experience Questionnaire, and developed their own chatbot usability questionnaire. The authors' chatbot usability questionnaire was not a valid measure of usability as this was the first time it was used. Fortunately, they provided the questions in their article and the formulas for calculating the resulting scores [94]. The researchers identified that the chatbot usability questionnaire correlated better with the User Experience Questionnaire score than the SUS score and that there was a possibility that the chatbot usability questionnaire measured constructs that were closely related to CUIs [94]. Valtolina et al [92] used three questionnaires in their study: SUS, User Experience Questionnaire and the IBM Computer System Usability Questionnaire to evaluate their healthcare knowledge CUI and asked participants open-ended questions.

Micoulaud-Franchi et al [95] used items from the Acceptability E-Scale to measure participant interaction usability with an embodied conversational agent designed to help with mental health disorder diagnosis interviews. The Acceptability E-Scale is a questionnaire that explores both technology acceptance, satisfaction and usability [95]. The authors found a more significant correlation of satisfaction with usability than technology acceptance which aligns well with the ISO definition of usability, including satisfaction [85].

In one study about the use of CUIs in electronic health records, usability was a significant factor in accepting this interaction by healthcare professionals [16]. Kumah-Crystal et al [16] identified that participants could not accurately use the system to input the desired health information into the electronic health record and thus spent additional time to correct the errors. Approximately 70% of participants reported that this was why they did not want to continue using the voice user interface [16]. This study identified that accurate speech recognition must be a primary functionality for voice user interfaces in a healthcare domain where errors in data could significantly impact a person's health. The ISO definition of usability also suggests safety as one of its measures [85]. However, this research was surprisingly one of the only significant studies highlighting safety as a consideration for CUI usability in healthcare.

2.6.4 Objective Usability Measures

Although most studies used subjective aspects to measure usability, the most commonly used objective usability measures involved participants performing specified tasks using the CUI. Denecke et al [96] evaluated the usability of a chatbot designed to perform self-anamnesis, where patients answered questions about their medical history. Participants' ability to successfully interface with the CUI and complete the tasks designed by the researchers was measured as a binary result (i.e. yes/no) [96]. This binary completion result was also performed by Hess et al [86] for the evaluation of a self-management medication CUI [86]. Denecke et al [96] additionally recorded issues that occurred while participants were completing the tasks.

For performance benchmarks, Holmes et al [94] used the task completion times of the CUI developer as they were the most experienced individual with the CUI. Additionally, unlike other experimental procedures, the authors in this paper had participants perform the task up to four times [94]. The authors hoped to identify if completion times improved with each repetition but only found that after the first attempt, participant completion times were optimized, which may result from the non-visual hierarchy of CUIs. Ponathil et al [53] also used completion times for tasks and compared completion times to a benchmark of a standard visual interface currently in use. They found some tasks such as sharing information or accessing the platform that could be completed faster using the CUI, but many tasks took much longer using the CUI than the visual interface [53]. These tasks included inputting family health information, setting up a user profile, and editing information [53]. However, the authors identified that the CUI was more helpful and had greater perceived ease of use compared to the visual interface.

The data analyzed for evaluating these objective measures were often the log report of the participants' conversation with the CUI [86]. The efficiency was identified as the number of steps required to complete the task [86]. The dialogue's quality was identified by how long it took the CUI to respond to the participant and how adequate the response was [86].

2.6.5 Infrequently Used Usability Measures

Open-source CUI testing platforms were also used to measure usability objectively. This was only found in one study by Cameron et al [90]. The authors combined the SUS with the Chatbottest. This chrome extension is used to measure the following categories: onboarding, personality, chatbot answering, chatbot understanding, navigation, error management, and intelligence [90]. This chrome extension provides a score on a scale of 100 for each category depending on the log data produced in the conversation [90].

Only one study used observation to evaluate the usability of the CUI. Valtolina et al [92] applied a semiotic engineering method called the Communicability Evaluation Method to empirically study the reception of messages from an interface to a user. The researchers assigned one of 13 tags during the experiment when there was a communicability breakdown, some of which were labelled as “I give up.”, “Oops!” or “What is this?” [92]. The frequency and context in which the tags were assigned during the experiment were then analyzed to determine when and how usability issues occurred, as well as to detect patterns [92]. The authors expressed that their study was unfortunately unable to identify any patterns due to the lack of communicability breakdowns during the experiments, which may suggest that CUIs provide acceptable communicability.

2.6.6 Principal Findings

After analyzing the previously discussed articles to identify usability measures for CUIs, it has been identified that there is no agreed-upon approach to CUI usability evaluation to inform design or acceptance. However, several commonly observed approaches are used in the recently published literature to measure the usability of CUIs in a healthcare context. Depending on the experiment's focus, usability was found to be evaluated using both a single measure and multiple measures. Studies that focused on usability often used more than one objective and subjective measure to identify usability of the CUI under investigation. However, there was often a lack of objective measures used.

One of the most frequent measures was the SUS questionnaire. The SUS is a validated subjective measure [88]. Some studies used additional questionnaires such as the User Experience Questionnaire and the IBM Computer System Usability Questionnaire to validate the SUS scores or provide additional insight into the user experience. To provide additional subjective insights, few studies included an interview at the end of the experiment to identify usability issues that the questionnaires did not capture.

Objective measures of usability often included an analysis of communication logs with the CUI. They identified if tasks were completed correctly, as well as how long it took to complete tasks. Conversational logs have not been used to measure satisfaction with the CUI. Therefore, all studies that analyzed conversation logs used questionnaires to subjectively capture other usability aspects included in the ISO definition of usability. Very few studies objectively measured observational aspects to determine usability with CUIs. One study did use an objective technique but could not produce enough data to identify usability patterns.

Given that there was no specific ISO standard that identified measures to use when evaluating CUI usability, it was expected to find varied CUI usability evaluation methods in the literature. However, some reviews of CUI usability measures done by Ren et al [97] and Abd-Alrazaq et al [88] stressed that there is a clear need to standardize objective measures for healthcare CUI usability [88, 97]. This is critical for comparing performance and suggests that CUI researchers should increase their use of conversation logs for this evaluation [88, 97].

The previous studies that measured CUI usability relied on subjective measures through the use of questionnaires. Most studies also involved a developed CUI where a participant could interact with the system. Research that used objective measures relied on conversation logs after completing the experiment. There was limited successful research done on measuring usability by observing participants interact with the CUI during an experiment, and qualitative interviews drove no research. This indicates an opportunity for future research to find novel ways to understand usability through in-depth interviews.

2.6.7 Conclusion

The integration of CUIs into graphical user interfaces and other applications is growing in prevalence and can be an effective way for humans to interact with information. In the healthcare context, the literature has identified that significant research has been conducted to develop CUIs to improve the patient experience with healthcare information. Despite the growing integration of CUIs in healthcare, there is an increasing need to further understand this technology's usability, given that healthcare is a safety-oriented domain. Current research methods to evaluate usability are varied across the current literature. Despite there being an ISO standard for usability and several validated subjective measures, there are no standardized CUI usability measures in healthcare, to inform the design and development of this technology.

Current research has identified varying degrees of effectiveness with subjective and objective usability measures for evaluating CUIs. While many studies successfully employ subjective measures to understand usability, few studies use objective measures such as the conversation log with the CUI to measure usability. Fewer studies use observational data, and no studies explore the potential usability based on rich, qualitative interviewing methods. Future research can meaningfully benefit by combining subjective questionnaires with detailed interview data to understand the potential usability of CUIs in healthcare from primary users' perspectives and inform design before developing this technology.

Chapter 3

Methodological Approach

Buckley and Chiang have defined research methodology as "a strategy or architectural design by which the researcher maps out an approach to problem-finding or problem-solving" [98], and that choosing a methodology is dependent on the characteristics of the research problem [99]. One methodology of choice is mixed-methods research:

> *"The class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, theories and or language into a single study"* [100, p. 120].

As a result of the background and literature review described in Chapter 2, the research conducted for this thesis uses mixed-methods to approach the design of a VA for complex home care. This approach's objective in this research is to build a foundation for understanding the current processes of home care concerning information management and communication and the perceived usability and adoption of VAs in this complex domain. As this is a relatively new field with limited existing literature, qualitative research methodology is considered a suitable approach [101]. Combined with quantitative methods, mixed-method research can capture both generalized and nuanced perspectives from a diverse population to inform design [102].

3.1 Study Design & Participants

There are four parts to the exploratory, mixed-method study that were included in this thesis: (1) caregiver demographics, (2) caregiver work domain, (3) caregiver experiences with VAs, and (4) caregiver expectations for VAs in a home care context. To examine the diversity of home care experiences and VA perspectives, this study included family caregivers and hired caregivers. Specifically, family caregivers were included for CSHCN as well as older adults with complex healthcare needs. Hired caregivers included individuals that were employed either by an agency or a family caregiver, to provide healthcare services in someone's home environment. The primary methods used for data collection in these four parts of the study were interviews and questionnaires.

Participants were recruited online between June 28^{th} and September 25^{th}, 2020. Snowball sampling was employed to recruit some of the participants, where at the end of the interview, participants agreed to share the research study with their acquaintances who met the eligibility criteria for participation [103]. Given the COVID-19 pandemic it was difficult to recruit participants who were providing home care, as they did not have time to participate while caring for someone with complex medical conditions along with navigating the complexities of working from home. Snowball sampling can impact the random sampling of the study [103]. However, snowball sampling is especially advantageous for exploratory research, allows for studies to be conducted in areas where it may be difficult to recruit participants, as well as supports the discovery of unique characteristics of participants in a population that would otherwise be difficult for the researcher to recruit [103, 104]. While snowball sampling is often criticized for not being generalizable to a population as the sampling is not random, the objective of qualitative research is to gather diverse perspectives and explore a central phenomenon [104].

In total, we interviewed 22 caregivers who provide care services in complex home care. Specifically, we recruited seven family caregivers of CSHCN, nine family caregivers of older adults with complex health conditions, and six hired caregivers of older adults with complex health conditions. Due to the COVID-19 pandemic, all participants were interviewed virtually in their home or their workplace. The first part of the interview focused on understanding the caregivers' background and the home care situation where they provided care. The second part of the interview captured the caregivers' work domain concerning managing and communicating information and care responsibilities in their home. Participants were explicitly asked to describe how they navigate caring for someone in their home, communicate with other caregivers, and the factors that influence their home care environment. The third and fourth parts of the interview focused on identifying participants' everyday experiences interacting with VAs and their expectations for VAs to support information management and communication processes.

At the end of the interview, the participants completed 12 Likert-scale questions about their expectations for VAs in a home care context and were asked to respond on a seven-point scale verbally. Participants were additionally provided with the opportunity to qualify their selections on the Likert-scale. The study materials, including the information and consent letters, recruitment materials, interview script, questionnaire, and thank you letter, can be reviewed in Appendix A.5.

3.2 Data Collection Methodology

3.2.1 Semi-Structured Interviews

Interviews are the most common qualitative research method that can provide a rich understanding of a phenomenon being explored [105]. Semi-structured interviews are a hybrid approach to interviewing that combines the benefits of structured and unstructured methods [105]. According to Corbin, the benefits of structured interviews are that they provide a specific guideline for the interviewing researchers to follow. They can address specific research questions through both open-ended and closed questions and work particularly well with large sample sizes when there is more than one interviewer [106]. However, structured interviews fall short on flexibility. They do not readily permit a researcher to dive into new concepts that sometimes emerge during an interview and prevent the researcher from exploring potential interesting topics about a participant's response that are not directly related to the research question [106].

According to Gray, the benefits of unstructured interviews allow a researcher to direct the interview and explore various aspects of the interviewees' thoughts and experiences. These interactions are more representative of a natural conversation with some control [107]. They allow for adaptions to occur as necessary during a participant's interview as well as permit probing questions [107]. The drawback of this interview style is that without structure, the resulting data among several participants may be challenging to analyze if multiple interviewers are conducting independent interviews [107]. By combining the benefits of structured and unstructured interviews, semi-structured interviews have the advantage of a structured protocol with the opportunity to explore participant's responses in greater detail if needed.

3.2.2 Questionnaires

Questionnaires provide a subjective, quantitative result that can be analyzed using statistics and other numerical methods, resulting in a generalized indication of a study topic. While several established questionnaires were used to evaluate user experience with technology, this study employed a custom questionnaire for exploring participant perspectives about VA design based on prior literature as none currently exist.

The purpose of the questionnaire in this study is to quantitatively measure caregivers' perspectives about VA design features to inform adoption, as well as encourage additional insights into the qualitative understanding of participant's unique viewpoints. As summarized in the *Handbook of Survey Research, 2010*, optimal questionnaire design involves the use of simple language and syntax, avoids ambiguity, strives for specific wording, provides an exhaustive list of mutually exclusive options, and avoids loaded questions, double-barreled questions, and questions with double negations [108]. This handbook's authors suggest these recommendations based on the complex cognitive processes involved with question answering that include interpreting, memory searching, integrating, and responding. However, these common recommendations are often applied for questionnaires conducted without face-to-face interaction with the researcher or anonymously through crowd-sourcing platforms.

In this study, the questionnaire is conducted over a video calling platform, providing face-to-face interaction with participants. This mode has been suggested as a preferred mode for conducting a questionnaire, especially for participants who are above the age of 65 [109, 110]. While the questionnaire designed for this study addresses most of the recommended factors for optimal questionnaire design, some of the questions may require participants to think deeply before responding. However, when conducted face-to-face, there may be greater flexibility for using cognitively challenging questionnaires. Bowling suggests that face-to-face questionnaires may provide the least cognitive burden for participants as long as they are also provided with a visual response scale. This may be a result of shared cognitive resources between audio and visual perception. Face-to-face questionnaire methods also allow participants to ask the interviewer to clarify the question, which supports cognitive processes involved with question answering and the quality of the response [109]. Face-to-face questionnaire administration may build rapport between the interviewer and interviewee to support genuine responses from the participant [109]. However, it is important to consider the potential for social desirability bias when conducting a face-to-face questionnaire [109].

3.3 Data Analysis Methodology

3.3.1 Qualitative Analysis

Qualitative research in the context of interviews is described by Seale et al [111] as the interaction between the interviewer and interviewee about a topic to produce rich data:

> *"Interviews are, by their very nature, social encounters where speakers collaborate in producing retrospective (and prospective) accounts or versions of their past (or future) actions, experiences, feelings and thoughts"* [111, p. 16].

For analysis, Seale et al [111] explain that interview data examination is focused on *"what actually happened"*. Two commonly used approaches to qualitative data analysis are (1) Theoretical, and (2) Inductive [112]. Theoretical thematic analysis grounds the data in a philosophical position or framework and often provides a means for identifying concepts that are not common-sense and would otherwise be ignored [111]. Inductive thematic analysis is not guided by theory and is strictly directed by the content of the data [111]. Seal et al [111] argue that both approaches can produce high-quality findings if they are appropriately applied to the type of research being conducted.

The most commonly used method to analyze qualitative data is called 'coding.' Saldana describes a 'code' in the context of qualitative data as the following:

> *"A code in qualitative inquiry is most often a short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data"* [113, p. 4].

Beyond naming categories in the data, coding is a much more involved process that requires a deeper understanding of the data. It requires identifying the conditions, interactions among the actors, strategies and tactics, and consequences of capturing the emerging themes from a participant's responses [114]. For example, coding can be further divided into several specific methods that can be employed to reveal a deeper understanding of the data. One example is 'process coding,' which involves creating words with '-ing' endings to describe an action in the data [113]. This coding method is particularly applicable for studies that aim to understand *"the routines and rituals of human life"* for problem-solving [113]. Another example is the method of 'values coding,' which are codes that *"reflect a participant's values, attitudes and beliefs, representing his or her perspectives or worldview"* [113]. Although there are many specific coding methods, their purpose is not to use them as the sole approach but to use them as a potential lens for analyzing data [113].

3.3.2 Rigor in Qualitative Research

With the subjective nature of qualitative research, and despite being recognized as a vital tool, the quality of this research methodology has been a controversial topic amongst researchers [112, 115]. One of the primary approaches to achieving rigour in qualitative research is saturation [115]. However, saturation can be achieved through more than one avenue, for example, through the number of participants or by code saturation [115]. While not always the case, sample sizes as small as six participants can be justified to provide sufficient data to develop meaningful themes when the sample size is diverse [116, 117, 118]. For example, when participants are from a specific demographic such as caring for a child with a medical complexity, where they come from unique backgrounds as a result of their child's condition and the subsequent experiences they face to provide care [119]. In research with small sample sizes, generalisability is often not the primary objective, but rather to explore behaviour and in-depth understandings on participants' views and perspectives [120]. However, results of small sample sizes can be generalized when sufficient participant demographic data is provided [119]. With respect to code saturation, when there are no new codes identified amongst a set of interviews [119], saturation might depend on the order that the interviews are conducted in [117]. However, when sample sizes are small, it is generally feasible to analyze all interviews to ensure saturation in the analysis.

3.3.3 Triangulation Design

There are four major types of mixed-methods designs: Triangulation Design, Embedded Design, Explanatory Design, and Exploratory Design [121]. As one of the most commonly used approaches for validating research findings, Triangulation Design was used in this research:

> *"Triangulation seeks convergence, corroboration, and correspondence of results from the different methods"* [122, p. 62].

Triangulation Design aims to collect data about the same topic that is complementary yet different to support the strengths and weaknesses of more than one method [121]. Triangulation Design combines qualitative and quantitative methods simultaneously in a study with equal weighting [121]. One traditional variant of the Triangulation Design is collecting and analyzing data about the same topic independently and then converging the results during the interpretation phase to validate findings with well-substantiated conclusions [121].

Chapter 4

Towards Designing In-Home Digital Health Tools for Family Caregivers of Children with Special Health Care Needs: An Exploratory Qualitative Study

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4.1 Overview

Background

Family caregivers of children with special health care needs (CSHCN) are responsible for managing and communicating information regarding their child's health in their home. While family caregivers currently capture information through non-digital methods, digital healthcare applications are a promising solution to support standardizing information management in complex home care across their child's health care team. However, family caregivers continue to use paper-based methods where the adoption of digital health tools is low. With the rise in home care for children with complex health care needs, it is critically important to understand the caregiving work domain to inform the design of technologies that support child safety in the home.

Objective

The objective of our study was to understand how family caregivers navigate information management and communication in complex home care for children with special health care needs.

Methods

This research is part of a broader study about the perspectives of caregivers across North America on integrating and designing digital health tools for complex home care. We conducted semi-structured interviews with family caregivers of children with special health care needs. Inductive thematic analysis was used to analyze the information management and communication processes.

Results

We collected data from five Canadian and two American family caregivers and identified five themes. First, family caregivers were *Continuously Learning to Provide Care.* They were *Updating the Caregiver Team* on their child's status and *Teaching Caregivers about their Care Situation.* As caregiving teams grew, they found themselves working on *Communicating with their Child's Educators.* Beyond the scope of managing their child's health information, family caregivers were additionally *Navigating Bureaucratic Processes* for their child's home care.

Conclusions

Family caregivers' experiences caring for CSHCN differ geographically and evolve as their child's condition changes and they grow towards adulthood. Family caregivers recorded information using paper-based tools, which did not sufficiently support information management. They also experienced significant pressures in summarizing information and coordinating two-way communication about the details of their child's health with caregivers. The design of digital health tools for complex home care may improve care coordination if they provide an intuitive method for information-interaction yet provide significant utility by delivering situation-specific insights and adapting to unique and dynamic home care environments.

Keywords: Children; Caregiver; Digital Health; Home Care; Qualitative Research; Technology

4.2 Introduction

Caring for children with special health care needs in a home environment involves several complex processes, significant use of health care services, dependence on medical technology, and increased responsibilities for sharing information by the family caregiver [25]. Mapping the interconnections for the most complex CSHCN reveals multilayer interactions and operations between several systems and subsystems of the health care system, all of which encompass the family caregiver and their child. These systems include but are not limited to the child's medical teams, physical and psychological development teams, diagnostics teams, educational teams, and other medical supports [25].

Home care is considered an ideal environment for CSHCN [25, 26]. In hospitals, the risk of errors and adverse events for children with complex health needs who require support through medical technology, enteral feeding, complex medication regimens and mental health services is significant [26]. However, the available technologies, services, and policies designed to assist family caregivers in coordinating care in a child's home do not currently meet their needs [25, 123]. Non-digital documentation methods that caregivers use create increasing amounts of physical health data in the home, potentially leading to errors, adverse events, and rehospitalizations due to the communication challenges and information management limitations associated with manual record keeping [124].

While literature identifies a need for developing an electronic health record for organizing, integrating and communicating health information in complex home care [25], the development of electronic health records remains a fundamental challenge for complex home care [55, 125, 126, 127, 128, 129]. Paper-based records continue to be used as there are no substantial digital technologies available that are as flexible and reliable [11, 130]. In the context of interoperability in healthcare, the goal is to "deliver information when and where it is needed" [130]. However, when billions of documents are still being created on paper, it becomes challenging to collaborate in real-time, find information, and analyze and understand its meaning [130].

Personal electronic health record applications and online portals connected to hospitals or home care agencies can improve the organization and communication of health information across caregiver teams [14]. Unfortunately, caregiver engagement with these technologies is low. Annual adoption rates for online portals ranges from 5-12.4% [13, 14]. The currently studied digital healthcare technologies do not encompass caregivers' complete information needs [131, 132, 133]. Also, interacting with these tools is often associated with challenges that involve visual hierarchies of information, increasing the interaction burden [11]. With their limited engagement in emerging digital health tools to support home care, caregivers do not experience the potential benefits of improving home-based health management and communication [14, 134].

Understanding the complex work domain of family caregivers who provide home care services is critically important given the increasing lifespans of CSHCN and the growing prevalence of home care [4, 9]. Few studies have investigated the potential engagement and impact of novel home care technologies to support caregivers, and, to the best of the authors' knowledge, there is limited understanding of how family caregivers navigate information and develop their management and communication processes. To support the design and refinement of digital health tools that can be integrated to intentionally facilitate better communication, improve the sharing of health-focused information and ultimately contribute to improving home care, this study captures the diverse experiences and perspectives of family caregivers of CSHCN.

4.3 Methods

4.3.1 Study Design

This research is part of a broader mixed-method study on the design of digital technology to support caregivers in complex home care. The extensive study involves interviews, surveys, and a modified Wizard-of-Oz interaction with caregivers. The focus of this paper is to address the gap around the experiences of family caregivers of CSHCN. We conducted qualitative, semi-structured interviews and used inductive thematic analysis to analyze the interview data [112].

This study was conducted remotely across North America to capture caregiver perspectives in Canada and the United States of America (USA). This research received ethics approval from the University of Waterloo.

4.3.2 Eligibility Criteria

Eligible participants were 18 years of age or older and a family caregiver for CSHCN in their home in North America. In the context of this study, CSHCN included children who had any combination of the following: chronic conditions, mental health issues, medication-related problems, and social vulnerability. A family caregiver was anyone who provided or coordinated care for CSHCN; they assisted the child with medication, feeding, medical treatments, medical technology use or other health-related tasks in the home.

4.3.3 Recruitment

COVID-19 restrictions led to a fully online recruitment between June 28th and September 25th, 2020. Hospitals, home health care and caregiver support agencies or groups via email and social media platforms such as Twitter and Facebook were contacted, then snowball sampling was done from existing contacts. Study participants were sent a thank you letter for their participation after the study, and no remuneration was given for participating.

4.3.4 Data Collection

Two researchers (RT, KM) conducted the interviews. Microsoft Teams was used to record the interviews, and only the audio-recordings were used for transcription. One of the interviewing researchers is an experienced interviewer and qualitative researcher (KM), and the other is a MASc candidate in Systems Design Engineering with prior experience conducting interviews (RT). After each interview, field notes were completed. There were two parts to this exploratory qualitative study: (1) caregiver demographics and (2) caregiver work domain. Participants were interviewed over video from their homes where they provide care for their children. The first part of the interview focused on understanding the caregivers' background and their home care situation. The second part of the interview captured the caregivers' work domain to manage and communicate information and care responsibilities in their home. The interviewers asked the participants to describe how they navigate caring for someone in their home, communicate with other caregivers, and the factors that influence their home care environment.

4.3.5 Data Analysis

The interview data were analyzed by means of inductive thematic analysis using the following steps: (1) The interviews were transcribed verbatim; (2) members of the research team read the transcripts and listened to the audio recordings to familiarize themselves with the data; (3) core team members thematically coded the data; (4) initial codes and themes were developed; (5) the data were presented to the full team for discussion and refinement. Data were stored and organized using QSR NVIVO 12 and Microsoft Excel 2021. All names and identifiers were made anonymous during the transcription process. Triangulation of the data was achieved using various geographic areas, multiple coders, and a multidisciplinary team of researchers interpreting results. Data saturation was reached after analyzing the first four interviews when no additional themes were identified. To confirm data saturation, the data from three additional participants were analyzed.

4.4 Results

4.4.1 Study Population

Seven family caregivers of CSHCN participated in this study (Table 4.1). Two family caregivers participated from the USA, and five family caregivers participated from Canada. Of the participants from Canada, 80% (4/5) were from Ontario. The youngest participant in this study was 33 years old, and the oldest was 40 years old. All participants identified as female, and the caregivers' experience providing care in their home for their child ranged from 4-18 years. Although small sample sizes may not completely generalize to larger populations, the objectives of this study were to explore the experiences of a diverse group of participants based on age, caregiving experience, and location, which lead to the

Table 4.1: Participant demographics and caregiving characteristics (n=7)

Characteristics		Family Caregivers
Age (years), n (%)		
	25-34	2 (29)
	35-44	5 (71)
Gender, n (%)		
	Female	7 (100)
	Male	0 (0)
Location, n (%)		
	Ontario, CA	4 (57)
	Alberta, CA	1 (14)
	Missouri, USA	1 (14)
	Minnesota, USA	1 (14)
Caregiving Experience (years), n (%)		
	0-5	1 (14)
	6-10	3 (43)
	11-15	2 (29)
	16-20	1 (14)

development of meaningful themes regarding information management and communication in this complex healthcare domain.

4.4.2 Thematic Analysis

The coding conducted by the research team led to the identification of 46 codes (Table 4.2). The list of codes was developed into five themes and four subthemes describing the information management and communication processes of family caregivers of CSHCN in a home care domain.

Table 4.2: Themes in communication and management of information in home care

Themes	Subthemes	Codes
• Continuous Learning to Provide Care		• Connecting with other families • Learning from health care professionals • Learning from therapists and technicians • Learning from training • Learning about medical technology • Learning by observing • "Figure it out on my own" • Navigating through information for complex children • Learning what to do in emergencies • Learning procedures
• Updating the Caregiver Team	• Maintaining Records	• Physical documentation • Identifying patterns • Burden of documentation • Documenting vitals, health status, and medications • Documenting holistic aspects of care • Documenting equipment settings • Desire for digital records • Adapting documentation as a child's condition changes • Transparency of record-keeping • Concerns for information security • Desire to ease record-keeping
	• "Sharing the Right Information with the Right Person at the Right Time"	• Posting information around the home for other caregivers • Feeling pressure • Financial consequences • Communicating with health care professionals • Ensuring situation awareness • Summarizing changes • Memorizing information
	• Strategizing Care with the Caregiver Team	• Sharing recent health information • Troubleshooting health care issues • Identifying appropriate therapies and treatments
• Teaching Caregivers about their Care Situation		• Teaching through documentation • Requiring background knowledge of caregivers • Sharing their child's journey • Sharing care expectations for home care tasks (e.g. feeding)
	• Communication Challenges in Teaching Caregivers	• Struggling with the consensus of caregiver training • Effectiveness of training • Trust in caregivers
• Communicating with their Child's Educators		• Receiving health updates from the school • Creating health care tracking documents for the school
• Navigating Bureaucratic Processes		• Information transfer to governing bodies • Caregiver scheduling • Negotiating caregiver hiring • Acquiring funding • Documenting caregiver information

4.4.3 Continuous Learning to Provide Care

Family caregivers of CSHCN explained that they were continuously gathering information to learn about their child's condition and then applying this knowledge in their home. They explained that they collected information from various sources, including trained professionals (3/7, 43%), media such as books, videos and other documentation (4/7, 57%), through observing other caregivers (2/7, 29%), and from family caregiver networks that connected them with caregivers of children with similar conditions (2/7, 29%).

At the onset of navigating through their home care situation, P1 and their caregiver team of nurses received specific medical information and training from their local children's hospital.

> *As soon as we got our team hired, we were able to send them all to [the hospital] for training, which is where my husband and I had to pass a course... to basically show we could save our [child's] life before we were discharged from the NICU. (P1)*

However, with the uniqueness of CSHCN conditions and treatments which can sometimes be rare and difficult to diagnose (4/7, 57%), the family caregivers in this study had varied experiences concerning the professional training or resources available to them.

> *There's only one type of parenting guidance that's out there. [Having a] child with all these complex needs... and you are expected to just know how to navigate or facilitate your way through all of it. (P4)*

The family caregivers who did not receive specialized training relied on their observation skills to mimic the required processes they saw in clinics or hospitals:

> *With our suction machine, when we initially came home with it, the day of discharge from the hospital, I was handed the suction machine, "Here's your machine. Go home bye". Nobody showed me... I have never seen a user manual for those things ever... At that point, I had gotten used to seeing them at the hospital... the wall-mounted suction machines. I kind of had a basic idea... Like, "OK, can somebody at least show me how to turn it on?" (P5)*

Family caregivers who communicated online with caregiving networks described that these were a tool to reduce their reliance on their healthcare team. They used this network to discuss their concerns and work together with others whose children had been through similar experiences:

> *I get a lot of information from a mom's group... You don't necessarily want to be calling the clinic every time something comes up... unless it's serious... So, you know, we might say, "Oh, I noticed she's starting to get stomach aches. What has the group seen?" That kind of thing. It also helps us to try a few things before we call the clinic and say, "She's experiencing these symptoms. We've already tried X, Y and Z," which those X, Y and Z I usually get from the mom's group, for things that they've gone through similarly. They're the people who know, they've been there. (P3)*

4.4.4 Updating the Caregiver Team

Family caregivers of CSHCN are often the primary knowledge holders for information about their child [135]. In this study, each participant discussed the pressure to maintain awareness of their child's history and current health status among all caregivers to ensure that their child received the best possible care. Their communication responsibilities are summarized with the following subthemes: *Maintaining Records*; *Strategizing Care with the Caregiver Team*; and ensuring that they are *Sharing the Right Information with the Right Person at the Right Time*.

Maintaining Records

A critical process that family caregivers carry out to update their caregiver teams is documentation. Every caregiver in this study implemented paper-based documentation at the start of managing their child's condition and recorded information such as vitals and medications (5/7, 71%), the status of their child's life-supporting equipment (2/7, 29%), or other holistic aspects such as behaviours and feelings (2/7, 29%). There were three caregivers (43%) who continued to record detailed information about their child in paper-based records every day, with children aged 4 to 13 years at the time of this study. The other caregivers (4/7, 57%) documented health information infrequently.

Retaining the detailed information about their child's care was a burden for the family caregivers in this study who were documenting every day, which was apparent when they described having to continuously condense and summarize this knowledge for other caregivers. For example, P4 expressed the challenges associated with the amount of information that they had retained and the impact that this had on the expectation for them to remain the primary knowledge sharer in their caregiver team:

> *There are always people added and incoming, and it seems like it's always on the parent to fill in the next carer, the next professional, on what's going on and answer their questions of what they may have from the previous professional. And it all comes down to the whole concept of the parent is the expert in their*

> *child... But we shouldn't have to be that role all the time, and that's very frustrating... We have team meetings at the school once a month with teachers and board members and all that stuff, and I'm expected to like come in with my binders of information and fill them in on everything that's happened in the last month... It's crazy exhausting. It was stressing me out considerably. (P4)*

Maintaining their child's health documentation in the home was not a responsibility that some of family caregivers in this study mentioned carrying out on their own. Multiple caregivers (4/7, 57%) described sharing documentation responsibilities with other caregivers and developing methods to ease their documentation processes through checklists and sign-off sheets.

> *I also have a binder that I, well, technically, I have three, but let's not get carried away. I have one I call [my child's] Bedroom Binder. And in [my child's Bedroom Binder] is the medication schedule and a check-off or a sign-off sheet so on every day of the month there is an opportunity to sign off every medication dose that [my child] receives that day, who gave... (P2)*

> *I would just have them like do a little checklist so that they wouldn't forget to do a med or something like that. (P7)*

There were no participants in this study who used a digital health tool to document and track information, despite their excitement and hope towards digitizing their current routines. One participant (P6) used a Google Home voice assistant to remind their child about medications and appointments. Another participant (P2) explicitly expressed frustrations with a software application that they tried to use to support the management of care information in their home. However, the associated steps involved with navigating the application and the limited customization rendered it useless:

> *One of the most annoying things about it is it's an app on my phone, and I have to sign into it every time I click on it. It pisses me off... I actually don't use this because it doesn't accept a couple of [my child] 's diagnoses. It doesn't recognize them. It doesn't recognize some of his medications, and it has rendered itself useless because these are [the] things we do every day... I had pretty high hopes and was really excited. And I'm just really frustrated and disappointed that it's not what I wanted it to be. (P2)*

Strategizing Care with the Caregiver Team

Along with providing care, participants described that their caregiver teams were also responsible for supporting the development and implementation of strategies to improve care quality in their homes. Capturing their child's health information was a critical step in the process of strategizing care, where many family caregivers in this study (5/7, 71%) explained that they provide their caregiving teams with the necessary details to identify correlations and patterns in their child's health.

> *When [my child] sees the complex care team at [the children's hospital], we'll take the chart with us if we need [the] clinicians to troubleshoot something with us. (P1)*

> *Between school and home, and for behaviours and possible seizures, we were recording [them] so we could take it to the doctors... I wasn't there [at school], and I was just trying to go by [what their educators were saying] (P6)*

“Sharing the Right Information with the Right Person at the Right Time”

A factor related to the documentation and communication of health information about their child was sharing the right information with the right person at the right time. The caregivers in this study expressed the demands and consequences associated with properly filtering the large amount of information they had to ensure that they shared the necessary details with those who need it:

> *I think that remembering to share the right information with the right person at the right time in the right way so that they hear what they need to hear so that they will be willing to help us is the precipice of my existence... I feel that pressure in every conversation I have about [them]. (P2)*

The financial consequences of remembering to share specific details with the right person at the right time also impacted family caregivers’ stress (2/7, 29%):

> *If we go into an appointment with a physical medicine specialist and I forget to tell [them] that [my child’s] got really good range of motion in [their] feet, so [they] only needs rigid AFOs... I can miss getting that prescription for AFOs. And without that prescription, I can’t get them covered or made because vendors in this area won’t even make you a pair of AFOs if you don’t have government funding. (P2)*

4.4.5 Teaching Caregivers about their Care Situation

Information management and health communication played an essential role for family caregivers who discussed teaching and training caregivers about their home environments, care plans, and specialized medical technology, which took time away from their child's care (6/7, 87%). Participants expressed that they needed a range of three to 80 hours to train each new caregiver. One participant (P2) explained that they often needed to train new caregivers every six months.

To support caregiving education and ensure that the caregivers in their home understood the nuances of their child's care needs, the family caregivers in this study developed their child's health care information into teaching materials, documentation, and training methods. Among several binders that P2 created in their home, one binder was specific to teaching other caregivers how to communicate with their child effectively:

> *[The] binder also has stuff about basic communication with [my child], and I have developed what I call a gesture dictionary... I start [my hired caregivers] with that piece right away: "You need to read this. You need to reference it when you can't figure out what [they're] telling you. This is really important." (P2)*

Along with physical documentation, the family caregivers in this study also relied on in-person training to communicate their home care's subtle nuances.

> *Picking up on [my child's] little signs that [they do], that's where... I have to tell them cause... that's kind of hard to have it written down. It really is a show-and-tell... you have to hear it to understand it. (P5)*

> *And it's trying to teach the workers how to tell the difference between "I don't want to" versus "I can't." (P6)*

While sharing the information related to their child's care and the specific processes involved was one aspect of their training, one caregiver specifically expressed the additional importance of communicating their child's growth:

> *The information I always wanted to share is where [my child] has come from... The fact that [they were] in a vegetative state for the longest time, [they] couldn't walk, [they] couldn't talk, [they] couldn't do anything and now [they run], [they do] track and field, [they play] basketball, [they] can talk... [They] can do a lot of stuff... I think it's important for people to always know where you've been. (P6)*

Communication Challenges in Teaching Caregivers

Despite the family caregivers' resiliency in this study, they still experienced communication challenges in their roles as caregiving educators (3/7, 43%). This was especially evident when participants expressed the challenge of training caregivers who already have a knowledge base and their own best practices:

> *Someone who has a willing heart, and mind, and a desire to look upon our world is easier to train than an HCA or LPN that's worked in the field, in institutions, for ten plus years because they've got patterns and rhythms and things that are important to them that I'm not really bloody interested in having in my home. (P2)*

P6 described the challenge of their hired caregivers being receptive to the training and their child's specific needs:

> *…and the information that you're willing to accept, right? Like I can train you on how to do a transfer 100 times, but if you're not receptive to the training, you're going to do it the way you want to. (P6)*

The effectiveness of their training was an additional concern for the participants in this study. They expressed uncertainty about knowing if their caregivers applied their training knowledge appropriately to provide care for their child.

> *I have several women that work for me who have no medical background at all… I can explain to them why I want them to do this, and they don't really get it. They don't understand contamination… And I don't know how to effectively explain that to people and get them to work through it. That's really difficult. (P2)*

Their inability to trust that their training was being implemented was one reason P7 no longer hired care:

> *I cannot trust people to do things or do it right or make the right decision. And even if they can't make the right decision… just knowing to call me. Some of the times where they brought [my child] to the hospital when [they] didn't need to go to the hospital, and they brought [them] to the wrong hospital rather than just calling me and asking… (P7)*

4.4.6 Communicating with Educators

Family caregivers of CSHCN attending school often had the additional challenge of navigating communication methods and information management with their child's educators

(3/7, 43%). Sharing information with their child's school was by verbal communication in-person or by phone and through written notes or email. Some family caregivers in this study experienced difficulties with receiving valuable information to track how their child was developing in order to continue to build on this development at home:

> *Who [my child is] at school is... very different... than who [they are] at home... We need to know what's going on there so we can mimic here... How did we get to this year with this many children who have needs and their people still don't understand how to do the these communications... (P4)*

The technologies used to support the sharing of information between their child's educators were not consistent. Caregivers described different methods that educators used to collect and transfer information about their child, which raised concerns for their child's safety.

> *It's a verbal chat, or it's an email or... we have been using emails more often because I don't answer my phone anymore... I like to have things written down. Or there's like a scrap piece of paper in [their] lunch pail or something... I do know now with the different portals, and stuff that different doctors have would have been easier in the moment... I had three adults that were being paid... [my child's] school supports... videotaping [my child] and walking around with that on their cell phone. So, there's no security or confidence that... it just opened up a whole can of worms. Or it had a potential of opening up a whole can of worms, but it's all we had... If there were secure ways of doing it, it would have been a little bit safer. (P6)*

In other situations, the family caregivers in this study (2/7, 29%) requested that their child's educators continue to track their child's health care metrics using their personally designed tracking sheets:

> *You would think - and there's only like four to six kids in [their] class - you would think that [their] teacher would be able to like fill out a quick form... but she never did it. So, then I realized like "OK, maybe it's because she feels like it's too much work," so I altered it to just be... kind of the general just circle it... So, the more people have to fill out, the less likely they are to do it. That's what I've realized... People are lazy, is what I've learned. [laughs] Even the really good ones. She's a fabulous woman, but like they're still lazy. (P7)*

Another family caregiver used a communication book, yet, despite their child's educators writing in them, the information did not provide insight into their child's care or development.

> *[Their] communication book would come back, and it would be like, "today [they] had a great day." (P4)*

4.4.7 Navigating Bureaucratic Processes

Although not directly related to health information management, navigating the management of their child's information with the bureaucracy of home care was a process that added another level of complexity expressed by some family caregivers in this study (2/7, 29%). Family caregivers expressed their responsibility to organize the necessary paperwork to have hired caregivers, such as scheduling, timesheets and payroll.

> *The main criticism of the family-managed home care program is the amount of paperwork that's required of families. But now that we've been doing this for two years, between my husband and I, it may take two to three hours a month to do payroll and the paperwork. (P1)*

> *Payroll is something that I have kind of hired out, so I have to make the schedule and tally the timesheets, but then I have a really lovely company that I've been interacting with since day one, and they have saved my butt more times than I can count, and they charge me a nominal [fee], and they do all of my EI and CPP, and they interact with the CRA on my behalf. They interact with WCB on my behalf. I send them signed checks. This is how much I trust this company, and they have never done anything wrong. If anything, they have saved my butt. (P2)*

4.5 Discussion

4.5.1 Principal Findings

This study examines how family caregivers navigate information and the processes involved with health communication in complex home care to support designing digital health information systems. Family caregivers of CSHCN are an underserved population with respect to the tools available to support them with managing their child's healthcare in their home [11]. Given that children with medical complexities account for one-third of all healthcare spending on child health in Ontario, Canada, it is critical to understand their experiences to inform the design of information management tools [136].

4.5.2 Differences in the Social Contexts and Healthcare Systems for Home Care Delivery

The context of family caregivers' social atmosphere and their health care system, which may be influenced by the political factors associated within their geographical regions, plays a role in family caregivers' home care experiences in this study. The social determinants of health have been shown in prior literature to influence inequities in our healthcare system [137]. There is also the need to use digital health tools to better account for these inequalities in our healthcare system in clinical settings [137]. As observed in this study, the design of digital health technology needs to consider supporting the context of home care. For example, for the participants in this study, information supports provided by the health care system were either abundant or unavailable, and opportunities for formally trained hired caregivers were readily available or non-existent. Life-supporting medical equipment is often a significant component of complex care for families of CSHCN [138, 139]. However, some families are not afforded the necessary instruction or formal training and take on considerable responsibility to ensure the safe and high-quality care of their child by learning to use these devices on their own. As Schaepe et al [24] argue, family caregivers are necessary and provide value and knowledge to their child's home care. However, there are significant risks to patient safety in life-threatening situations if family caregivers are not formally provided access to the required knowledge [24]. One recommendation provided by Foster et al [140] is to improve home care policies for families of children with medical complexity in the USA by including home health training through partnerships with the paediatric healthcare systems. In the context of digital health tools, there is potential to design information technology that can provide accessible information, for families who otherwise do not have the means for safely coordinating home care and providing health services for their child, addressing some of these inequalities [137].

In the context of the social attributes for providing home care with respect to caregiving stress and the support for caregiving services, some family caregivers share issues around having access to medically trained hired caregivers for respite care. Keilty et al [32] identified severe consequences for family caregivers of a child with a medical complexity who experience sleep disturbance, which may be relieved by addressing respite needs. While some participants in this study eventually received access to professionally trained caregivers to support their 24-hour home care, others navigated the hiring process, medical training, and supervision of hired caregivers independently; one may argue that these processes mirror those of a small business or full-time job [141, 142]. The challenge with receiving respite care in this study was either due to limited availability of professionally trained caregivers from local agencies or are a result of geographic location, where families were living in rural regions where local agencies did not exist, as identified in prior work by Weaver et al [143].

The additional challenge of training a stranger with no medical experience is an inequity that places considerable pressures and stress on family caregivers who may not be in a position where they have the time, resources, and financial capacity. They are simultaneously maintaining the health and safety of their child while training someone about their methods and processes for performing care. Respite care for the family caregiver may be minimal during the period of effectively training someone with no medical experience. As this study identifies, training a new caregiver may require up to 80 hours through several 1-8 hour shifts before the family caregiver and the trainee are comfortable caring for the child on their own. This study further identifies that the resources provided to support training are scarce. When they are available, the family caregiver is responsible for sharing the materials in an organized manner to support effective and efficient learning. With the compounding responsibilities for care, a majority of family caregivers quit their full time jobs to stay at home and provide for their child's healthcare needs on their own [138].

4.5.3 The Evolutionary Home Care Complexities for Family Caregivers of CSHCN

Information management and communication processes are dynamic for family caregivers of CSHCN [72]. However this study identifies that family caregivers remain steadfast users of paper-based systems which do not completely support the needs of their caregiving tasks. As their child grows older, the types of supports they need change and new caregivers enter and exit their child's caregiver team. Also, caregivers continuously learn new information about their child's complex health condition(s). As a result, the information they track on personally designed paper-based templates may change from recording vitals when first providing care to recording holistic aspects of care such as behaviours and feelings. They also design alternate versions of these forms for other caregivers to use. In some situations, family caregivers may record information less frequently. The family caregiver may only need to track information if their child is experiencing unusual symptoms to identify the underlying patterns and trends and report these to their team of clinicians in an email. Email messaging does not provide a standardized method for effectively communicating health information, and the paper-based methods that are currently used by the caregivers in this study to support these dynamic processes must be adapted by the family caregiver through changing their non-standardized record-keeping templates created on a computer, or by designing and printing new templates.

While documentation processes may change or reduce in frequency based on their child's evolving healthcare needs, new challenges emerge for navigating two-way communication of their child's care while attending school, which has also been identified by Mikles et al [144]. Though educators are often not trained medical professionals or health communicators, when they become responsible for supporting CSHCN in their classroom, they can be considered part of the caregiver team. The caregivers in this study are currently using technologies such as email, voicemail and written notes in an attempt to meet information exchange methods between their home and their child's school. No caregivers in this study were using digital health applications designed to support health information management and communication. With the technologies they were using, especially including paper-based documents or keeping information on photo and video storage applications on others' personal devices, there exist privacy concerns for misplacing sensitive information or for individuals to have unlocked access to information.

Non-standardized methods of communication that do not follow defined protocols for the type of information that needs to be shared are also associated with challenges. These challenges include communicating health insights that provide value towards improving the child's care and facilitating the organization of this information for efficient access by caregivers in the future. Although technology supports such as online portals have been developed for securely communicating health information from hospitals and other care facilities, and in some higher socio-economic situations there is standard physical documentation and hand-off protocols that can be provided to a family to support the communication of a child's development in school [144], the general needs of family caregivers of CSHCN to facilitate two-way communication with their child's educators have not been considered in the design of digital technologies.

4.5.4 Design Recommendations for Digital Health Technology

This study identifies a significant cognitive and time burden for family caregivers of CSHCN to accurately and concisely share complete information regarding their child's health to other caregivers [145, 146, 147]. Information sharing situations occur within caregiver hand-offs in the home, at caregiver team meetings in clinics and schools, and with their child's doctors and specialists [144]. Digital health tools have a significant potential to reduce the pressures on family caregivers while managing their child's information [11, 148, 149]. With the work that family caregivers currently carry out to overcome challenges related to the lack of caregiving support and resources, it is critical for the effective design of digital tools to support natural interactions while providing significant utility. First, the focus should be directed towards designs that reduce the need for family caregivers to organize their collected information manually, and in a physical manner. Many of the current technologies that caregivers use require manual entry of data and do not automatically collect information. Similar suggestions have been made in the context of health insurance tracking for families of CSHCN [150]. While systems to automatically monitor health conditions exist such as wearable devices or other ambient, non-contact tracking systems [151, 152], the complexity and uniqueness of CSHCNs home care with respect to the data that's required to track, may not always be suited to the use of these technologies. There may also be social or economic barriers that prevent the introduction of these technologies by family caregivers in their homes. As one example, voice interaction technologies to collect spoken health metrics or other details may be an alternate solution to enabling caregivers to collect information without physically interacting with a device [11]. While the spoken information may be unstructured, the data could be effectively stored in a structured database by the developed system.

Second, digital health tools should provide timely access to information, insights, and patterns specific to the context of the caregiver(s) that the information needs to be shared with. With the cognitive burden that caregivers face to accurately share information with others, digital tools should support caregivers to efficiently and effectively access the information they need depending on the context of care. In the clinical setting, design recommendations for the development of digital health technology to support healthcare management of paediatric blood marrow transplant patients has been described by Shin et al [147] similar to this context. While not explicitly describing how the user would interact with the technology to access insights about health data, their results similarly point towards the design of a digital health tool that provides general use in tracking patient symptoms, consult visits and medications, to support the caregiver's cognitive load to accurately remember details [147]. Similar to providing timely access to insights, in the context of clinical visits, Shin et al [147] also recommends providing overviews of the visit to the caregiver in a manner that promotes both an accessible understanding of the information to support an engaging clinic visit. To support the timely access to information, previous recommendations have also been made for the design of digital health technologies that facilitate document sharing between providers as well as family caregivers, and automatically sending new information to the individuals on the care team that require it [144].

Third, digital health tools should allow for flexibility and customization regarding the inputs and outputs of the display to meet the needs of complex home care over time. In a closely related caregiving domain such as child development in their educational institution, similar recommendations have been made for the design of digital health technology to support adaptation for changing caregiving information and communication needs. For example, the recommendations of Mikles et al [144] point towards customization of digital health tools in the context of configurable patient referral reports that provide customization that is relevant to the stakeholder receiving the information, including information such as test results, descriptions and notes, medications, languages, race and ethnicity, care summaries, health summaries and other relevant details [144].

Finally, any developed digital health tool should offer a shallow learning curve to promote a more intuitive interaction by all caregivers who need to interact with the information. Family caregivers already spend considerable time learning about their child's condition and the complex medical technologies and medication regimes they require [123, 153]. Providing a tool that provides a natural interaction could reduce the learning curve required to use digital health tools, as well as support future engagement by a wider group of users [11]. As a positive consequence, digital health tools that are easier to interact with may subsequently be used as a channel to support family caregivers to learn about the conditions of their child and their medical devices in a more effective manner [154].

4.5.5 Strengths & Limitations

This exploratory study captured perspectives of family caregivers of CSHCN from a diverse group of participants, which included socio-political differences and wide-ranging caregiving experiences grounded in factors including their caregiving experience, geographic location, and their child's medical conditions. Although the focus of this research was not on the impact of the COVID-19 pandemic, there is not significant research on this area conducted during times when caregiving practice has had to rapidly shift. Caregiver perspectives may have been influenced by the ongoing changes happening in our world today.

The demographics were limited due to the exploratory nature and the practicalities of conducting this study during COVID-19. While data saturation was achieved, allowing for the development of meaningful themes that provide a rich understanding of the experiences of the family caregivers in this study, a larger sample size would support generalizing these findings to a more diverse caregiving population. Future work will be able to build on this with broader demographics, and there is potential to examine this more deeply with different types of diagnoses, and long-term implications of changes in care.

4.5.6 Conclusions

We found that while each family caregivers in this study are facing varied experiences managing their child's care given their geographic location, the requirements associated with their child's complex medical needs, and the length of their caregiving experience, there are subtle similarities and differences noted by their social aspects of health. This pertains to how these caregivers manage and communicate health information given the supports that they are provided. Our study highlights some of the underlying inequalities in the information and caregiving supports for the family caregivers in this study based on their social status and the influence of their social-political situations, where there is an opportunity for digital health tools to provide support for these gaps in the healthcare systems by addressing unmet caregiving needs for medical device information access and training, shared awareness of their child's health information with other caregivers, and access to critical caregiving services such as respite care.

With the complex information processes that family caregivers of CSHCN are involved with each day, design recommendations for developing future digital healthcare technologies point toward solutions that facilitate intuitive interactions with family caregivers while providing them with utility through timely access to organized, context-specific data. Digital health tools for complex home care can improve the cognitive burden associated with the health care tasks involved with being a family caregiver of a child with a medical complexity, which may not only improve the coordination of care in their home but also their own health. As digital health tools continue to be developed, future research should focus on designing digital health tools in close collaboration with a diverse family caregiver demographic that includes their caregiver teams, to further improve information management and communication in complex home care that can meet the needs of a wide population of family caregivers.

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Chapter 5

The Complexities of Complex Home Care: Caregiver Experiences Managing Health Information and Communication for Older Adults

This chapter is being submitted for publication.

5.1 Graphical Overview

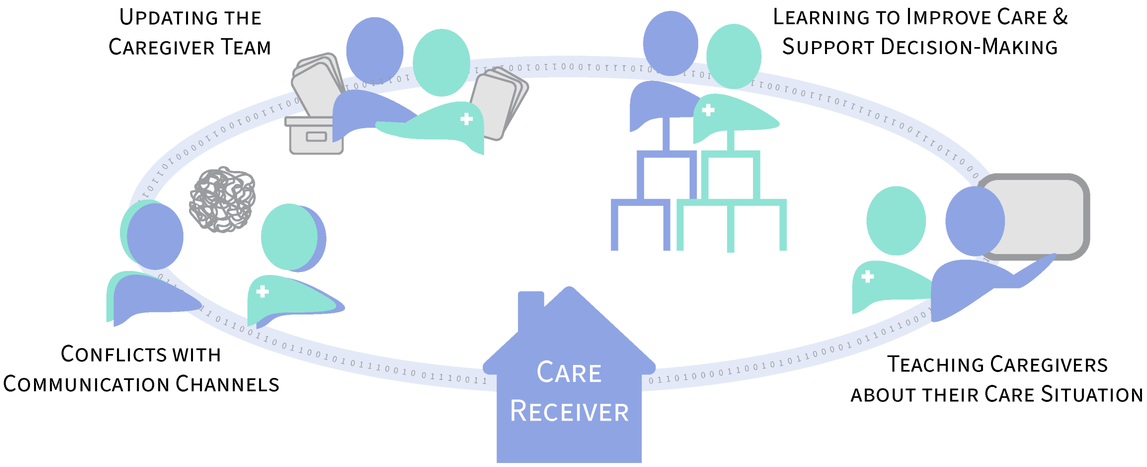

Figure 5.1: Graphical abstract to visualize information management and communication processes

5.2 Overview

With the rise in home care for older adults, there is a growing need to help caregivers manage and communicate health information to support patient safety. Designing technologies that facilitate information-interaction is a promising way to improve home care coordination. However, the current design and implementation of technologies or other interventions do not meet caregivers' needs, impacting adoption. Little is known about caregivers' current information management and communication experiences in complex home care for older adults. This research is part of a broader study about digital health technology design for complex home care. We conducted semi-structured interviews with 15 caregivers in Ontario, Canada and used inductive thematic analysis to identify four themes: First, caregivers are Updating the Caregiver Team to support situation awareness. Family caregivers are also Teaching Caregivers about their Care Situation. While caregivers were Learning to Improve Care & Support Decision-Making, they still experienced Conflicts with Communication Channels. The results identify that paper-based documentation remains an essential technology that caregivers adopt to support care coordination based on its perceived ease of use and flexibility. Furthermore, there is an overlap across information management and communication processes between different caregivers, potential for new technologies to provide collaborative support, and challenges for integrating new technologies in complex home care. New technologies may benefit from an interface mode that eases the interaction with health information to influence engagement and adoption in complex home care. Future studies should further explore the interaction characteristics of new technologies to improve the interaction experience with information management and communication technologies.

Keywords: Older Adult; Caregiver; Health; Home Care; Qualitative Study; Technology

5.3 Introduction

Home care is rapidly changing our healthcare system, yet unlike those in a regulated hospital, caregivers provide care outside a controlled environment [1, 7]. Uncontrolled environments increase patient safety risks such as adverse events commonly associated with ineffective communication and poor coordination among caregivers [155, 156, 157]. The proportion of home care patients in Canada and the United States of America who have experienced an adverse event in their home ranges between 4.2-13% [124, 158]. Even the most trained health care professionals lack the expertise required in some of the most complicated home care situations [159, 160].

Family caregivers who spend significant time providing care for their loved ones often feel burdened to maintain patient safety by always being present in the home [24]. Without efficient access to information and effective communication, family caregivers and health care professionals working in an elaborate home environment are both at risk for creating unsafe situations for the person receiving care [24]. A Pan-Canadian home care safety study determined that the most frequently reported adverse events are falls, medication-related incidences, and infections [124]. Improving inconsistencies with care and preventing breakdowns in communication could reduce the occurrence of these incidences by more than one-half [124].

While the literature identifies the implementation of an electronic health record as a solution to support standardizing communication across different stakeholders and providing efficient access to information, designing new technologies for home care remains a high-potential yet socio-technical challenge [125, 126, 127, 128, 161]. Patient conditions and health information can be highly varied and complex; their home environments are unique and involve diverse caregiver teams; and paper-based records are one of the more commonly used and preferred tools to document and share health information between caregivers [1, 11, 55].

Aspects associated with interface navigation, usability, system access and the ability to identify relevant information within increasing amounts of data are some of many attributes that may contribute to low user adoption of many technologies, preventing caregivers from experiencing the value that many systems could offer [131, 133]. Implementing new technologies for family caregivers and home health agencies may foster initial engagement during the novelty period of integrating new technology. However, without considering the human factors of complex home care that include the ability for these systems to enable efficient interactions, effectively support health information exchange among caregivers, and provide overall satisfaction through value, many of these high-potential tools experience a high attrition rate [132]. This research has been conducted to understand the processes involved with information management and communication by caregivers, providing guidance that can be used to design new technologies that improve care coordination for home care environments involving older adults.

5.4 Background

Home care is on the rise. This increase is a result of several factors that include but are not limited to increased costs at medical facilities, patient discharges with complex care regimens, the aging population, the prevalence of chronic conditions, the desire for independence in health management, and innovations in information technology [1, 7, 28]. For older adults, the main benefits of in-home care are improved well-being and the ability to age “in place”. While the patients’ conditions contribute to the complexity of home care, complexity also arises within the interactions among caregivers, the tasks and activities performed, and the equipment and devices used within a dynamic environment [1, 162, 163, 164]. While a few studies have investigated home care factors that describe the aspects of this model of home care, to the best of the authors' knowledge, less is known about the information processes involved in home care.

5.4.1 The Human Factors of Complex Home Care

To build on the home care model mentioned above, Beer et al [1] provided a descriptive account of the challenges discussed by health care providers in this work domain [162]. After interviewing Certified Nursing Assistants and Registered Nurses, their human-systems approach identified the importance of relationships among the caregivers and the care recipient. They also identified the impact of physical and affective strain on caregiver burnout, the effect of training on knowledge and skills, and the requirement to understand how to work with various medical devices across patients' homes [162]. Schaepe et al [24] also identified the importance of improving patient safety by having a partnership among caregivers and proposed improving support for family caregivers, including efficient access to information for problem-solving. Concerning the care recipient, self-care is a significant aspect of home care, especially for older adults with multiple chronic conditions [165]. Caldeira et al [165] identified that older adults take a holistic approach to self-care and seek out information from health care professionals and through personal research to support decision-making in their home since health guidelines are often not specific enough for their needs.

5.4.2 Complex Home Care in Ontario

In the province of Ontario, Canada, the number of home care patients categorized as complex is rising. In 2009/10, the number of individuals whose care was classified as complex was less than 40%; this rose to 70% in 2014/15 [4]. In Ontario, home care services allow older adults whose health care needs are acute, chronic, palliative or rehabilitative to continue to live in their community independently. The services provided for older adults include but are not limited to nursing, personal support, therapy, social work, medical supplies, and medical equipment. There is an expectation that a family member or a friend will supplement home care as an informal service. Family caregivers, on average, spend 20 hours per week caring for an older adult for approximately four years [3]. However, it is estimated that 150,000 Ontarians purchased an additional 20 million visits/hours of home care services per year to support their continued living in their home by formally trained caregivers [3]. In 2015, it was reported that 6,825 formal caregivers provided 24,770,820 visits/hours of care to 459,495 clients over 65 years of age [3].

5.5 Methods

5.5.1 Study Design

This research is part of a larger mixed-method study to identify the perspectives of caregivers across North America about digital health technology design to support information management and communication in complex home care. This paper presents the results of semi-structured interviews conducted with caregivers of older adults, and qualitatively evaluates the information and communication processes for caregivers working in complex home care. This study received ethics clearance from the University of Waterloo, and all participants were interviewed virtually from their homes due to COVID-19 restrictions. Informed consent was obtained verbally, and participants received a thank you letter for their participation. Participants were not provided with remuneration for joining the study.

5.5.2 Participants & Data Collection

Recruitment was carried out by contacting home health care and caregiver support agencies and groups via email and social media platforms and was followed up with snowball sampling, where it was known that five participants were recruited using this sampling method. Participants were included if they were at least 18 years old and either a family caregiver or a hired caregiver for an older adult who required complex care services in their home in North America. Complex care included individuals who had any combination of chronic conditions, mental health issues, medication-related problems, and social vulnerability. In the context of this study, a family caregiver was anyone who provided or coordinated care for a person who was a family member, a partner, or a friend; they assisted this person with health or medical-related tasks in their home. A hired caregiver was a home care nurse, personal support worker, or other caregivers who were hired to provide home care services. Two researchers (RT, KM) conducted the interviews. The interviews were recorded using Microsoft Teams, and only the audio recordings were used for transcription.

5.5.3 Data Analysis

The interview data were analyzed using an inductive thematic process [112]. Data were stored and organized using QSR NVIVO 12 and Microsoft Excel 2021. The coding process involved the following steps: (1) Microsoft Stream's closed-captions feature was used to transcribe the audio recordings; (2) two researchers reviewed and anonymized the transcripts; (3) the core research team listened to the interview recordings and read through the transcripts to familiarize themselves with the data; (4) the interview data were thematically coded, and the core research team regularly discussed emerging themes; (5) the final list of codes and emerging themes were reviewed and refined by the entire research team. The thematic analysis was organized around each caregiver population: (1) family caregivers and (2) hired caregivers. One participant's interview data from the hired caregiver population was not analyzed in-depth because they did not consent to have their interview recorded for transcription.

5.6 Findings

5.6.1 Participant Demographics

There were 15 caregivers that participated in this study (Table 5.1). We recruited from various regions in Canada and the USA; however, all participants in this study participated from Ontario, Canada. The youngest participant in this study was 24 years old, and the oldest was 83 years old. While most of the participants identified as female, two identified as male. Caregiving experience ranged from four months to 13 years.

5.6.2 Themes

There were 39 codes identified by the research team (Table 5.2). The codes were organized into four themes describing the processes related to information management and communication experienced by caregivers of older adults in complex home care: (1) Updating the

Table 5.1: Participant demographics and caregiving characteristics (n=15)

Characteristics		Family Caregivers	Hired Caregivers
Number of Participants, n (%)		9 (60)	6 (40)
Age (years), n (%)			
	18-24	1 (11)	0 (0)
	25-34	1 (11)	1 (17)
	35-44	0 (0)	2 (33)
	45-54	0 (0)	1 (17)
	55-64	1 (11)	1 (17)
	65-74	2 (22)	1 (17)
	75-84	4 (44)	0 (0)
Gender, n (%)			
	Female	8 (89)	5 (83)
	Male	1 (11)	1 (17)
Caregiving Experience (years), n (%)			
	0-5	6 (67)	4 (67)
	6-10	2 (22)	1 (17)
	11-15	1 (11)	1 (17)

Caregiver Team, (2) Teaching Caregivers about their Care Situation, (3) Learning to Improve Care & Support Decision-Making, and (4) Conflicts with Communication Channels.

Updating the Caregiver Team

Updating the caregivers with pertinent health information about an older adult in their home was a concept discussed by all caregivers in this study. However, their methods and reasons for communicating information varied depending on their situation and caregiving role. Overall, every participant in this study described creating written notes kept in a central location in the home. For example, one family caregiver documented information about medications and recorded details about their spouse's reactions. A hired caregiver expressed the need to continue using paper-based records for older adults for reasons related

Table 5.2: Themes in communication and management of health information in complex home care for older adults

Themes	Codes	
	Family Caregivers	Hired Caregivers
Updating the Caregiver Team	• Physical documentation • Keeping personal notes to support safety • Calling & texting caregivers • Leaving notes for caregivers • Reminding caregivers • Ensuring awareness of the patient status • Bringing information to doctors • Transparency of record-keeping • Managing medications • Desire to ease documentation	• The burden of physical documentation • Keeping personal notes to support safety • Calling & texting caregivers • Leaving notes around the home • Capturing holistic aspects • Handing off care • Concerns for information silos
Teaching Caregivers about their Care Situation	• Sharing the client's perspective • Expressing concerns • Providing instructions • Planning together • Talking about embarrassing tasks • Struggling to teach caregivers • Worrying about the quality of caregiver training • Observing in-home treatments	
Learning to Improve Care & Support Decision-Making	• Understanding medications and the health condition • Learning from caregivers & HCPs	• Having prior knowledge • Learning from caregivers • Learning through observation • Learning from the client • Reviewing documentation and health care records
Conflicts with Communication Channels	• Impacting care continuity • Communicating with a loved one about their health • Communicating health concerns with HCPs • Communicating concerns with other caregivers	• Establishing communication boundaries • Coordinating with caregivers • Feelings of control over information sharing

Note: HCPs - Health Care Professionals

to transparency of record-keeping and having information stored in one location for the family caregiver to review.

> *At that time, they made written notes to… all of the people in their company that were coming to see [my spouse]… and the practice was they would have written notes that they kept on top of the refrigerator, and I think they did that*

> *in every home. Notes on top of the fridge... I would keep some notes, and there were times when I would make detailed notes about [my spouse's] reaction to the medication... The palliative care doctor was trying to get it just right. So, I had times when I would write things down every day. (P10, Family Caregiver)*

> *In the home, it's still very basic now, as much as you can roll your eyes with that. I gotta say, we find it's also helpful because... if every agency has their own electronic information, that's great for keeping their records. But there's, remember; there's all these different people coming into the home... Sometimes you need an old-fashioned three-ring binder to keep everybody straight... I can just think about a family that I was visiting two days ago where they found they needed that because, again, like different PSW's are coming in. So maybe [they] have a definite cognitive deficiency and [they] can't remember what [they] had for breakfast. Or honestly... the last time you had a poop which is really important information. So, there's just a day-by-day record of what's going on with the individual people, and then when the family comes in a couple times a week, then they go, "Oh, OK. This is what's been happening with the PSW's..." So, in a way that is important to have good old notes written down. (P5, Hired Caregiver)*

It was also observed that creating written documentation placed a burden on both the family caregiver and the hired caregiver. For example, one hired caregiver expressed that they were required to record every detail of their shifts at specific time intervals. The sheer volume of documentation was one of the hardest aspects to balance in their work even when family caregivers designed documentation to support efficient interaction:

> *I just do a nice log sheet and [my hired caregivers] write down, you know, did [they] take [their] meds... did you have a bowel movement, [are they] sleeping or not? ...I'm pretty good at creating a form, and they have to fill this in. And that's how we communicate. And that's how, well, they endorse, you know, one person comes, one person leaves, and they just look at the notes. There's a meds chart which I make out... (P8, Family Caregiver)*

> *If you work with ten people... you have to care them, and you have to document... whatever happens to these... ten people. That's why the PSW job is very hard. That makes it hard. You don't have time to even to eat something, take a break... (P9, Hired Caregiver)*

When record-keeping was completed and shared digitally using software applications as part of an eShift model of care among some hired caregivers, this information was used for updating health care professionals about the person's care where other supervising caregivers monitored the events that occurred during a shift. Family caregivers who were coordinating the documentation of home care for an older adult also wanted to contribute to these digital documentation methods but did not have the means to convert their paper-based systems.

> *[The online system is] between the person who's in the home as the PSW, and the delegating nurse... I can go in to see that information through our system. There's an additional link... where if I have a [PSW] who I know has eShift, then in the morning I can log in and see how their night was (P5, Hired Caregiver)*

> *I would like to be able to make that easier for [my caregivers]. I don't know how. But I understand that in some institutions, they do the record-keeping on computers. But I don't have a program or anything like that. (P8, Family Caregiver)*

The type of information recorded in the home varied depending on the patients' conditions and the caregiver's record-keeping motivation. Family caregivers expressed that they were only documenting when they felt it was necessary to share progress updates or noticeable patterns with health care professionals. Hired caregivers strongly believed in capturing the health of their clients not only from their vitals but also holistically:

> *But what about that person? What about how they're feeling that day? What they're thinking that day? How about, you know... Just a little thing... They had a hard time getting their retainer out... I get tired of reading documents that said, "changed the sheets, toileted them twice..." Like big deal, we all know they have to go the bathroom or [they] could be changed. But how about... asking them, "How do you really feel today? I don't wanna hear "good." I wanna know how you really feel. What are your thoughts?" Like, really get into it and document that. None of this "oh, every day, same document" big deal. What's the point of even documenting [then]? (P4, Hired Caregiver)*

To complement the physical notes that were kept in one location in the home, caregivers additionally implemented written notes that were context specific. Sometimes, they placed notes at various locations in the home to capture their caregivers' attention when they were not available to update them in-person or could not rely on contacting caregivers through other means.

> *We posted notes all over the place. It was the only way... I made up a sheet, a couple of them I actually ended up having to make. I put them on the bathroom wall for... when they came in... There was one for the morning, one for the daytime, one for evening, and it was simply, "This is what [they] require." It was listed... They didn't have to search through charts... The easiest thing for me at that time was to put sheets on the wall and say, "You need this, this, this and this," and I had so many thank-yous from PSW's that were coming in from the [agency]... And they said, "You know, I could just look at that, and I knew exactly!" (P13, Hired Caregiver)*

> *I would leave a note physically saying, "Hello, please use a plastic bag to cover my [family member's] foot when you are going to be giving [them] a sponge bath." So those things I would have to manually do just writing it down. (P6, Family Caregiver)*

Beyond physical documentation, the other process involved in updating their caregiver team was verbal communication during handoffs. Caregivers updated others on new information to ensure their awareness of how their home care situation changed since the incoming caregiver's last visit and reminded them about critical safety information that can have serious consequences if not carried out properly.

> *It's reminding them stuff like [thickening the drinking water] where I find some PSWs forget and just give [them] normal water, which is a really, really big risk because my [family member] is prone to something called aspiration, which means if [they] eat any food that can go in [their] lungs, which has happened before, then that can develop into pneumonia... And we've had to take [them] to*

> *the hospital multiple times for that, and that can be really scary because someone like [my family member], who is more vulnerable and prone to getting like disease and infection. Especially, taking [them] to the hospital like now [during the COVID-19 pandemic] is pretty scary, so yeah, it's just a lot sometimes. (P6, Family Caregiver)*

> *Yeah, it's more of the times that you hand over [the client], like, "[they are] OK." Whenever there's someone's turn to take over my shift, I would just say that "[they have] been OK. [they have] been very calm, but there are times that [they] had to do some... [they are] a bit manic at the time, but overall [their] behaviour is OK." Usually, I tell them that [they] already ate that [they] already took [their] meds at this time, so, and I usually tell [them] that the only thing that's missing is this and that, [their] meds for this hour. This meds for this time usually. (P2, Hired Caregiver)*

In situations when in-person communication was not possible but important information needed to be shared with the caregiver teams to support planning and decision-making, caregivers used telecommunications devices to share updates via a phone call or a text message:

> *If it's really important, then I'll call the agency and tell them that [their] workers need to know that such and such is happening... like if there's been a fall, for instance. Then I let them know, and they have to know those things anyway. (P7, Family Caregiver)*

> *Especially with younger people, with younger family members, they will often text me on my work phone. That's the most efficient way I find, I text. I called,*

> *but I find it even easier to text a lot with the visiting nurses who I talked to recently. (P5, Hired Caregiver)*

While some hired caregivers in this study use applications that are developed to track information such as vitals and other qualitative health information, and have been more reliant on digital communication during the global COVID-19 pandemic, these details are only shared among other hired caregivers within a specific agency or local healthcare system. For example, these notes can be sent to the visiting nursing agency and then to the person's primary visiting nurses. Other hired caregivers who have mobile applications on their phones use this software to see the tasks that they are required to complete as set out by their agency, where as they complete these tasks they interact with the checklist. However, the details stored in these applications are not directly available for the family caregivers in this study, where any information that is communicated is paper-based.

Teaching Caregivers About their Care Situation

Family caregivers specifically discussed the role of ensuring an understanding of the nuances and preferences within a home care situation. They described their responsibility for communicating their family's needs in terms of home care services and the challenges of providing instructions for the specific care needs in their home.

> *And we've had some trouble with navigating that sort of thing where... Finding PSWs, especially at a time like now, is pretty limited. It's just been... a little bit difficult to get them to understand like our perspective and what the client needs. What my [family member] needs... They tend to have somebody that oversees them, and so we've been working a lot with [them] in terms of*

> *expressing our concerns, our needs. And [they're] pretty willing to negotiate with us, which I find pretty good, and I just think the biggest thing is just being open to having discussions with them... If we feel like something is not going right or if you feel like something could be changed, they're pretty good... Sometimes being willing to make those adjustments or accommodations for us, so I just think having more line of transparency. (P6, Family Caregiver)*

To ensure quality care was being provided, family caregivers felt responsible for observing their hired caregivers. They wanted to ensure that their caregivers implemented the necessary safety measures specific to the patient and the home environment. They were also worried about the quality of treatment that their loved ones received when they were not around to observe but were not sure what they could expect otherwise.

> *Well, I'm there for half of the shift because [my spouse] does the last half as an exercise plan, and that's done downstairs. And so, I see it... if there's a problem, they'll tell me. But the thing is, I don't know whether they're covering this safety issue [of watching for falling] when I'm not around. That's my biggest worry. And I can't be all there all the time. It's just not possible. If I see something not right when I'm with [them] for the last half hour [of their shift], then I will say, "This is not right. You have to stand here, or [they'll] fall over". That kind of thing. Some of them like it and some of them don't like it. (P7, Family Caregiver)*

Two caregivers in this study provided care for each other and received no regularly occurring support from hired caregivers. They expressed the challenges of supporting each other's care in the home, which included learning from and supporting each other by talking through tasks that they normally would not have assisted with before.

> *Well, depending on the kind of people you are, like, the first time you have to suddenly help your partner in and out the shower, on and off the toilet... If that's not been part of your life, there's a lot of embarrassment. There's a lot of talking through that, and it's something that... is nice if you've got someone coming in that isn't the partner to help to pave that way. (P14, Family Caregiver)*

Continuous Learning to Improve Care & Support Decision Making

Family caregivers and hired caregivers in this study were continuously learning about the patient's conditions and the nuances of the home care situation to improve the quality of the care they provided and support their decision-making. The degree to which family caregivers felt the need to learn the information resulted from their loved one's condition or symptoms. Navigating the complexities of cognitive impairment by reading and working with health care professionals was a significant task for some caregivers in this study in their desire to learn how to support their loved ones better:

> *[My spouse] had delirium frequently and trying to navigate through the delirium where you can't deny what somebody is experiencing in a delirious state... [They] thought at one point that the [University] was managing our house and actually owned our house, and we were in something odd and different... I could never quite understand it. (P10, Family Caregiver)*

> *The Parkinson's, I've learned that, and I know [my sibling] really well... I've learned that the more you can engage them intellectually and emotionally with contact, with people, and with things that they like and love, well, you know, the*

> *better they are even with their mobility… I read up on things. I learned about [my sibling's] medications, and I know the effects of all of them, and I know the effects of that horrible [medication they were] taking that caused psychosis... I've got an informational sheet from some of the people who worked with us who have gone on to become RPNs and so on. [They] gave me a whole hand-out on how to deal with delusional behaviour, and I've read about it too. (P8, Family Caregiver)*

While some of the information that family caregivers were learning from health care professionals supported their loved ones, learning more about providing care in the home also supported their well-being, especially for performing physical tasks.

> *You know, I was doing things wrong for a while too. [My sibling has] mobility issues, so you stop motion with Parkinson's and [they] would have difficulty getting up out of a chair. So, we devised a way of counting and using momentum to pull [them] up. And then I realized I'm hurting my back this way, and so I just stopped that, and I learned from some of the physiotherapists who I've had through [the agencies]. I've had various physiotherapists and occupational therapists come in, and they gave us instructions. (P8, Family Caregiver)*

The family caregivers in this study were not medically trained professionals. They did not necessarily have a knowledge base of information to support medical decision-making, unlike half of the hired caregivers in this study, who were trained nurses. Having a knowledge base helped hired caregivers with decision-making and their ability to identify symptoms, patterns and trends quickly:

> *Well, I was doing it with the knowledge base. People that don't have a knowledge base have... Like, even the pre-identified wounds on [their] leg... ulcers. I knew right away, but someone that didn't have that background wouldn't have pushed the issue. (P13, Hired Caregiver)*

Finally, learning from physical documentation was also necessary to support decision-making, especially for hired caregivers who might visit multiple clients in a single day. They relied on recorded notes to learn about the most recent events that occurred in the home and used this information to plan their care.

> *I also look up their records of what happened all throughout the weekend, so yeah. It's usually placed on the table here in [my client's] home. It's just like the first thing that you go over when you come here is to look at what happened in the previous day and... the previous hours of the shift at the beginning of your shift. So yeah, you look at it. You try to summarize what happened and what time [their] previous extra dose was given so that whenever [they are] pretty weak, at the time of your shift, you can say that "OK, we can give [them] an extra dose at this time," it's safe to give [them] an extra dose. (P2, Hired Caregiver)*

Conflicts with Communication Channels

The participants in this study experienced several issues regarding the exchange of information with other caregivers. Challenges with communication and coordination impacted care continuity and increased their feelings of frustration. Communication challenges existed between family caregivers and hired caregivers, the client and their hired caregivers and between hired caregivers and other healthcare professionals. Sometimes, the communication challenges were a result of the patient's condition and language barriers:

> *[My family member's] speech is a little bit slurred, and so it's hard for people to understand when [they're] talking and understand what [they're] saying. And so, if [my family member is] trying to communicate with the PSW's and they don't understand [my family member] that can make [my family member] frustrated and [they] might yell or overreact, and then the PSWs get frustrated and then they don't want to come back anymore... (P6, Family Caregiver)*

> *So, it's getting that information to them because some of them, their language, their first language isn't English in almost all cases so... If there's a heavy accent, that's a real problem. If there's literacy issues, you know, one [hired caregiver] was very lovely, and so on, but [they] couldn't see very well, and [they were] no good at writing anything down... [They] just... [They were] good, [they] would be good for some situations but [my sibling] requires someone with a little bit more, I don't know, the ability, at least to write notes and understand [them]. (P8, Family Caregiver)*

The communication challenges between family caregivers and hired caregivers in this study were especially evident when there was a lack of two-way communication in situations where actions were required by both parties to maintain the safety of the patient in the home. The technologies used to support communication only provided a one-way conversation with no feedback or confirmation of the receiving caregivers' understanding.

> *Most of the time, my frustration was with communicating with the home care and caregivers... There was no connection with me. I got to call a number and*

> *leave a voice message. And then I may or may not have heard back. . . There was a question in my mind that there was an infection going on, and I didn't speak with the... It was a difficult situation I had. [Their family caregiver], that was the person that was [their] spokes... or [their], power of attorney for personal care and, [their family caregiver] would say to me, "[P13], you handle it." But [the family caregiver was] the micromanager, so I handled what I could. (P13, Hired Caregiver)*

Finally, the challenge in communicating among caregivers was evident with hired caregivers communicating with other hired caregivers and family caregivers. This raised frustrations for one hired caregiver concerned with the effectiveness of the communication that was occurring as it placed unnecessary stresses on the caregiver team.

> *I was frustrated in the fact that if I identified a problem, then I had set the rules that if I'm helping, I needed to. . . There needed to be only one person calling the doctor's office. Only one person, you know, calling the [agency]. They didn't need multiple phone calls from multiple members or care providers because it was not effective. I tried to set those up at first, and for a little while [their family caregiver] managed and then [they] couldn't do it anymore. [The family caregiver] had. . . verbally given all of these people consent for me to handle everything. . . so there were huge issues that way. And then [they] would start calling and, I mean, I had, it was, it was a horrible situation for me because then I had become almost threatening to say, "Listen, you know if you want to take over and you want to do this then I'm stepping out because this doesn't work for me" and they still said, "No, I can't do it on my own. I don't know enough." Those kinds of interactions were challenging. (P13, Hired*

Caregiver)

5.7 Discussion

This study describes the experiences of caregivers of older adults, which provides a foundation for understanding the complexities of information management and health communication processes in complex home care. While information collection and storage consists of paper-based technologies and communication that occurs via email, phone calls, texting or in-person currently support care coordination, there is potential for new technologies or interventions to meet the complex needs of caregivers [11, 35, 36]. With the aging population worldwide, and the increasing number of caregivers supporting the healthcare system by providing home care services [1, 5, 6], there is a critical need to develop new systems for caregivers in this context. Launching this development with an in-depth understanding of the caregivers' experiences in this complex work domain is essential [6].

5.7.1 Bridging Caregiving Processes for Improved Collaboration

In this study, our caregivers' experiences in complex home care situations included caring for older adults who have any combination of chronic conditions, mental health issues, medication-related problems and social vulnerability. With the complexity of the caregiving situations that this study observes, family caregivers and hired caregivers are increasingly involved with overlapping processes that support information awareness within caregiver teams. In comparison, there is significant literature that argues the importance of including family caregivers as collaborators in home care and bridging their contributions to home care with hired caregivers [62, 125, 166].

Macias-Colorado et al [167] identified specific issues regarding the communication between family caregivers and hired caregivers, where health information shared by the hired caregiver is not effectively verified as understood by the family caregiver, leading to risks for adverse events. This was especially concerning when information were shared between individuals who have different levels of healthcare training [167]. Broekema et al [168] identified that improving communication has the opportunity to reduce caregiver burden and support decision-making. While improved communication and support for family caregivers to understand health information has been previously identified [167, 168], our study observed that hired caregivers are diligent towards understanding their client's care situations and ensuring that other caregivers understood the care situation. However, with some of the challenges that they experienced with documentation burdens and establishing communication roles among a team of caregivers, their current methods could be more effectively supported to remove some of the burdens associated with the ongoing task of situation awareness in the home.

From the family caregiver perspective, our study also observed the challenges they experienced with communication to other caregivers about health related information. In other contexts such as clinical settings, Cohen et al [169] identified that while family caregivers were engaged in the care of their loved one, an older adult, professionally trained caregivers such as nurses sometimes did not always recognize family caregivers as an important individual that should be integrated into the provision of care. In the context of home care, our study observed that hired caregivers were diligent to ensure collaboration with the family caregiver, despite communication challenges. In particular, the family caregivers in our study played a critical role as educators of the home care situation. While most literature focuses on communication for educating family caregivers about the healthcare system and a patient's health condition [170, 171, 172, 173], which is important to support their capability as a family caregiver, it is also important to highlight that family caregivers are in a unique position to share their specific caregiving knowledge to other caregivers. They are the experts of their loved one's home environment and nuances of their care. Given the non-standardized home care environment, it is critical for other caregivers to learn these details as it enables them to provide care services in an environment where they have the necessary information to adapt how they provide care, if needed.

Beyond their role as an educator, family caregivers also captured health information in the home and provided other caregivers with timely health updates to support situation awareness and ultimately promote patient safety by reducing uncertainty. While the issue of uncertainty in home care has been identified in previous work by Harrison et al [174] in their study on the palliative care needs of family caregivers, current technologies and interventions used to manage information do not sufficiently support reducing uncertainty or support caregivers in their efforts to educate others. In the situations from our study, the lack of two-way communication highlighted some of these contributing factors.

Family caregivers take on a significant workload to coordinate home care for older adults [27]. Maintaining the continuous awareness of caregivers who are constantly moving throughout the home can be a significant undertaking for a family caregiver when information management methods and communication protocols involve paper-based documentation and standard messaging functionality on telecommunications devices. Building a collaborative environment for effective information exchange with these methods requires organization, effective documentation design to capture various health metrics, and establishing communication protocols with caregivers. While there exist caregivers in this study who could manage these processes, others may not have had the means or the time to facilitate this interaction, given that it reflected many of the responsibilities of a full-time job [141]. However, with the increasing overlap observed in the processes by family caregivers and hired caregivers that this study identified, there is potential for the design of new technologies and other interventions that can successfully be used collaboratively by both caregiver groups, to improve communication.

5.7.2 The Potential for New Technologies in Complex Home Care

Qualitative studies conducted to understand the needs of caregivers in the context of home care have provided recommendations for the development of future technologies that support caregiving processes. Tang et al [62] interviewed caregivers to explore their care coordination processes, the challenges they faced, and the tools that they implemented to address those challenges. Similar to the findings in this study, they identified challenges with updating the caregiver team [62]. For example, in their study this lead to an issue involving duplicate medication prescription refills [62]. They also identified issues related to information becoming construed as it was passed from caregiver to caregiver [62]. In our study, we found that the lack of two-way communication between caregivers resulted in uncertainty with knowing if other caregivers received and understood information that was shared digitally or in paper notebooks. They also experienced challenges with establishing an understanding of caregivers' communication roles and responsibilities in the home. Based on their findings about communication in the context of home care, Tang et al [62] identified several design recommendations for technologies to support family caregivers' needs and improve coordination in complex home care when multiple caregivers are involved, that align with our results. Their recommendations where for a mobile application for family caregivers, and included functionalities such as messaging, customization, shared calendars, checklists, medication lists, knowledge about the patient's condition, and for patients to interact with the system and record their emotions using emoticons [62].

In another similar study, Holden et al [175] performed a qualitative artifacts analysis with family caregivers' of patients with dementia, to determine how their current tools supported their health information management processes. Their results identified the importance of technologies that allow all caregivers to communicate with healthcare professionals, and that care management technologies for decision-making should support acquiring multi-sourced information, maintaining up-to-date information, and sharing information with all caregivers involved in the patient's care. Similar to the findings from this study, they identified a time burden for caregivers to manage information coming from various sources using paper-based technologies, as well as challenges with communicating with healthcare professionals [175]. We observed similar findings to Holden et al [175] with hired caregivers and family caregivers providing information both verbally and through paper-based methods, to establish an understanding of the information or provide reminders to others. With respect to non-functional requirements for new technologies to support care management and communication, Holden et al [175] recommended that information technologies should be controlled by the primary family caregiver, allow for the creation of information templates that meet the caregivers' needs, accommodate a range of digital literacy skills, and provide a trustworthiness design. Functional recommendations involved providing a means for sharing a patient's care journey, the ability to update information as the patient condition changes and delegate care tasks to others, and notifications that remind caregivers to add missing information [175]. They also recommend features that include sharing concise health reports, guiding caregivers through regulatory-type documentation processes, and providing log details that include data about the source of the information that has been digitally entered [175]. New technologies with features such as the ones described by Tang et al [62] and Holden et al [175] may provide effective support for the caregivers from this study if they can be effectively integrated into their care routines as collaborative tools. As highlighted in this study, the integration of new technologies to support caregiver collaboration remains a challenge.

While some hired caregivers in our study used digital tools to communicate with other health care professionals and hired caregivers, these tools were not widely available to family caregivers to join as a collaborator. Paper-based records or templates remained family caregivers' primary method for collecting information to be shared with others in the home, because it was often a readily accessible tool with a shallow learning curve and they had the means to customize it to meet their needs [176, 177]. Other methods of communication were by phone, text or email. Despite the recommendations for designing new technologies, paper-based documentation and communicating through text messaging were surprisingly recommended or preferred by some of the caregivers in this study to manage and communicate information.

5.7.3 The Challenges for Adopting New Technologies in Complex Home Care

Regardless of the the potential for new technologies to support information management and care coordination, one of the challenges of building technologies for older adults' home care environments identified across each information and communication aspect of this study was the remaining reliance on paper-based records by home healthcare systems [175]. While paper-based records may support data collection and provide a means for caregivers to understand a patient's conditions and current health status if they are effectively designed, they lack real-time two-way communication [178, 179]. They do not support caregivers to adapt to change in a fast-paced, dynamic home environment and are limited in supporting cognitive work across homes with non-standardized interfaces [147]. As family caregivers take on increasingly critical roles in complex home care situations, supporting cognitive work is important for patient safety [180].

From Ozok et al's [181] study on the perspectives of caregivers to adopt new technologies, they identified in their interviews that personal health records would be perceived as useful if they could replace a paper-based system because it would keep relevant information in a single location and save physical space, as also supported in other literature [62, 175]. In comparison, our study identified the continued reliance on paper-based records by many caregivers of older adults, as a tool that is still useful to communicate between caregivers and share information. Based on this conflicting observation, the successful implementation of new technologies for caregivers of older adults may only be achieved once the usefulness of new technologies provided by the interaction experience, exceeds that of paper-based documentation.

Given the vast experiences of the caregivers in this study, the complexities of their home care situations, and their capacities to provide care, we can build on the recommendations in the previous literature by suggesting that along with meeting caregivers direct needs for information management and communication, the adoption of new technologies may be achieved by going beyond the unmet information and communication needs: providing greater satisfaction by improving the interaction mode. For example, providing an information-interaction mode that eases both the flexible storage and retrieval of information in a standardized and structured manner, that is also personalized towards the users' level of health literacy. In previous studies, Sezgin et al [11] proposed the use of voice interaction technology as a more effective method to interact with health information, and Holden et al [175] proposed developing hybrid solutions that integrate electronics into paper-based technologies to enhance the interaction and functionalities of paper-based records. The interaction experience provided by these alternative technologies may foster adoption after deployment. However, to the best of the authors' knowledge, there have been no developments of these technologies deployed in the context of complex home care that have been studied for efficacy or measured the user interaction to evaluate changes in user engagement and satisfaction.

While the focus of this study was to capture the complex work domains of caregivers providing home care services to provide an understanding of their current processes, there is a need to bridge the gap in health information interaction technologies not only between caregivers, but also their patients. Future research should specifically explore the interaction experience by both caregivers and their patients with new technologies, by measuring flexibility, the naturalness of the interaction and usability.

5.7.4 Strengths & Limitations

This study's exploratory nature captured wide-ranging perspectives of family caregivers and hired caregivers of older adults working in complex home care environments. While our study was not focused on the COVID-19 pandemic, there is currently no significant research conducted during a period of a global pandemic in this area of caregiving, where some caregivers practices have been required to shift to and rely on alternate communication methods in a quick manner. The caregiver perspectives that were described in this study may have been influenced by the nature of the global pandemic and the stresses that they experienced during changes in their loved one's care.

Due to the exploratory nature of this work and the pandemic's impact, participant demographics were limited. While snowball sampling was known to recruit five participants, this research captured the perspectives of a diverse population who have unique experiences and viewpoints based on their caregiving characteristics. There is an opportunity to further build on this work in future research through the inclusion of broader demographics.

5.8 Conclusion

From the findings in this study, we can further understand caregivers' experiences with health information management and communication in the context of complex home care. While diverse caregiving experiences were captured from both family caregivers and hired caregivers in complex home care situations, there were notable similarities in the information and communication processes conducted by each caregiver group. As caregiver collaboration is critical for effective coordination and communication, the identified similarities within the current processes involved may play an influential role in designing future information systems and new home healthcare technologies that can be integrated across caregiver populations. The overlapping processes involved with maintaining continuous awareness of the home care situation that were identified in this study and the reliance on developing and implementing paper-based documentation points towards future technologies will need to employ an interaction that exceeds the usefulness of that interaction, for the adoption by caregivers of older adults. Future research should focus on identifying how to improve the information-interaction experience with new home care technologies, to further understand caregivers' needs and the factors that influence the successful implementation of technologies in complex home care.

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Chapter 6

Technology Acceptance of Voice Assistants in Complex Home Care: A Mixed-Method Study

This chapter is being submitted for publication.

6.1 Overview

The diffusion of Voice Assistant (VA) technology in society is increasing due to its novelty, ease of use and fundamental utility, as previously identified through applications of the technology acceptance model (TAM). There is also an increase in demand for home care with caregivers providing healthcare services for children with special health care needs (CSHCN) and older adults choosing to age at home. Providing care in home environments is complex, and often there is considerable pressure on caregivers to document information and ensure care continuity. Digital information management and communications tools may support care coordination. However, current technologies have low adoption rates because they do not holistically capture stakeholders' needs. VA technology is a promising method for interfacing with digital health information in the home environment and may influence the adoption of digital health tools by caregivers. This study explores the perspectives of caregivers on the adoption of VA technology to support caregiving and inform the design of future technologies in complex home care. Interview and survey data from 22 caregivers with diverse backgrounds and caregiving experiences were collected. Three themes were identified: First, caregivers Perceived Usefulness for VAs to support documentation, care coordination and person-centred care. Second, caregivers Perceived Ease of Use for navigating information. However, they also had voice interaction concerns. Third, caregivers' Attitudes Toward Use were influenced by their overall concerns, excitement, and expected costs. The interview and survey data suggest that the caregivers in this study have similar expectations for VA technology design in complex home care. The TAM and survey results point towards the potential for VAs to support family caregivers and hired caregivers by easing their information management and health communication in the home. However, beyond information interaction, the impact of VA personality traits on caregivers' perceptions of the care situation and the passive collection of audio data to improve the

user experience through context-specific interactions are critical design considerations that should be further examined.

Keywords: Digital Health; Voice Assistant; Home Care; Older Adult; Children; Technology Acceptance

6.2 Introduction

While engaging in natural spoken conversation is the most common way of communicating information, humans increasingly interact with information through computers. The Turing test is often used to determine whether the exchange with a computer can be distinguished from a human, measuring the interaction's humanness [182]. Significant research has been working towards imitating natural language conversations. However, this area has not yet been fully realized as a prominent means for human-computer interaction [183, 184, 185]. With advancements in natural language understanding and speech processing, the adoption of VA technology such as Apple's Siri, Amazon's Alexa, Microsoft's Cortana, and Google's Assistant is increasing. This rise in adoption is primarily due to the ability for VAs to reduce barriers to accessing information, social attributes influencing the development of trust and significant advancements of the technology [185, 186, 187]. While VAs are commonly used to support everyday activities such as playing music, checking the weather and listening to the news, emerging research explores potential healthcare applications. Possible areas of benefit for voice interaction have been identified for hands-free documentation and data retrieval from electronic health records by healthcare professionals and intelligent, multimodal assistance through supporting telehealth utilization or detecting respiratory conditions [12].

Acknowledging home care and the growing adoption of VAs, an application domain of these two avenues is supporting individuals who provide care services in a home environment [8]. Effective and accurate speech-based communication and health information sharing between caregivers positively impact reducing the risk of adverse events, especially when a home care situation involves chronic conditions, complex medication regimens, social vulnerability and diverse caregiving teams [124, 146, 157, 188]. While caregivers currently use paper-based documentation, separate software applications and telecommunication devices to coordinate care, there are limitations with non-standardized technologies to support health information interaction and decision-making within an often unpredictable and dynamic home environment [1, 11, 178]. Despite the continued development of digital solutions to address the need for improved information management and health communication in the home, annual adoption rates for technologies such as online portals only range from 5-12.4% due to challenges with usability and interface navigation [13, 14].

Interacting with a digital system through a VA may provide a more natural, intuitive and efficient way to engage with health information in complex home care by family members and their caregiving teams [8, 11, 189], and may positively impact caregiver burnout due to better-supporting care coordination in a home [5, 190]. Vocal recording of health events and documentation using VA technology has shown promise for relieving a caregivers' burden documentation, especially when support can be personalized [11]. For caregivers of children with special health care needs (CSHCN), VAs can support autonomy to self-manage health information as they transition towards adulthood [189]. For older adults, VAs have demonstrated improvements in independent living and health maintenance [87, 191, 192]. With the potential that VAs establish around support in a home care environment, it is critical to better understand stakeholders' perspectives in a way that informs safe, accessible and effective system design [12].

To date, there is no substantial research exploring caregivers' attitudes about the design of VAs to support caregivers who are providing care in a complex home environment. This study uses the technology acceptance model (TAM) to better understand and map caregivers' initial perspectives on VA design, explicitly examining how family caregivers and hired caregivers perceive the use of VAs to interface with health information and support caregiver communication.

6.3 Background

6.3.1 Technology Acceptance Model

The Technology Acceptance Model (TAM) is a systems theory that enables a better understanding of the critical aspects of user acceptance of a novel system and how design decisions may impact the successful integration of information systems in a work domain [2]. The model has been commonly used to evaluate the factors influencing healthcare technology adoption [60, 193, 194, 195] and has also been used to assess the adoption of voice interfaces in automated systems [196]. The TAM's primary components are Perceived Usefulness, Perceived Ease of Use, and Attitudes Toward Use. Perceived usefulness is "the degree to which a person believes that using a particular system would enhance his or her job performance," while perceived ease of use is "the degree to which a person believes that using a particular system would be free from effort" [13]. Attitudes are the external factors, often based on prior experiences, that influence the behavioural intention to use a technology [2].

Pal et al [197] evaluated the adoption of VAs using the TAM with participants from Amazon Mechanical Turk. They identified that users perceived low utilitarian value for VAs [197]. Adoption was strongly influenced by novelty and excitement more than the design features affect how functional the system is [197]. They also determined that a user's enjoyment with the interaction plays a critical role in adoption [197], a finding that Sohn et al [61] also recognized. To influence further adoption, Pal et al [197] recommended that VA developers improve this technology's usefulness by enabling high-quality interactions for the specific set of tasks that they design a VA to support.

In another study by Pal & Arpnikanondt [198], their analysis of VA acceptance using the TAM identified that the retention of VAs by users would require a strong relationship between context-awareness and a detailed knowledge base. The result of Moriuchi's [199] use of the TAM agreed with Pal & Arpnikanondt's, where improved user engagement with VAs requires contextual awareness combined with valuable and easy-to-use functionality. Moriuchi also identified that consumers are using VAs to support decision-making processes [199]. Although the TAM has been used to study the overall adoption of VAs, there is no significant literature evaluating the potential acceptance of VAs in healthcare and the theoretical impact of design decisions on adopting VAs by caregivers working in complex home care.

6.4 Methods

6.4.1 Study Design

This research is part of a larger mixed-method study to identify caregivers' perspectives in Canada and the United States of America about the use of VAs to support information management and communication in complex home care. This paper focuses on the semi-structured interview results and survey data. Caregivers' initial mental models about using VAs are analyzed to provide insight on how design decisions may impact the successful integration of VAs in complex home care. The survey data quantitatively captures participants' initial perspectives on the design features for VAs in complex home care while exploring their perspectives of potential functionality beyond their current mental models.

This study was approved by a University of Waterloo Research Ethics Committee. All participants were interviewed virtually from their homes due to COVID-19 restrictions. Informed consent was obtained verbally, and participants received a thank-you letter for their participation.

6.4.2 Participants & Data Collection

The research team recruited participants through home healthcare and caregiving agencies, social media groups, and snowball sampling. The recruitment objective was to engage participants with diverse backgrounds, ages, caregiving experiences, and experience with VA technology in their homes. Eligible participants were either a family caregiver or a hired caregiver for an adult or child who required complex care services in their home in North America. In this study, complex care was defined as individuals with any combination of the following: complex chronic conditions, mental health issues, medication-related problems and social vulnerability. A caregiver was as anyone who provided or coordinated care for someone in their home, and participants were not required to have prior experience with VAs. However, if participants expressed that they did not know what a VA was, the researchers explained that VAs are a technology that allows for humans to interact with information on a computer system through voice and audio.

Two researchers (RT, KM) conducted the interviews. First, caregivers were asked to describe their current experiences with VAs in their daily activities. Second, caregivers were asked to describe their initial beliefs and expectations for VAs to support their caregiving work domain. At the end of the interview, the participants were asked 12 Likert-scale questions about their expectations for VAs in a home care context (Table 6.1). Participants were asked to verbally respond to each question on a seven-point scale ranging from strongly disagree to strongly agree. Microsoft Teams was used to record the interviews, and only the audio recordings were stored for transcription.

Table 6.1: Likert-scale questions on caregiver expectations for voice assistants

Number	Question *In the context of home care, a voice assistant should...*
1	not have a personality.
2	not remember details about this person's medical condition.
3	record this person's health information when I ask it to.
4	retrieve previously recorded health information for me.
5	not teach me how to effectively work with different medical technology in the home.
6	remind me about time-sensitive tasks such as medications, treatments or therapies.
7	not guide me through the steps required to perform tasks.
8	not assist me in an emergency situation.
9	understand complete sentences.
10	understand specific keywords or queries.
11	not listen for specific events that are occurring in the home to support caregivers perform tasks.
12	listen for specific events that are occurring in the home to remind caregivers to record the details of their tasks.

6.4.3 Data Analysis

The interview data were analyzed using a theoretical thematic process [112], with the TAM being used to guide concept identification. First, the interviews were transcribed verbatim, and all names and identifiers were made anonymous. The research team listened to the interview recordings and read through the transcripts to familiarize themselves with the data. Core team members discussed each interview, thematically coded the data and regularly met to discuss emerging concepts and themes. The final list of codes was organized into concepts and themes and presented to the entire research team for discussion and refinement. The survey data was analyzed by calculating response rates. The survey results were triangulated with participants' qualitative responses and represented graphically.

6.5 Findings

6.5.1 Participant Demographics

There were 22 caregivers that participated in this study (Table 6.2). Participants were grouped by caregiver type, including family caregivers of older adults, hired caregivers of older adults, and family caregivers of CSHCN. Participants were recruited from various regions across Canada and the United States of America. The youngest participant in this study was 24 years old, and the oldest was 83 years old—most of the participants identified as female (20/22, 91%), while two identified as male. The participants' caregiving experience ranged from four months to 13 years. More participants had minimal or no experience with VAs (12/22, 55%) than participants who did have experience with VAs (10/22, 45%). One participant was not asked about their experience with VAs, and one participant's qualitative data from the hired caregiver group were not analyzed in-depth as they did not consent to their interview being recorded.

6.5.2 Themes

The TAM was used to organize the qualitative findings of participants' initial beliefs and expectations for VA functionality in complex home care, based on their current knowledge and experiences. There were 25 identified concepts that were organized into three themes and eight subthemes (Table 6.3).

Perceived Usefulness

Participants discussed VA design features that would provide utility to their home care situation, which were organized into three subthemes: (1) Documentation, (2) Care Co-

Table 6.2: Participant demographics and caregiving characteristics (n=22)

Characteristics		Family Caregivers of CSHCN	Family Caregivers of Older Adults	Hired Caregivers of Older Adults
Number of Participants, n (%)		7 (32)	9 (41)	6 (27)
Age (years), n (%)				
	18-24	0 (0)	1 (11)	0 (0)
	25-34	2 (29)	1 (11)	1 (17)
	35-44	5 (71)	0 (0)	2 (33)
	45-54	0 (0)	0 (0)	1 (17)
	55-64	0 (0)	1 (11)	1 (17)
	65-74	0 (0)	2 (22)	1 (17)
	75-84	0 (0)	4 (44)	0 (0)
Gender, n (%)				
	Female	7 (100)	8 (89)	5 (83)
	Male	0 (0)	1 (11)	1 (17)
Location, n (%)				
	Canada	5 (71)	9 (100)	6 (100)
	USA	2 (29)	0 (0)	0 (0)
Caregiving Experience (years), n (%)				
	0-5	1 (14)	6 (67)	4 (67)
	6-10	3 (43)	2 (22)	1 (17)
	11-15	2 (29)	1 (11)	1 (17)
	16-20	1 (14)	0 (0)	0 (0)
Virtual Assistant Experience, n (%)				
	Minimal-No	4 (57)	5 (56)	2 (33)
	Experienced	3 (43)	3 (33)	4 (67)
	Unknown	0 (0)	1 (11)	0 (0)

ordination, and (3) Person-Centred Care. First, participants believed that VAs would be helpful as a digital tool for managing their documentation through organizing health data and subsequently manipulating a digital record through recording and retrieving information. One participant mentioned that they would especially "love to be able to use it, like, with the online notebook of some sort" (P16, Family Caregiver - CSHCN), and participants specifically described the usefulness of maintaining documentation in the context of medication management. For example, participants expressed that a VA could support the recording of drug reactions and the monitoring of medication adherence:

> *I think keeping notes, like being able to just speak out loud, and if it automat-*

Table 6.3: Initial expectations for voice assistants to support health information management and communication in complex home care

Themes	Subthemes	Concepts	Family-CD	Family-OA	Hired-OA
Perceived Usefulness					
	Documentation	Organizing information	✓		
		Recording & Retrieving information	✓	✓	✓
	Care Coordination	Teaching caregivers through instructions	✓	✓	✓
		Reminding caregivers	✓	✓	✓
		Leaving messages for caregivers		✓	✓
		Calling others	✓	✓	✓
		Supporting physical tasks	✓	✓	✓
	Person-Centred Care	Providing autonomy for care	✓	✓	✓
		Supporting mild cognitive impairment		✓	✓
		Supporting medication management	✓	✓	✓
Perceived Ease of Use					
	Navigating Information	Interacting by voice	✓	✓	
		Supporting aftercare	✓		
		Information retrieval		✓	
	Voice Interaction Concerns	Being misunderstood/unheard	✓	✓	
		Engagement by the caregiver team			✓
		Challenges interfacing with computers		✓	✓
		Negative influence on physical activity			✓
Attitudes Toward Use					
	Concerns	Standards for documentation			✓
		Medication management	✓		
		Privacy of information	✓	✓	✓
	Excitement	Learning new technology	✓	✓	
		Appreciation for voice-based technology		✓	
		Excited about home care technology	✓		
	Cost	Environmental benefits			✓
		The financial cost of the system	✓		

Note: CD – child, OA – older adult; ✓– concept mentioned by at least one participant from the corresponding caregiver group

> *ically set a date and a time for when I spoke to it with an observation that was important... if I wanted to record something about the medication. (P10, Family Caregiver - OA)*

> *I could ask my specific question: "Alexa, did [the patient] take [their] hydromorph contin today?" (P5, Hired Caregiver)*

Second, each caregiver population in this study discussed VA functionalities that would impact care coordination. However, participants had unique expectations about the degree to which VAs could provide coordination support. For example, participants mentioned design functionalities that included setting reminders for medications, communicating with others and guiding a caregiver through the steps of a medically related task:

> *If they got a little notice, that was like, "Hey, it's time for the medication!" I definitely think it could really be helpful. (P21, Family Caregiver – CSHCN)*

> *Certainly, managing medications, timing, and if I wanted to be reminded. (P10, Family Caregiver - OA)*

To support communicating with others, participants expressed that VAs could specifically assist with care transitions. For example, participants explained that they could use the VA to leave a PSW a personal message to listen to when they arrived at their house. Some participants (3/22, 14%) also suggested that VAs would help them contact their patient or loved one, health care professionals, or others on the caregiver team.

> *Well, communication with the PSW's. If I wasn't here, let's say when [my spouse] ... I couldn't leave [them] alone in the latter stages. But in the earlier stages, I thought I could go off to the grocery store and leave [them]. That was up until I came home and found [them] in a delirious state and thought that was a mistake. But if I could, and I wanted to, leave instructions for a PSW... (P10, Family Caregiver - OA)*

> *Like again, I don't know its capacity, but if it has, like say, "Siri, connect me with the doctor's office," "Call the doctor's office." (P13, Hired Caregiver)*

For guiding a caregiver through tasks, participants mentioned that the caregiver could individually set a VA to provide instructions for procedures (P13, Hired Caregiver) or examples of exercises (P22, Hired Caregiver). The family caregivers of CSHCN detailed some of the specific contexts where a VA could support teaching their caregivers—for example, guiding caregivers through the steps involved with administering medication or operating a medical device such as a suction machine. While the family caregivers of CSHCN in this study currently create teaching materials to support their home care, they expressed that this interaction method might positively influence the engagement of their hired caregivers with their teaching materials, improving respite care:

> *Taking somebody through the steps of…, "This is that schedule," "This is the bottle of medication," "This is what it says," "These are the steps you go through to safely measure and administer medications." And it can be generic… "Don't touch the pills," "How to put powder in a syringe and then suck water up in it without losing all the powder." (P2, Family Caregiver - CSHCN)*

> *The instructions would be in the binder with pictures and all that…, or they're on YouTube, and they would still call me and, "How do I…," and I would be like, "OK. Go to the Binder, flip open the page. You see this?" …It's like, "Press on/off in the upper left corner. Now, wait 20 seconds. Alright, now hit 'volume total.'" Like, yeah, if I could have just like made little recordings like that… maybe people would use it! (P21, Family Caregiver - CSHCN)*

Family caregivers of older adults also described the use of VAs as a tool to provide instructions to caregivers, where the addition of a visual representation for the steps involved in a task may improve the caregivers' capability to carry out the physical actions:

> *There might be able to be demonstrations of how to care for certain physical elements... Guide you... But even if it could be done, if there was a screen, if it could be done pictorial. (P10, Family Caregiver - OA)*

Finally, beyond directly supporting a caregiver's tasks in the home, the participants in this study described the use of their patient or loved one interacting with the VA. They expressed that VAs could support self-care by providing autonomy in managing their medications, supporting cognitive processes, and as a friendly assistant to interact with during medical procedures. For example, one participant already used the reminder functionality afforded by the Google Home to provide their child, who was beginning to take more responsibility for their care, with more autonomy for taking their medications.

> *We had the medication set up all around, kind of in [their downstairs] apartment. So, we set it up, you know, "set a reminder for [them] to take the pills on top of your white freezer with the Green Cup at 8:00." (P8, Family Caregiver - CSHCN)*

For adults who may have mild cognitive impairment or physical disabilities, participants expressed that VAs could support their autonomy through reminders about their care. For example, one caregiver mentioned that VAs could help an older adult through reminders, specifically when to expect their hired care to arrive, without finding the information physically.

> *If you could have said things like, "Siri, what time does my home care person arrive?" And if it could have given the appointment time to [them] verbally [they] wouldn't have had to search through papers (P13, Hired Caregiver)*

Participants also discussed the importance of supporting cognitive processes to keep older adults oriented with their environment and assist with medication management through verbal cues. Specifically, participants mentioned that caregivers could interact with a VA to check if a patient or loved one had taken their medication. A care receiver could also check their medication history.

> *I'm noticing now too [they] will have like symptoms of dementia... early-onset... and [they] will keep repeating the same question over and over, and for someone like [them], it's really important to make sure [they're] orientated to the date to the time of the year to the day of the week, just to make sure [they're] aware of what's going on. So, I will ask [them] questions like, "Hey, Google, tell me the time." or "Tell me the weather outside." (P6, Family Caregiver - OA)*

> *Having a verbal cue for the person to take their medication, but like as a backup. Seeing if it has been done. (P5, Hired Caregiver)*

> *I'm beginning to think... something to remind you when and how often you've taken your medication would be good. (P14, Family Caregiver - OA)*

In the context of interacting with VAs during a medical procedure, one participant described that a VA could interact with their child to keep them calm while they changed their tracheostomy.

> *[My child] could like use it to talk [them] through a medical procedure, and that might calm [their] anxiety down a bit... And just like in a kid-friendly way... that would be cool to have in-home. (P1, Family Caregiver - CSHCN)*

Perceived Ease of Use

In this study, participants commented explicitly on the ease of using a VA in a home care context organized into two subthemes: (1) Navigating Information and (2) Voice Interaction Concerns. First, participants mentioned that VAs would ease their documentation. They expressed that interacting by voice would facilitate recording and retrieving information because *"it's as long as it takes me to talk, which is good because I don't have to input stuff" (P8, Family Caregiver - CSHCN).* A voice-based system could *"give you information... instantaneously" (P6, Family Caregiver - OA).*

Participants also described the affordance of multitasking that a VA could provide. They expressed that while they are working on one task, they could speak to the system and have health information documented directly during that moment. The ease of recording by voice may reduce the burden of physically writing information on paper; however, participants still desired to obtain a physical copy of the data if needed.

> *Sometimes I'm in the middle of doing something else... and I need to remember this thing. But if I stop what I'm doing, then... maybe it's not that simple to just stop what I'm doing. Or if I wait until the end, I'm going to forget because I just don't have a very good memory... (P3, Family Caregiver - CSHCN)*

> *I think it'd be great if the caregivers could find a way that they didn't have to write in the logbook. I would think that they would be able to just say, "OK,*

> *ate lunch da da da da," and then something would be printed up (P18, Family Caregiver - OA)*

The ease of record-keeping by voice could also support a caregivers' capacity to perform aftercare. For example, one participant mentioned that if their child were having a seizure, they would be able to physically care for them while maintaining accurate documentation of the event:

> *If my [child's] in the middle of a seizure: "Siri, note that [they] had started a seizure at this time," "Siri, note that [they] stopped," so I'm not having to wait for [them] to get done and try to remember all the time. (P16, Family Caregiver - CSHCN)*

Second, despite the design functionality of VAs that would ease documentation, there were essential concerns about this method of interacting with health information. One caregiver (P3, Family Caregiver – CSHCN) mentioned that using a VA may not be a more straightforward method for managing their child's health information. However, they expressed the need to integrate the technology into their routine first to determine if it would be a valuable alternative to other technologies, processes or practices. There were also concerns with their voice commands being accurately understood by a VA, which may lead to a problematic interaction:

> *[Siri] just... it wouldn't register what I was saying... if I have that [for home care], is it going to even register what I'm saying? (P16, Family Caregiver - CSHCN)*

> *I find that because my [family member] had a little bit of a speech impediment, unfortunately, when we use the Google home mini, sometimes it isn't able to understand [them] very often... Even today, I was playing a song, and [they] wanted it to stop. So, [they] said, "Hey, Google. Stop." And it just didn't understand. So that was pretty frustrating because [they] told me today too that it doesn't understand [them], and that kind of made me sad as well. (P6, Family Caregiver - OA)*

One participant was strongly opposed to interacting with VAs in complex home care. Their perceived trust in VA technology, hesitations about information privacy and the accuracy of recording information by voice negatively influenced their perceived ease of use. While participants identified the need for all members of the caregiver team to be comfortable interacting with the VA, conflicting beliefs about the ease of record-keeping using a VA might negatively influence care coordination:

> *I don't think it's a good idea; I don't like that idea. Things can get messed up. You know, certain things could be left out. I mean, it's always glitches with computers, and they frustrate me all the time. (P4, Hired Caregiver)*

Another participant mentioned an essential caveat for technology like VAs being easy to use. While they believed that VAs might support individuals with mild cognitive impairment, their concern was that this might negatively influence their physical activity as other technologies have done in the past.

> *I must admit I have real reservations about them; the more electronics do for us physically... The two things that, for health for seniors and keeping them*

> *in their home, they have to have mobility, and I mean I can see it supporting cognition. Things to keep them in their home longer. But I'm sorry, it's like the remote on the TV. I used it all the time, don't get me wrong, but, you know, that getting up and moving to turn on the TV used to be sometimes the only activity those like seniors see. So, I'm not sure it's necessarily a good thing in that respect. (P13, Hired Caregiver)*

Attitudes Toward Use

The external factors influencing the participants' behavioural intention to use VAs in complex home care were organized into three subthemes: (1) Excitement, (2) Concerns, and (3) Cost. Despite varied experiences with VAs, the participants in this study were "quite excited to think about what we could do with the technology" (P13, Hired Caregiver). They initially expressed passion towards developing digital solutions for home care and their willingness to learn a new technology that could support their caregiving tasks (4/22, 18%). However, participants also expressed concerns about using VAs, grounded by the current methods they used to document health information in the home. As a first example, one participant explained that health information should not be obtained from a VA, but "should come from the individual and... come from the patients. It should be, you know, only... your patient and your caregivers" (P4, Hired Caregiver). Another participant mentioned that using VAs for medication management cannot compare to their current system for tracking their child's complex medication regimen, which currently provides a physical cue for measuring adherence:

> *For example, remembering to take [their] meds. I don't know that I would use [a voice assistant] for that, and the reason being... you can forget to tell it*

> *that [you] took it, but... my little pillbox doesn't lie. So, if it's in there, I know you didn't take it. [There's] no "I just forgot to tell it," "I actually did take it," kind of thing. (P3, Family Caregiver - CSHCN)*

Privacy of information was also an essential concern for participants. In one situation, the family members of one participant influenced them not to purchase a VA based on the perception that *"those things know what's going on in your house all the time" (P12, Family Caregiver – OA)*. Another participant further expressed concerns that others could access health information stored on VAs *"and anybody can get it cause it's out there" (P4, Hired Caregiver)*.

Finally, although the financial cost was an initial concern mentioned by one participant in this study, one hired caregiver also noted the cost of their current documentation methods on our environment and how the use of VAs could support the reduction of that cost:

> *When it's paper-based, it's basically really a big waste... of paper. So, at least if you're just using Alexa or a virtual assistant... it would be at least... let's say... kinder to nature... If we're looking at [my client's] records of [their] things, whenever we try to record the chart, we basically have a load thick of this paper. (P20, Hired Caregiver)*

6.5.3 Quantitative Findings

The quantitative findings were represented graphically (Figure 6.1, Figure 6.2, Figure 6.3) by each caregiver population. In this study, most participants agreed that a VA should record someone's health information when they ask it (21/22, 95%) and retrieve previously documented information (21/22, 95%). They also agreed that a VA should remember the details of someone's medical condition (19/22, 86%) with the requirement that the data is not stored in a publicly accessible database:

> *As long as there's privacy, I think it should. It should be able to retain it. If I came in as a home care or PSW, even as a family member, and I say, "When did this happen?" I didn't have to go back through my notes. My machine can testify who did the treatment last. I mean, that would be very helpful... Anything that records, and I don't have to chart, I'm on board! (P13, Hired Caregiver)*

All of the study participants agreed that voice assistants should remind them about time-sensitive tasks such as medications, treatments, or therapies (22/22, 100%). With respect to interaction preferences with voice assistants, the participants often expressed their desire to have the option to speak using specific keywords (21/22, 95%) and complete sentences (18/22, 82%):

> *I'd like to do both... I don't want to have the task of remembering how I'm supposed to interact with it. (P14, Family Caregiver – OA)*

For more dynamic interactions, most participants agreed that voice assistants should guide them through the steps required to perform tasks (21/22, 95%), teach them how to use different medical technology in their home (18/22, 82%), and support them in an emergency (18/22, 82%). However, there was less agreeance about a voice assistant having a personality (14/22, 64%), listening for a particular activity in the home to remind caregivers to record the details of their tasks (16/22, 73%), and listening for a specific activity in the home to support caregivers perform their tasks (9/22, 41%). The unique perspectives on VA support in an emergency, teaching or guiding caregivers, and listening to activity in the home are further described in the following sections.

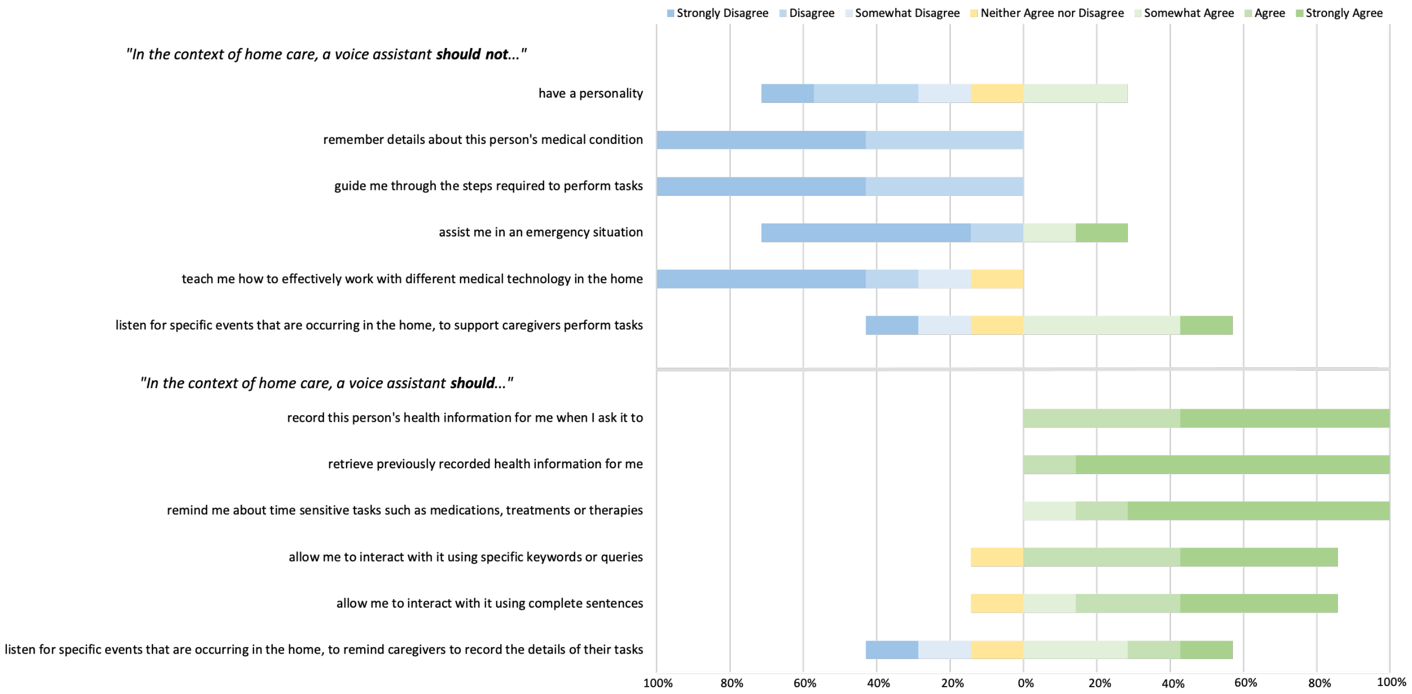

Figure 6.1: Family caregivers expectations for voice assistants in complex home care for CSHCN (N=7)

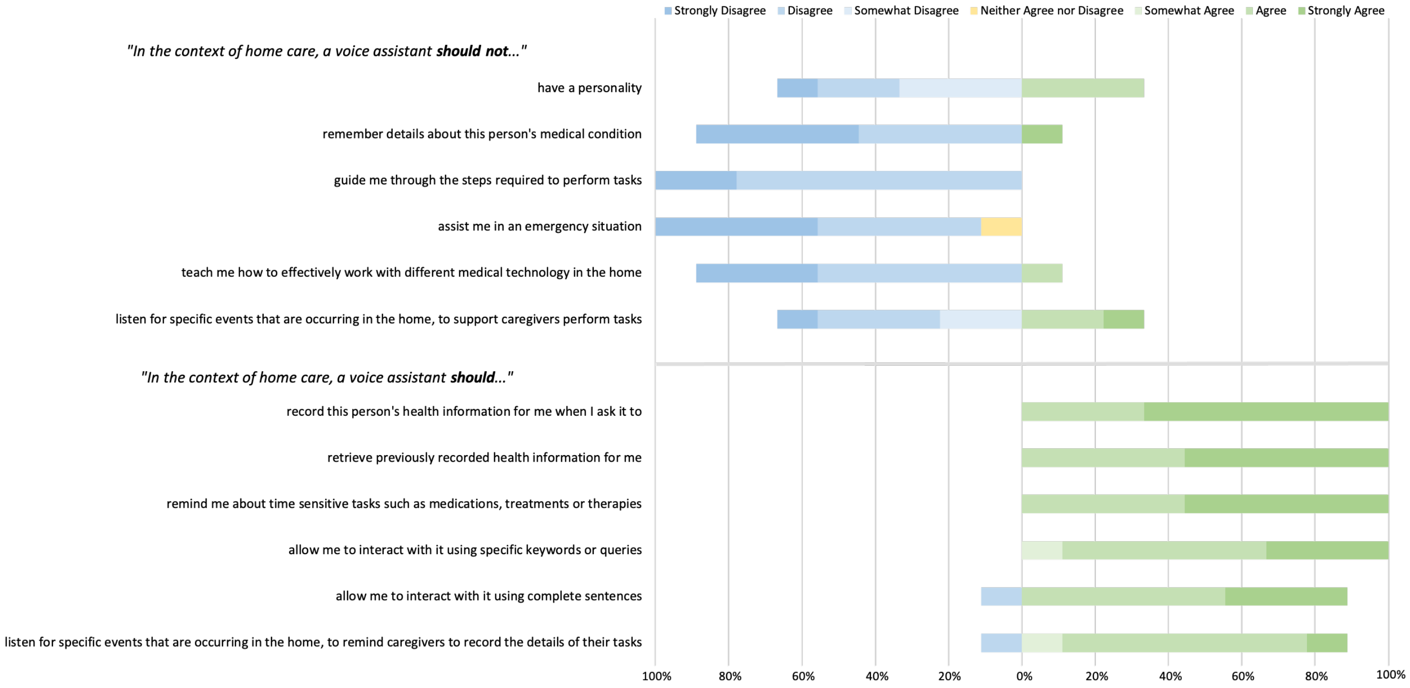

Figure 6.2: Family caregiver expectations for voice assistants in complex home care for older adults (N=9)

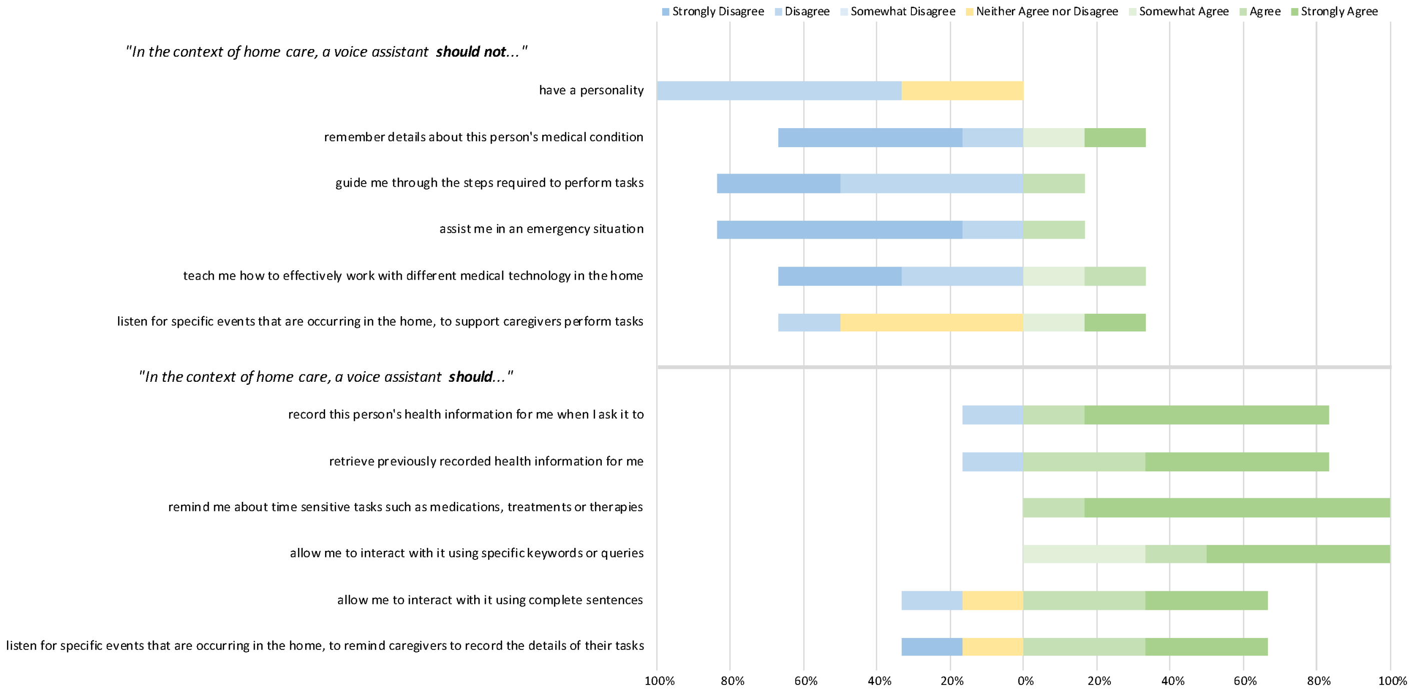

Figure 6.3: Hired caregiver expectations for voice assistants in complex home care (N=6)

Voice Assistants with a Personality

The participants who agreed that a voice assistant should have a personality expressed that they would want “A happy, positive, smiley one, instead of these basic voices” (P8, Family Caregiver – CSHCN). One participant mentioned that VAs could have a personality because they are still a computer that provides objective responses:

> *Well, otherwise, it’s just like talking to a box or a machine. You would expect the virtual assistant always to be right. You see... So, if you’re right, then you can go on with having a personality, and I would presume that it would be a positive personality or happy personality. (P17, Family Caregiver – OA)*

However, participants were also concerned about the influence that a personality could have on vulnerable caregivers. While they observed the benefit of VA personality on user engagement, the concept of a personality coming from an objective device might impact the perception of care by caregivers and care receivers:

> *I strongly feel that it shouldn’t have a personality... I think that could actually kind of take advantage of vulnerable people, to be honest... I know that there’s an argument to be made the exact opposite—that it would make it more user-friendly, it would make it warmer, it could be a companion to the person, etc. You know there’s a lot of lines you can cross... I think one of the things you have to keep in mind is to... have a line between medical care and personal care so that you’re not medicalizing your loved one too much. You’re remembering that you’re keeping your personal relationship with them... If you had a virtual assistant that sounded very friendly... this could just be confusing,*

> *or it could... there's something about it that's just not sitting right with me. (P7, Family Caregiver – OA)*

Assisting in an Emergency

While most participants (18/22, 82%) agreed that VAs should assist caregivers in an emergency, they expressed that this functionality should be limited to calling emergency services (e.g., calling 911) and that calling for help from a human should be the extent of a VA's support. For example, participants (2/22, 9%) expressed that a home care situation would be too complicated for a computer to help:

> *Say [they] vomit: "Mabel, [they've] vomited. I'm going to put [them] on [their] side now." That sort of thing. "What side should I put [them] on?" Well, then they can't make that decision anyway. That's not a good example. (P17, Family Caregiver – OA)*

> *[With] the medical conditions my [child] has... I don't think I'm anywhere near trusting a device... Yeah, not yet. (P9, Family Caregiver – CSHCN)*

Teaching and Guiding Caregivers through Tasks

Guiding caregivers through tasks in the home was a potential VA functionality that many caregivers (21/22, 95%) mentioned *"is exactly what this virtual assistant should be able to do" (P14, Family Caregiver – OA)*. However, other participants (4/22, 18%) disagreed by noting that VAs should not be initially teaching caregivers how to do tasks that they have never done before and should not necessarily teach every caregiver about the details of operating sensitive medical equipment in the home. The participants emphasized the importance of having in-person training and the need for setting access limitations for specific caregiver populations, especially in the context of learning how to use a device that dispenses medication.

> *Some of my hesitation... was that I was defaulting to the importance of... face-to-face... If you're training a new nurse, from my experience, you want someone there on the premises training you in-person: One, for the registered staff to have... confidence in the new person, new trainees' ability, but also, I would think to instill more confidence in the patient in the new caregiver. (P5, Hired Caregiver)*

> *The keyword there is teach me. I wouldn't have [a medical device] in the house if somebody hadn't already taught me how to use it. (P17, Family Caregiver – OA)*

> *I was thinking specifically about... devices that dispense medication, and I was thinking about safety and security. Not letting people, for example, know how to use a pump... I want some lockout feature on the assistants so the family can't go, "Alexa, how do I unlock this?" (P5, Hired Caregiver)*

Listening to Events of the Home

The participants' perspectives about an always-on VA capable of unprompted responses were seen either as a privacy issue or as significant support for home care safety. Concerning privacy, participants expressed that they did not like the idea of VAs being present and having the ability to speak without prior notice. While participants mentioned that they observed the VA's potential to notify them about safety events concerning the care situation, other participants said they would not be comfortable with unprompted interactions. This was perceived as an invasion of the private activities in their home.

> *In some situations, that could be of significant support and... some situations, that might also be like an invasion of privacy. (P2, Family Caregiver - CSHCN)*

> *If it's all related to the care, then it should be able to listen, but it's... that's a little bit dicey... (P10, Family Caregiver – OA)*

Participants expressed that unprompted responses from VAs would support peace-of-mind for their respite care with respect to safety. One participant described that unprompted responses from a VA could be used to remind their PSW where to stand when they are performing physical therapy with their spouse:

> *That would be great for me because I'm not in the room when these caregivers come, and they're going to be the ones to tell them to stand behind [my spouse]. (P17, Family Caregiver – OA)*

Finally, one participant mentioned that VAs could listen for unexpected accidents in the home, such as a fall, and promptly notify caregivers to take action. They also noted the potential for VAs to identify caregiver abuse:

> *That could be a huge safety component... to identify caregiver abuse... because really there is caregiver abuse... And I'm not doing blaming... We overwhelm caregivers in the home. We just overwhelm them. Not professional ones that are coming in but, I'm talking about individuals who just aren't caring but are left to care. (P13, Hired Caregiver)*

6.6 Discussion

This study captures the initial perspectives of a diverse population of caregivers about the acceptance of VAs to inform digital technology design for complex home care. This study identifies the importance of utility and the ease of interaction for influencing technology adoption by organizing participants' initial responses using the TAM. The expectations for VAs to support caregivers manage and communicate health information may positively impact caregivers' desire to integrate VAs in complex home care. However, triangulation with the quantitative results also identifies critical design concerns and ethical considerations for adopting VAs in this work domain.

Expectations Across Caregiver Populations

This study identifies that the participants' perspectives may represent one caregiver population, as shown from the similar graphical representations in Figure 6.1, Figure 6.2, Figure 6.3. Combining participant responses into a single graphical representation affords a collective analysis of the results (Figure 6.4).

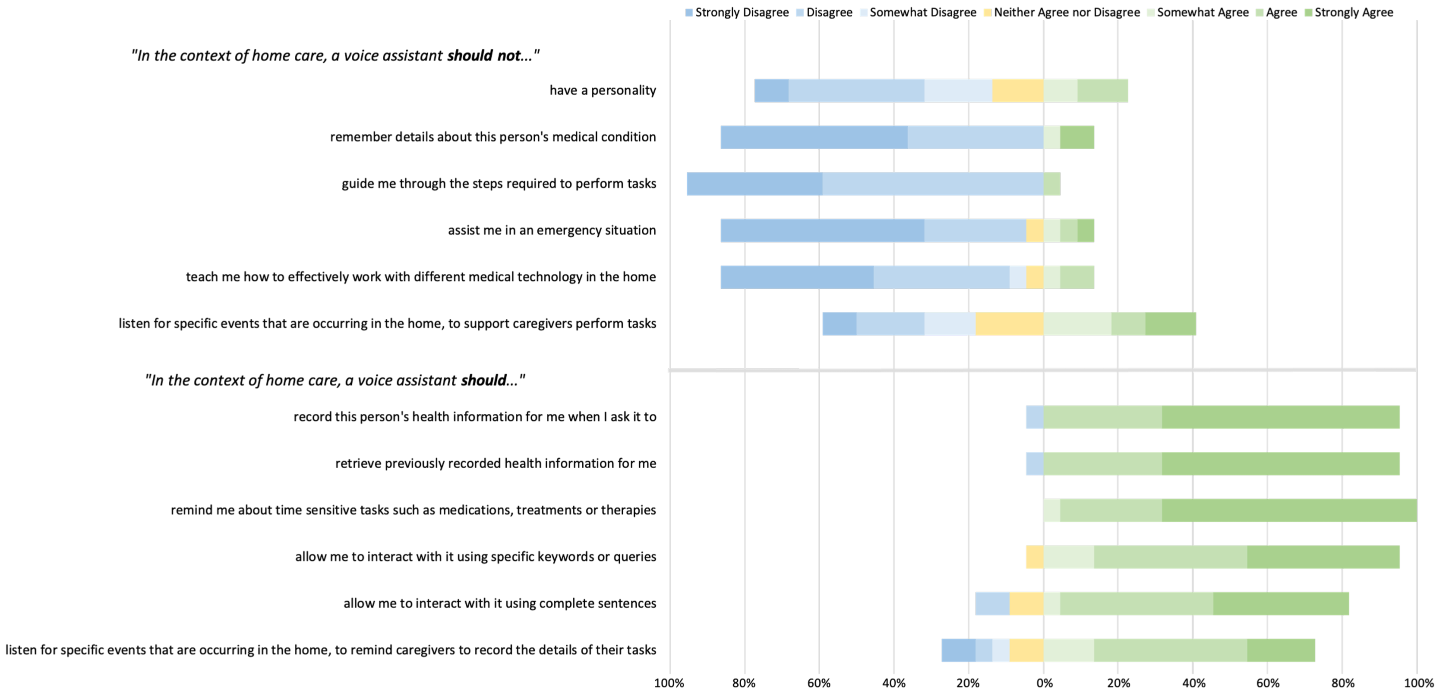

Figure 6.4: Combined caregiver expectations for voice assistants in complex home care (N=22)

With respect to the Perceived Usefulness of VAs, the participants in this study expect VAs to provide utility for processes such as maintaining and navigating detailed health records and supporting aspects of care coordination. These potential functionalities align well with prior research on the proposed integration of VAs in home care [11]. Participants mainly discuss documentation utility in the context of medication management, which Corbett et al [82] also identify. Participants in this study specifically observe usefulness for documenting details about observed reactions to a drug and tracking adherence. For care coordination, participants describe the ability to curate tailored information about the home care situation for other caregivers and effectively communicate among the caregiver team by leaving messages and setting verbal cues or timely reminders.

With respect to the Perceived Ease of Use of VAs, the participants in this study express the ease of documentation afforded by voice interaction, especially in situations where they provide aftercare. The expected ease of interacting with VAs through specific keywords or commands as well as speaking naturally to a VA further influences the perceived ease of use. However, concerns with their voice being misunderstood by the VA, prior frustrations interacting with computer systems, and the need for all caregivers to be comfortable interacting with the technology may negatively influence the ease of use if this prevents information from being efficiently updated.

The home care environments and healthcare complexities between CSHCN and older adults are diverse with respect to the individuals involved, the caregiving tasks, and the equipment used. A family caregiver and hired caregiver's responsibilities may differ from caregiver training and their relationship to the care receiver. However, there are inherent similarities among caregivers' general expectations towards the design of VAs for complex home care. The similarities in expectations for VAs across caregiver populations point towards designing a digital health tool that provides similar design features for both family caregivers and hired caregivers.

Supporting Care Recipient Independence

Chiang et al [200] measure improved outcomes of job satisfaction and reduced caregiver burden by implementing a home care concept for older adults that involves providing care receivers with the knowledge and resources required to maintain their independence in their home [200]. Based on our study's findings, where participants express utility to support daily activities and medication management by older adults, VAs may assist this concept of providing independence in the home, reduce caregiver burden, and improve caregiver peace-of-mind. However, this study also identifies the concern for reduced physical activity of older adults interacting with VAs to maintain their independence. Reduced physical activity of older adults could lead to significant health consequences [201]. While this research focuses on caregivers' perspectives, it is recommended to explore the views of care receivers to better understand their acceptance of VAs in complex home care and the potential impact that VAs could have on their daily physical activity, and capability to manage self-care.

6.6.1 Personality Traits for Voice Assistants in Complex Home Care

The participants in this study have varied expectations for the inclusion of personality traits for VAs in complex home care and how this may influence their interaction with health information. Baptista et al [202] identify that personality could influence the users' perceptions of a VA's role in a health care context. In their study, participants perceive the personality of an embodied VA for diabetes management as a "friendly coach" more than a "health professional" [202]. A scoping review by Car et al [203] identify other personality traits in studies with VAs in a healthcare context: “informal,” “human-like,” “culture-specific,” “factual,” “gender-specific,” and “conversational agent.” When designing VA personalities for family caregivers, this population can be considered vulnerable; it is essential to consider the influence that a personality trait might have on their reliance on this type of technology in different caregiving situations. While the design of VAs currently includes human-like personality traits for healthcare applications in specific contexts such as adherence to active living regimens and psychological difficulties [204, 205], the participants in this study expect VAs to assist in more than one context. A consistent personality trait for VAs may not be appropriate for every home care situation and may negatively influence a caregiver’s perception. Future research should explore how personality traits can influence caregiver engagement, reliance on technology, and medical decision-making.

6.6.2 Caregiver Expectations Towards Intelligent Support

VA technology currently uses artificial intelligence in speech analysis and natural language understanding to enhance user interaction. Prior literature suggests that the future of VAs could include intelligent aspects that support care by providing context-specific insights on data or disease detection to support medical decision-making [10, 11]. An intelligent VA for home care would require a significant knowledge base vetted by healthcare professionals and predictive algorithms based on audio data collected from the home care environment. However, as VA technology advances from information interaction to intelligent support, the increase in potential value is proportional to the risk of adverse events [11]. For health care software that involves artificial intelligence, Powell [206] suggests that the role of intelligent systems in a healthcare context should be complementary to the user and their task and not the primary medical decision-maker.

The extent to which the participants in this study initially expect a VA to assist their tasks suggests that caregivers might prefer less intelligent VAs that strictly provides a means for retrieving previously entered information. Caregivers mainly wish to direct the interaction with VA technology, where the information exchange is not expected to advance beyond their initial intents. For example, the caregivers in this study discuss using a VA to create reminders or instructions for procedures from the information they would consciously provide to the system. When they need assistance, the caregivers in this study discuss contacting other caregivers through the VA rather than thinking to ask a VA to assist them based on data collected about the home or a pre-existing digital knowledge base.

While context-specific interactions may improve engagement and adoption of VAs by general consumers, this functionality may also involve predictive algorithms to enhance the system's intelligence [197, 199]. With the uniqueness of the participants' caregiving backgrounds and home care experiences, some participants would be positively inclined towards a VA that provides context-specific support. However, creating contextually aware VAs would involve storing audio data about the activities occurring in the home. Passively collecting audio data about the home environment raises an ethical consideration regarding the use of data to report on home events ranging from accidents to potential caregiver abuse. Without including an option to control the 'always listening and analyzing' functionality, as developed by Alrumayh et al [207], this may increase caregivers' concerns with VAs in complex home care.

6.6.3 Strengths & Limitations

The mixed-method nature of this exploratory study on participants' initial expectations about using VAs in complex home care captured the unique perspectives of the potential primary users of this technology. There is no significant research conducted using the TAM for understanding VA adoption, and none captured during COVID-19. While demographics are limited, where it was known that five participants were recruited using this sampling method, our results offer preliminary insight into diverse situations, with future work expanding to examine more viewpoints including people being cared for, various health care professionals, regulators, and technology experts, ultimately bringing a holistic understanding of the system itself and its potential. An increased sample size through further research may provide more insight into the existence of any differences between caregivers' perspectives in the quantitative data.

6.7 Conclusion

This study provides the early emerging research into understanding caregiver perspectives about the use of VAs to support complex home care. The results suggest that there are similarities in expectations across different caregiver populations, which encourages the development of VAs that meet broad caregiving population's needs. The TAM specifically supports identifying that VAs could support caregivers' current healthcare documentation methods and care coordination in the home due to the ease afforded by a voice user interface. There is potential for VAs to support care recipient independence in the contexts of both CSHCN and older adults. Beyond information interaction, there are ethical considerations regarding the use of a VA that provides contextually specific insights from collected audio data, given the complexity and the diversity of activities occurring in the home. The design of VA personality traits should carefully evaluate the potential influence on vulnerable caregiver populations' perception of care. Future research should focus on integrating VAs into specific contexts of information management and communication for complex home care to further understand the factors influencing adoption with respect to the design of this technology.

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Chapter 7

Discussion & Conclusion

This thesis provides a foundation for understanding the design considerations, expected usability, and technology adoption of VAs from the diverse experiences of caregivers working in complex home environments. The research results presented in Chapter 4 and Chapter 5 illustrates the complexities of health information management and communication that caregivers face in complex home care and how this understanding can inform designing digital health tools that provide utility and promote engagement. The research results presented in Chapter 6 describe the potential for VA technology to be adopted in complex home care while also illustrating critical usability and design considerations for human-information interaction and patient safety. Through combining these findings, the foundation for designing VAs for caregivers in complex home care is supported as a potential solution to improve health information management and communication in complex home care. Although the current body of research has contributed to the conceptualization of the potential for VAs in complex home care and evaluated the usability of this technology for self-care and other specific health-related tasks, none significantly examines caregivers' experiences and perspectives in-depth before approaching the development of such a system. The exploratory nature of the research conducted for this thesis contributes to understanding home care and VA integration to improve caregivers' and care receivers' experiences, to fill this gap.

7.1 Caregiving Processes & Technology Acceptance

7.1.1 Designing for Usefulness

When combining the findings from our qualitative analyses about health information management and communication with caregivers' initial beliefs about design functionalities that VAs could provide in the home, we can identify the mappings between the technology and the work domain. Several connections can be made between the work domain and caregivers' perspectives regarding the ease of use and usefulness of VAs, as shown in Figure 7.1. Caregivers perceive utility for VAs in the context of three key areas: (1) documentation, (2) care coordination, and (3) providing autonomy to the person receiving care. With the caregiving processes of updating the caregiver team, caregiver communication, and teaching caregivers, combined with an understanding of caregivers' interaction preferences, there is potential for designing VAs that improve caregivers' information interaction experiences and relieve some of the burdens and pressures of caregiving.

When considering the caregivers' range of perspectives in this research along with advancements in VA technology, design features could be intricately tailored towards the caregiver to directly meet their usability needs. Currently available VAs have voice printing technology, functionality which allows for the system to identify a specific user by their voice [185]. Rehman et al [208] have integrated voice printing in a VA for a healthcare context, where this functionality also plays an important role in supporting aspects of the Health Insurance Portability and Accountability Act. By capitalizing on this integrated functionality to understand which caregiver is involved in the interaction for providing authenticated, context-specific information, and combing it with location and motion-based sensors that are ubiquitous on mobile devices such as smartphones and smartwatches, this data can be used to recognize the user's environment and their caregiving situation. With this information, VAs could optimally display health information for specific users, whether through an audible and/or visual interface from a stationary device such as a smart speaker, or as a companion application on a smartphone or wearable device connected to specific user accounts.

For family caregivers, one important situation where VAs could provide support is in the context of reporting information to a clinician. VAs that are currently integrated onto smartphones or other mobile devices through downloaded applications with specific user logins could use location and accelerometer data (e.g. if they are sitting in a doctor's office) to automatically switch into an interaction mode that supports the family caregiver's cognitive processes. The interaction could support the user by presenting health information summaries, trends and other important documentation to a clinician during their conversation, without requiring the family caregiver to remember this information. VAs could listen for and recognize discussion topics, search a secure database of the patient's health information for relevant content, and prompt the family caregiver about timely discussion topics. Currently, Mavropoulos et al [209] are developing a system that integrates multiple sensor data to improve the human-machine interaction with VAs in the healthcare context of rehabilitation, where their work is currently in preliminary stages. Finally, as an ambient functionality, VAs could also record the details of the meeting and present a concise summary for future reference, using language that is tailored to their health literacy.

For hired caregivers, one important situation where VAs could provide support is at the beginning of their shift in their client's home, specifically to support shared situation awareness. The handoff of information during a shift changeover can be a challenging aspect of caregiving when multiple clients are involved [62]. VAs used on a hired caregiver's mobile device could capitalize on their location and previously inputted schedule data to provide context-specific information to them about the prior care activities that recently occurred in the home and the current status of the client, to ensure a complete understanding of the caregiving situation. VAs could also remind the caregiver about their upcoming schedule of tasks that need to be completed during their shift such as medications, therapy or other timely caregiving events, using language that is also tailored to their health literacy.

7.1.2 Designing for Ease of Use

It is additionally essential to take advantage of the naturalness of the interaction that VAs can provide to caregivers. While the usefulness of VAs is a critical concept that the TAM identifies in this research, the other significant connections between the TAM and the caregiving processes involve the perceived ease of use for VAs in the specific context of navigating information. The inherent method of using voice commands to interact with health information through VAs has potential to support each of the caregiving processes from this research.

In complex home care, the exchange of information is fundamental to the successful outcomes of learning, sharing knowledge, teaching, communicating, and the bureaucratic processes of caregiving [126, 127, 210]. Information is dynamically flowing among caregivers within these sub-domains of the work environment. However, the structure of information makes accessing it inefficient. One of the primary benefits that voice user interfaces provide compared to graphical or other physical user interfaces is the removal of visual hierarchies [11, 79]. Without the need to search through towers of binders, notebooks, and filing cabinets filled with health information, voice commands can provide users with a single action or simple set of steps to efficiently retrieve the information they desire.

Furthermore, advancements in machine learning algorithms for VA technology are beginning to enable multi-intent and multi-entity commands, where users can provide several pieces of information to the VA in a single command, reducing the number of interactions required for a user's goal(s) to be achieved [211, 212]. For example, a multi-entity command for inputting a medication could include both the name of the medication and the amount being dosed. A multi-intent command could be to enter that the medication was given to the patient, and to also record an observation note about how the patient was feeling. Although these functionalities are not implemented in consumer products, there is increasing potential for VAs to be designed to allow users to interact using a command that has more than one intent, to achieve their task goal(s) [211, 212]. Rehman et al [208] have shown potential for building a VA in the specific context of supporting patients with glaucoma and diabetes, that understands multiple intents from the users single command and provides an appropriate response. Their preliminary findings show that a VA that understands multiple intents and scores well on a user experience questionnaire as a result of this functionality [208].

While multi-intent and multi-entity interactions are already common in communication between humans, providing a means for this type of natural interaction with a VA to access desired information may enhance both the utility and ease of use, and ultimately improve caregivers' interaction experience with this technology. The utility of the interaction would be contingent on the VA consistently mapping a user's intents and entities to a correct response that the user can understand. However, the potentially improved ease of interacting with VAs over other technologies and information retrieval methods could positively influence engagement with this type of digital health tool, supporting long-term use.

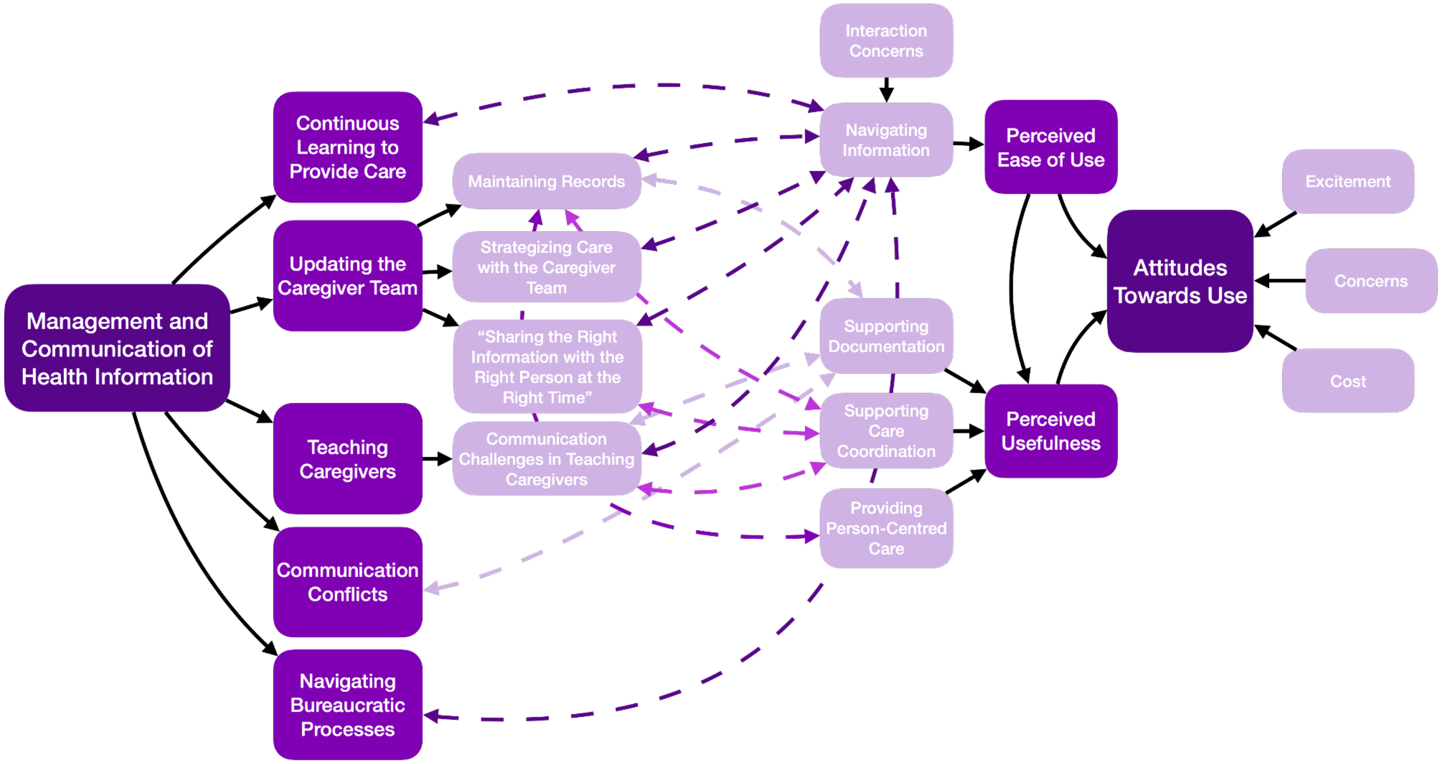

Figure 7.1: Connections between information management processes and expectations for VAs in complex home care

7.2 Technology Adoption in the Experience Age

This research highlights the potential usability considerations and impact that VAs can have on information interaction in complex home care by family caregivers of CSHCN, family caregivers of older adults, and hired caregivers. In alignment with Rogers' Diffusion of Innovation framework [51], there is generally a perceived relative advantage for VAs to support health information management and communication. However, the challenge of perceiving tangible, immediate outcomes may provide a barrier for early adoption. In this research, the difference in the perception of immediate value is especially evident for family caregivers who are coordinating several processes on their own, in addition to caregivers who have already integrated VAs into their homes for basic tasks, where they currently perceive significant utility for this technology. As suggested by Rogers [51], late adopters may need to observe the usability of VAs for their home care through others, or have the opportunity to trial the system in parallel to their current processes to identify if the experience provides added value.

For early adopters of VA technology for complex home care, it will require time and effort to build a knowledge base on a VA regarding a patient's health and the coordination of their care, potentially prolonging the time before caregivers experience significant advantages of the system. However, once compiled, the perceived advantages of interacting with a VA would become more apparent. Early adopters may perceive utility for VAs sooner if the technology integrated with standard, comprehensive knowledge bases for complex home care tasks, that can be built on and modified by the caregiver to meet their specific needs.

One additional barrier from Rogers' Diffusion of Innovation framework is compatibility and complexity. There are hesitations about transitioning to a new form of technology and the associated learning curve for caregivers who have significant experience managing information for their home care. The mentality, “if it ain’t broke, don’t fix it,” is synonymous with the finding that caregivers who have established methods that work for their homes observe the integration of new technology as an additional burden, regardless of the potential benefit that it may provide. In this case, engagement and interest through the perceived enjoyment of the interaction may be the influencing factor supporting adoption, as previously suggested as the primary factor for VA adoption today [197]. While the perceived integration effort may be a significant influence, the satisfaction associated with using a VA may overcome this barrier to adoption by providing a short moment of enjoyment for interacting with health information in an otherwise stressful environment.

7.3 Strengths & Limitations

The virtual research environment employed by this study supported a broad online outreach to capture diverse caregiving experiences. However, one limitation is that the demographics were limited, and data were gathered in online settings, which may be slightly different from data gathered in person. While this allowed for participants from a wider range of locations, the small sample size may limit generalizations of this research. While caregivers are more likely to be female [27], there were only two male participants in this research, and there was a lack of representation for family caregivers and hired caregivers of older adults from the USA. Only two participants from the USA who cared for CSHCN participated in this research.

Another consequence of the COVID-19 pandemic was its impact on the chosen methodological approach. With the current research restrictions, the researchers could not be immersed in each participant’s home care environment and directly observe their caregiving situations. An ethnographic approach may have provided greater insight into integrating digital health tools in complex home care. For the methodological approach in this research, participants needed to recall their experiences, which might be influenced by memory bias. However, the resulting saturation of the thematic analysis across participants supports the validity of the findings.

7.4 Conclusions

With its variable environment, tasks, and technologies, home care is a complex work domain for caregivers - both hired and familial. Increasing demands for care services in the home identify the critical importance of evaluating the human factors that influence caregivers' capabilities to inform the design of technologies that can support patient safety and improve the caregiving experience. The research conducted for this thesis provides a foundation for understanding the complex processes involved with health information management and communication to support the future development of practical digital health tools that can provide a more natural and intuitive interaction with information. Although this research identifies critical design considerations and concerns that may impact the adoption of digital health tools in complex home care, there is potential for innovative technologies to provide significant support for caregivers if these elements can be successfully addressed. Implications of this research will support developers of digital health tools to grasp the nuances of the human experiences they are building for and create innovations to enhance that experience and improve our healthcare system.

7.5 Recommendations & Next Steps

With the rise in complex home care and the increasing responsibilities for caregivers to provide care services in patients' homes, there is an emerging need to integrate digital health tools to support information management and communication. Future research should continue to understand this complex domain to inform the design of methodologies, processes, policies, and technologies that improve patient safety and the caregiving experience. With the exploratory nature of this work on individual caregiver experiences, there is potential for future research to provide meaningful contribution by understanding complex home care through interviews with caregiver teams. Analyzing caregiver teams would better understand collaboration and team situation awareness to identify the human factors opportunities for reducing the risk of adverse events.

With respect to VAs, this research identifies the need to measure human-information interaction with digital health technology in complex home care, objectively. Future work should identify the relationships between caregiver perspectives and expectations for VAs with the actual functionality provided by this digital health tool. Studies that involve specific caregiving contexts related to documentation and navigating health information and explore caregivers' acceptability of VAs that provide intelligent support should be carried out. Future research in this domain should also explore the use of voice and audio interaction with health information in the field and how the usability compares to current technologies that provide a visual interaction, in specific information contexts. With the current use of visual tools and the potential elements of risk that are associated with not displaying affording visual functionality for health information or reminders, there may be a need to provide both methods of interaction in real world use contexts with VAs.

For the adoption of digital technology in complex home care, an interesting avenue for a future research study would be to directly connect the baseline of caregivers' current experiences with digital technologies and how this impacts actual adoption and integration into their caregiving workflow. While caregivers in this study had experience with digital technology such as phones, computers, and VAs, none of them had directly integrated specially designed software tools that integrated health data tracking and communication across all caregivers. A future study could involve establishing the degree to which caregivers have experience with digital health tools that enable health data tracking and communication, as well as their comfort levels with integrating these tools into their current routines, and then examine how this has influenced their adoption of current and future tools.

It is also critical to examine the design of digital health technologies in complex home care from an equitable and ethical perspective. With the varied social and economic statuses of caregivers, the factors impacting inclusivity and accessibility should be identified for the application of digital home care tools when expanding the demographics of participants in future research. Specifically for VAs, the language for interacting with health information should also be considered across a range of health literacy skills to identify how caregivers expect their voice commands to be understood and how VAs should appropriately respond in various contexts. Finally, ethical considerations should examine the factors involved with risk management when using an audio display compared to traditional visual displays, and the rights of caregivers and patients to their health information with respect to how information is stored and shared.

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APPENDICES

Appendix A

Study Materials

A.1 Information Letter

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Title of the study: Towards Designing a Virtual Assistant for Home Care

Principal Investigators:

Catherine Burns, Ph.D., P.Eng.
University of Waterloo
Department of Systems Design Engineering
Faculty of Engineering
Email: catherine.burns@uwaterloo.ca

Kate Mercer, Ph.D.
University of Waterloo
Department of Systems Design Engineering
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Email: kate.mercer@uwaterloo.ca

Student Investigator:

Ryan Tennant, MASc Candidate
University of Waterloo, Department of Systems Design Engineering
Faculty of Engineering
Email: ryan.tennant@uwaterloo.ca

To help you make an informed decision regarding your participation, this letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter, please ask one of the investigators prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

Study Summary

You are invited to participate in a research study about the use of a Virtual Assistant like Alexa, Google Assistant, or Siri, by caregivers. With the rise in home healthcare, there is a strong need to support caregivers in the home care environment. The purpose of this research study is to identify the design requirements and considerations for building a Virtual Assistant that will assist family caregivers and hired caregivers while they care for someone in their home.

First, we are interested to understand the work that family caregivers and hired caregivers do in someone's home. In Part 1 and Part 2 of our questionnaire, we ask participants demographic details about their home care experience and work environment. This includes the specific situation in which they were providing care, their tasks, their tools, and how they communicated information in a person's home.

Second, we are interested to understand what caregivers think about using a Virtual Assistant to support their work. In Part 3 of our questionnaire, we ask participants about their current use of Virtual Assistants in their home. In Part 4, we ask what they think a Virtual Assistant should be able to support them with. In Part 5, participants will listen to four audio recordings of someone speaking with a Virtual Assistant about home care tasks. Participants will complete a questionnaire about each recording. Finally, in Part 6, we ask participants about using Virtual Assistant technology in their future home care work.

This research is part of my (Ryan Tennant) master's level thesis project. Participants will receive an appreciation letter for their participation.

I. Your responsibilities as a participant

Participation:

Participation in this research will consist of completing online questionnaires and a virtual interview through Microsoft Teams. You will be provided with a link in order to access the call either by phone or through a webpage. During the study you will be asked to answer questions related to your experience as a caregiver and your perspectives on Virtual Assistants in home care. This research study also consists of listening to audio files of someone speaking with a Virtual Assistant, in which you will be asked about your opinion related to what you heard.

There are six parts to this study that you will complete in one session. This research study should take you approximately 60 minutes to complete. In Part 1, Part 2, and Part 3, we will ask you about your experience as a caregiver for someone who requires complex care, and in Part 4 of this study, we will ask you about your opinions regarding a Virtual Assistant in home care which will include an online questionnaire that you will complete through Microsoft Teams. The researcher will read or display the questions using screen sharing and ask you to select from the available responses. In Part 5, we will ask you to listen to four audio recordings and answer questions related to what you heard. Finally, in Part 6, we will ask you additional questions about using a Virtual Assistant in home care, which will include a second online questionnaire that you will complete through Microsoft Teams. As in Part 4, the researcher will read or display the questions to you and ask you to select from the available responses. With your permission, we will audio record your responses and later transcribe the conversation using Microsoft Teams closed-caption feature.

Eligibility:

In order to participate in this study, you must be at least 18 years of age, be able to speak and understand written and spoken English and have experience as a family caregiver* or a hired caregiver (e.g. home care nurse, personal support worker, other) for a person who requires complex** care services in their home, in North America.

*A family caregiver can be identified as a person who:

- Provides or coordinates care for a family member, a child, a partner, or a friend;

AND

- Assists this person with medication, food, medical treatments, medical technology/tool use and/or other health related tasks in the home

**Complex care refers to persons who have a combination of chronic conditions, mental health issues, medication-related problems, and social vulnerability.

If you are not eligible to participate in this study, your responses will be removed from all datasets and destroyed according to University of Waterloo policy.

II. Your rights as a participant

Voluntary Participation:

Your participation in this study is voluntary. You may decide to leave the study at any time by letting the researchers know. You may decline to answer any survey question or interview question (e.g. by requesting to skip the question) that you prefer not to answer. With your permission, the interview will be recorded to facilitate collection of information.

Remuneration:

If you choose to participate in this study, you will not receive payment for your participation in the study. In appreciation of your time, you will receive a Thank You letter from the research team.

Benefits of the Study:

Participation in this study may not provide any personal benefit to you. The study will, however, benefit the academic community by contributing to our understanding of:

- The work of family caregivers and hired caregivers in the context of home care.
- The design requirements and considerations that need to be made when designing a Virtual Assistant to support these caregivers in the context of home care.

If you choose to, you can provide the researchers with your email address and we can notify you with the results of this research study when they are available at the end of December 2020.

Associated Risks:

There are no known anticipated risks associated with participation in this study. You may choose to withdraw from the study at any time by letting the researcher know that you would like to stop the study.

Confidentiality:

If you choose to participate in this study, any directly identifying information that includes your name and contact details that you share will be kept confidential and will not be associated with the data. We will keep your identity confidential by assigning an ID code (e.g. P-001) to each dataset. The dataset, without direct identifiers, may be shared publicly but your identity will be confidential. Anonymous quotations may also be used with your permission.

The dataset will include variables that might act as indirect identifiers. This includes your age, gender, and the background details about your specific caregiving situation.

Only the research team will have access to the study data. The dataset will be securely stored on a password protected computer at the University of Waterloo. The dataset will also be electronically archived after completion of the study and maintained for a minimum of 7 years.

You can withdraw consent to participate and have your data destroyed by contacting any of the researchers before December 1st, 2020. Consent cannot be withdrawn after this date because papers and publications will be submitted for publication. All data will be destroyed according to University of Waterloo policy.

Since this interview is being conducted virtually, we encourage you to locate yourself in an environment where you feel comfortable sharing your experiences as a caregiver, as well as listening to audio.

III. Questions, comments, or concerns

Ethics Clearance:

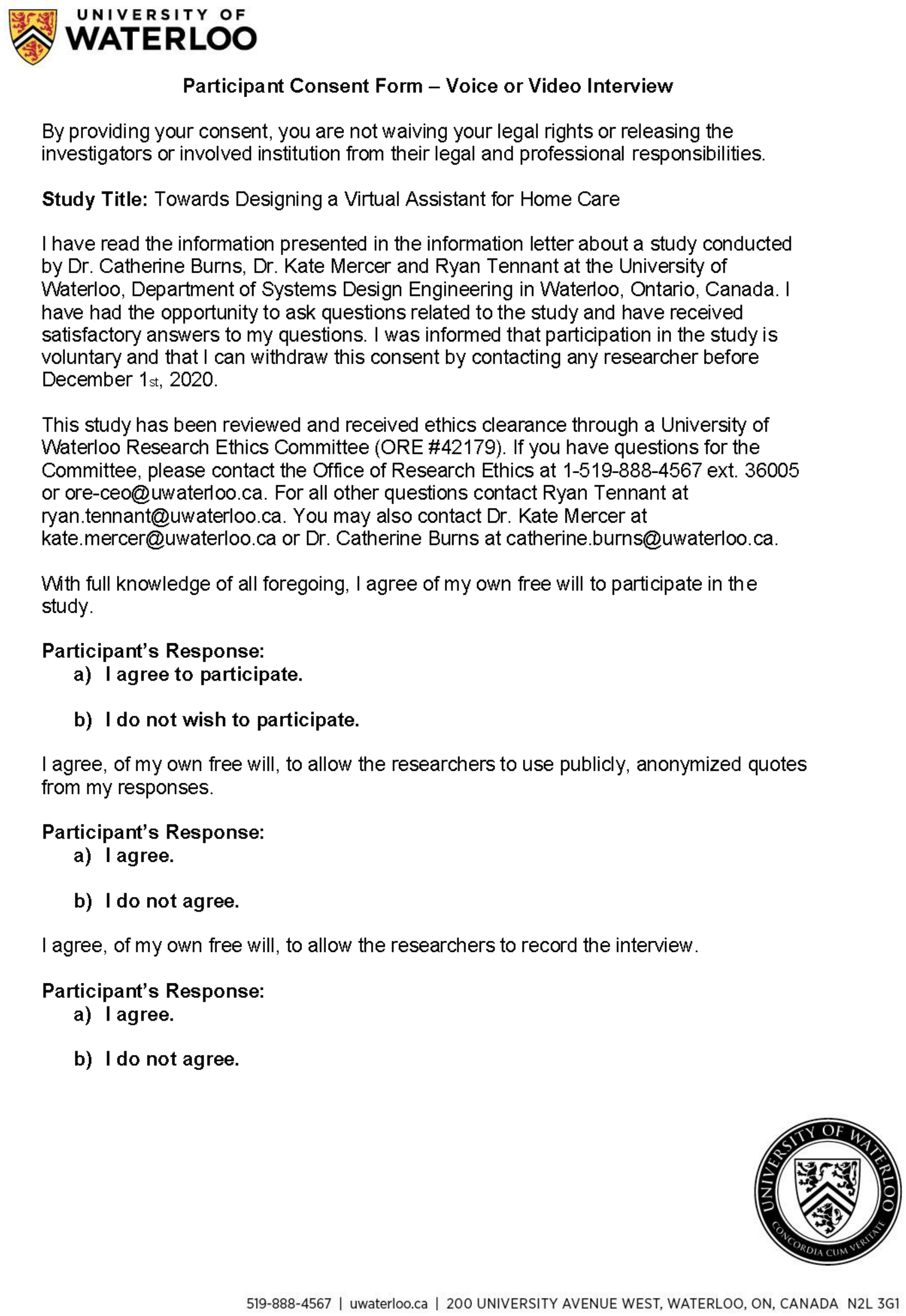
This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42179). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Contact Information:

If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please contact Ryan Tennant at ryan.tennant@uwaterloo.ca, Kate Mercer at kate.mercer@uwaterloo.ca or 1-519-888-4567 ext. 42659, or Catherine Burns at catherine.burns@uwaterloo.ca.

Thank you for your consideration to participate in this research study.

A.2 Consent Letter



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Participant Consent Form – Voice or Video Interview

By providing your consent, you are not waiving your legal rights or releasing the investigators or involved institution from their legal and professional responsibilities.

Study Title: Towards Designing a Virtual Assistant for Home Care

I have read the information presented in the information letter about a study conducted by Dr. Catherine Burns, Dr. Kate Mercer and Ryan Tennant at the University of Waterloo, Department of Systems Design Engineering in Waterloo, Ontario, Canada. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions. I was informed that participation in the study is voluntary and that I can withdraw this consent by contacting any researcher before December 1st, 2020.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42179). If you have questions for the Committee, please contact the Office of Research Ethics at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For all other questions contact Ryan Tennant at ryan.tennant@uwaterloo.ca. You may also contact Dr. Kate Mercer at kate.mercer@uwaterloo.ca or Dr. Catherine Burns at catherine.burns@uwaterloo.ca.

With full knowledge of all foregoing, I agree of my own free will to participate in the study.

Participant's Response:

a) **I agree to participate.**

b) **I do not wish to participate.**

I agree, of my own free will, to allow the researchers to use publicly, anonymized quotes from my responses.

Participant's Response:

a) **I agree.**

b) **I do not agree.**

I agree, of my own free will, to allow the researchers to record the interview.

Participant's Response:

a) **I agree.**

b) **I do not agree.**

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A.3 Recruitment Materials

Email Recruitment for Email Lists

Hello [Name of Organization],

My name is Ryan Tennant and I am a master's student working under the supervision of Dr. Catherine Burns and Dr. Kate Mercer in the Advanced Interface Design Lab in the Department of Systems Design Engineering at the University of Waterloo in Waterloo, Ontario, Canada. I am conducting an online research study about the use of a virtual assistant (e.g. Alexa, Siri, Google Assistant) for complex home care by family caregivers and hired caregivers (e.g. home care nurses, personal support workers, other). I was wondering if you would be willing to share this study with the employees at [Name of Organization], as well as this PDF recruitment poster. I have outlined the message that I am asking to be shared below. If you have any questions, please contact me at **ryan.tennant@uwaterloo.ca** or my supervisors Dr. Catherine Burns – catherine.burns@uwaterloo.ca or Dr. Kate Mercer – kate.mercer@uwaterloo.ca.

Message to share with email list:

"This message is being sent on behalf of Ryan Tennant from the University of Waterloo in the Department of Systems Designing Engineering:

Hello,

My name is Ryan Tennant and I am a student researcher at the University of Waterloo in the Department of Systems Design Engineering in Waterloo, Ontario, Canada. I am conducting an online research study about the design of a virtual assistant (e.g. Alexa, Siri, Google Assistant) for complex home care by family caregivers and hired caregivers (e.g. home care nurses, personal support workers, other). I am recruiting participants who have experience being a family caregiver in North America and I was wondering if you or someone you know would be willing to participate. The study involves completing online surveys and a virtual one-on-one interview with a researcher, which will take approximately 60 minutes to complete. During the study you will be asked questions related to your experiences as a family caregiver or hired caregiver and your perspectives on Virtual Assistants in home care. Additional details about the study can be found in the attached PDF document.

The final decision about participation is yours.

If you are interested in participating in this study or have any questions or concerns, please contact me by emailing ryan.tennant@uwaterloo.ca. I can send you the Information Letter for this study which includes all of the details about the study and eligibility. We can have a call where I will go over these details with you and answer any questions you may have concerning the study. You can also contact my supervisors Dr. Catherine Burns (catherine.burns@uwaterloo.ca) or Dr. Kate Mercer (kate.mercer@uwaterloo.ca) if you have any questions.

Sincerely,

Ryan

Ryan Tennant, BASc
MASc Candidate
Department of Systems Design Engineering, Faculty of Engineering
University of Waterloo
200 University Avenue West, Waterloo, ON, N2L 3G1"

If you have any questions or concerns for me about sharing this study with your email list, please contact me. You can also contact my supervisors with any questions or concerns.

Thank you,

Ryan

Ryan Tennant, BASc
MASc Candidate
Department of Systems Design Engineering, Faculty of Engineering
University of Waterloo
200 University Avenue West, Waterloo, ON, N2L 3G1

Website Recruitment – Graduate Studies and Postdoctoral Affairs

Title of Study:
Towards Designing a Virtual Assistant for Home Care

Name of Graduate Student:
Ryan Tennant (Master's Candidate), Department of Systems Design Engineering

Description of Study:
We are looking for volunteers to take part in an online study about their experiences as a caregiver and their opinion on using a virtual assistant (e.g. Alexa, Google Assistant, Siri) in a complex home care situation. As a participant in this study, you would be asked to virtually meet with a researcher by voice or video call to be interviewed. You will be asked about your care situation, your work, your experience with virtual assistants, and your opinions on using a virtual assistant in a home care environment. You will also complete questionnaires and listen to audio recordings of someone speaking with a virtual assistant.

Participant Requirements:
In order to participate in this study, you must be at least 18 years of age, be able to speak and understand written and spoken English and have experience as a family caregiver* or a hired caregiver (e.g. home care nurse, personal support worker, other) for a person who requires complex** in-home care services in North America.

*A family caregiver can be identified as a person who:

- Provides or coordinates care for a person who is a family member, a child, a partner, or a friend;

AND

- Assists the person with medication, food, medical treatments, medical technology/tool use and/or other health related tasks in the home

**Complex care refers to persons who have a combination of chronic conditions, mental health issues, medication-related problems and/or social vulnerability

Length of time of Study:
60 Minutes

Other Information:

In appreciation of your time, you will receive a Thank You letter from the researchers and access to the study results when they are available.

Supervisor/Co-supervisor information:
Supervisor: Dr. Catherine Burns
Co-supervisor: Dr. Kate Mercer

For questions about the survey please contact:
ryan.tennant@uwaterloo.ca

This study has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42179).

Department of Systems Design Engineering

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PARTICIPANTS NEEDED FOR RESEARCH ABOUT VIRTUAL ASSISTANTS IN COMPLEX HOME CARE

We are looking for volunteers to take part in an online study about their experiences as a caregiver (e.g. family caregiver, home care nurse, personal support worker, other) in North America, and their opinion on using a virtual assistant (e.g. Alexa, Google Assistant, Siri) in a complex* home care situation, in order to build an intelligent virtual assistant for home care.

As a participant in this study, you would be asked to virtually meet with a researcher to be interviewed. You would be asked about your care situation, your work, your experience with virtual assistants, and your opinions on using a virtual assistant in a home care environment. You would also complete questionnaires and listen to audio recordings of someone speaking with a virtual assistant.

Your participation would involve **1 session**
which will take approximately **60 minutes**.

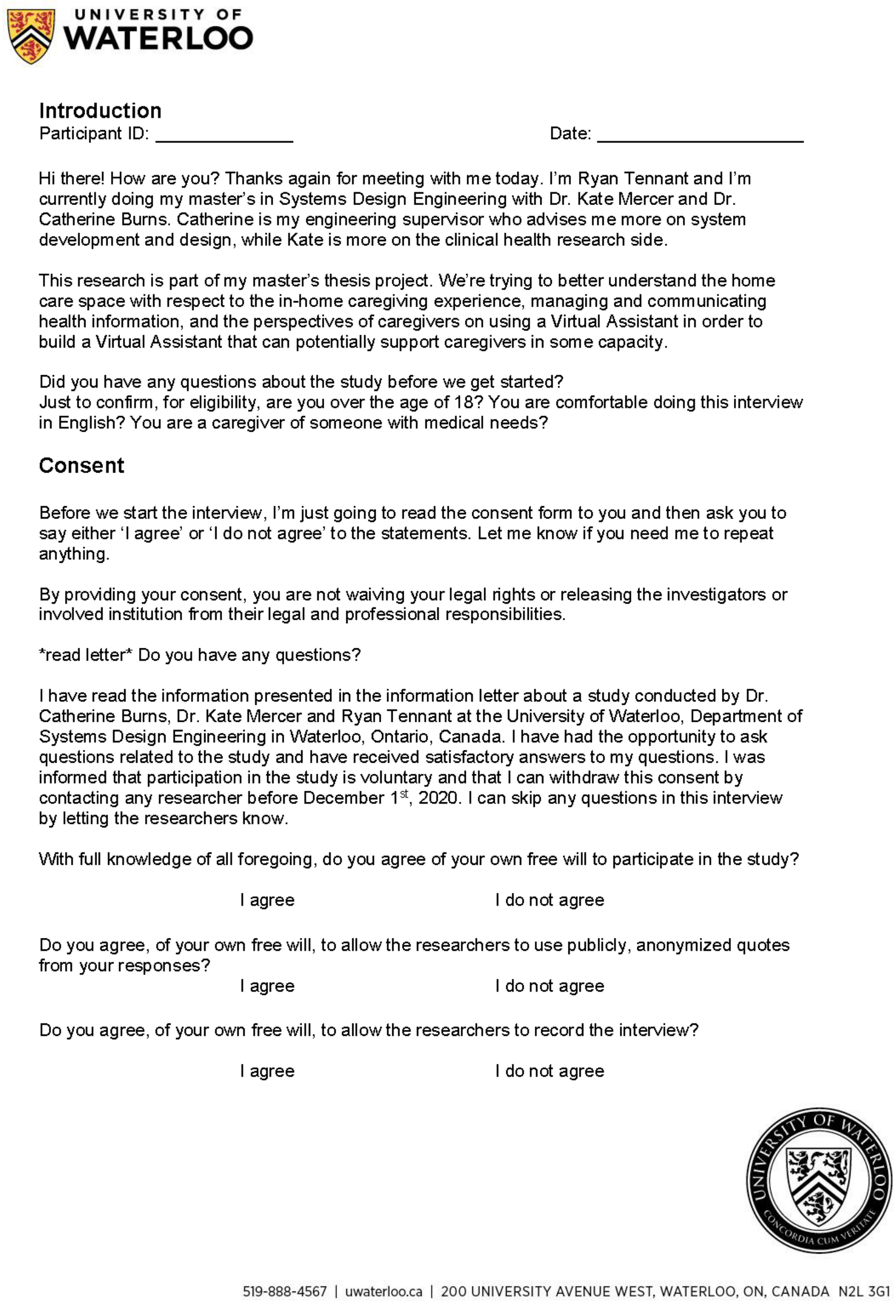
For more information about this study, or to volunteer for this study, please contact:

Ryan Tennant
Department of Systems Design Engineering
at
ryan.tennant@uwaterloo.ca

*In this study we define complex care as persons who have a combination of chronic conditions, mental health issues, medication-related problems, and social vulnerability

This study has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42179).

A.4 Interview Script



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Introduction

Participant ID: ______________ Date: ____________________

Hi there! How are you? Thanks again for meeting with me today. I'm Ryan Tennant and I'm currently doing my master's in Systems Design Engineering with Dr. Kate Mercer and Dr. Catherine Burns. Catherine is my engineering supervisor who advises me more on system development and design, while Kate is more on the clinical health research side.

This research is part of my master's thesis project. We're trying to better understand the home care space with respect to the in-home caregiving experience, managing and communicating health information, and the perspectives of caregivers on using a Virtual Assistant in order to build a Virtual Assistant that can potentially support caregivers in some capacity.

Did you have any questions about the study before we get started?
Just to confirm, for eligibility, are you over the age of 18? You are comfortable doing this interview in English? You are a caregiver of someone with medical needs?

Consent

Before we start the interview, I'm just going to read the consent form to you and then ask you to say either 'I agree' or 'I do not agree' to the statements. Let me know if you need me to repeat anything.

By providing your consent, you are not waiving your legal rights or releasing the investigators or involved institution from their legal and professional responsibilities.

read letter Do you have any questions?

I have read the information presented in the information letter about a study conducted by Dr. Catherine Burns, Dr. Kate Mercer and Ryan Tennant at the University of Waterloo, Department of Systems Design Engineering in Waterloo, Ontario, Canada. I have had the opportunity to ask questions related to the study and have received satisfactory answers to my questions. I was informed that participation in the study is voluntary and that I can withdraw this consent by contacting any researcher before December 1st, 2020. I can skip any questions in this interview by letting the researchers know.

With full knowledge of all foregoing, do you agree of your own free will to participate in the study?

I agree I do not agree

Do you agree, of your own free will, to allow the researchers to use publicly, anonymized quotes from your responses?

I agree I do not agree

Do you agree, of your own free will, to allow the researchers to record the interview?

I agree I do not agree

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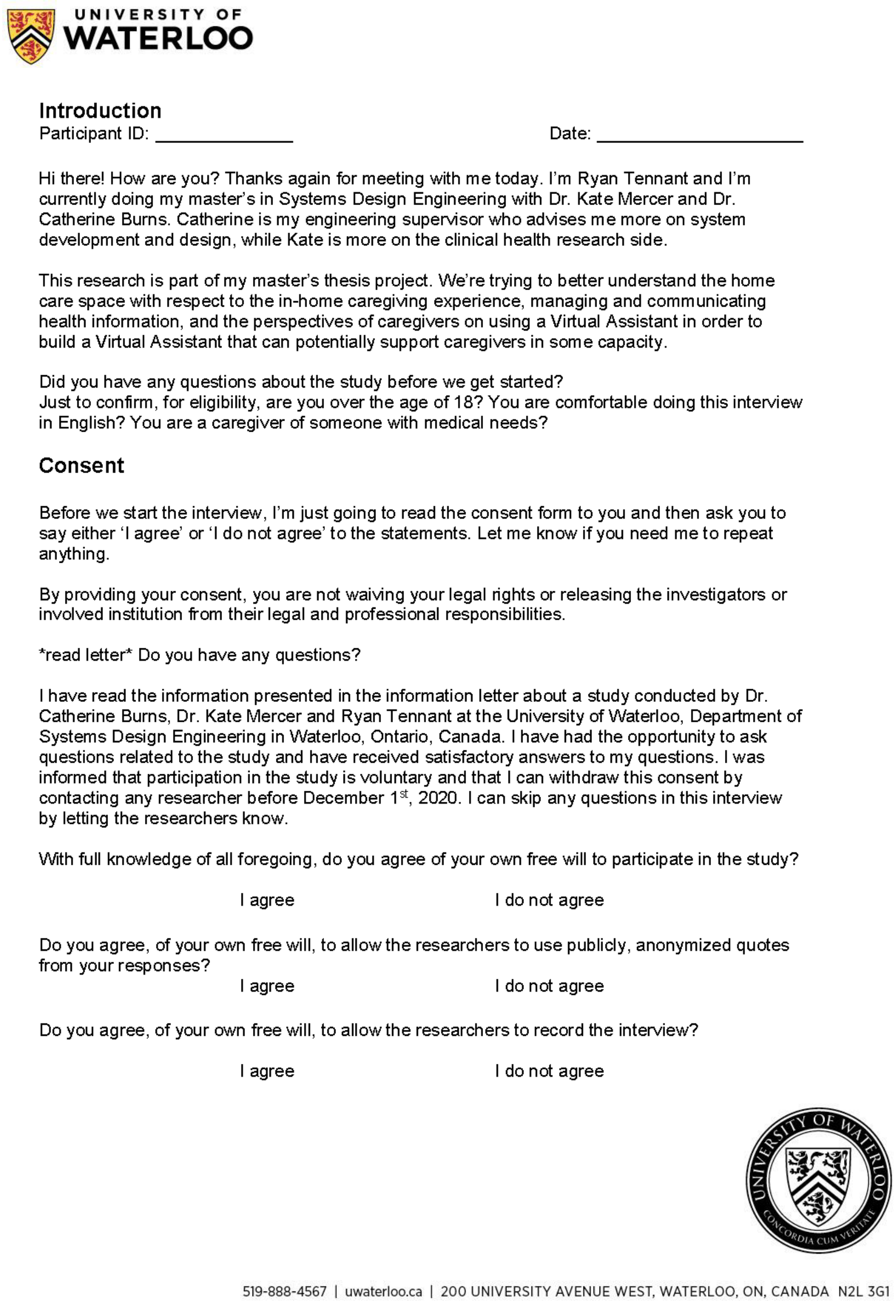

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Do you have any questions before we get started?

Part 1 – Demographics

I'm going to start the interview now, and I would just like to let you know this is when I'm going to begin recording. Please let me know at any point if you would like a break from the interview, or from recording.

I have a couple demographic questions that I'd like to ask you. Again, none of these are mandatory and you can choose to skip any of the questions.

Would you mind telling me your age and which gender you identify with?

Age: ______________________________

Gender: ___________________________

Where are you located? ______________________________

In your original email you mentioned that you are currently caring for your [person type]. How long would you say you have been providing medical care for him, in his home?

1. I'd first like to talk a bit today about the in-home care you have set up for your [person type]. Can you tell me about how you've navigated caring for them in your home, and what you've needed to learn to do to provide care?

   <u>Prompts</u>:

   a. Would you mind speaking more on learning about your [person type]'s condition and the treatments or therapies that they need?

   b. What different types of technology supports do they need at home?

   c. Who else is on your [person type]'s care team? What is their role?

   d. Do they take any medications for [condition(s)]? How many medications do they take and how do they take them?

Part 2 – Caregiving Experience

2. Now I'd like to talk more about your experience caring for your [person type]. What are some of the major factors or tensions that influences the quality of care that your [person type] receives in your home? You can comment on both before and after COVID-19 if you've noticed a change.

<u>Prompts</u>:

a. Could you talk a little bit about your feelings of control?

b. What information do you need to care for your [person type]? What information do you need from others in your [person type]'s caregiver team? What information do you need from other sources?

c. How did the setup of your house change to care for your [person type]?

d. Do you often document details about your [person type]'s care in your home? How do you do this? Who can see the information that you record?

e. What impacts your ability to document information in your home?

f. Have you received formal training to care for your [person type]? Have you been trained to use the medical technology? What did the training consist of?

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3. You mentioned that there are other caregivers on your child's care team. Are there times when these caregivers take over primary care responsibilities for your [person type]? Can you talk a bit about what typically happens when another caregiver takes over primary care responsibilities for your [person type]?

   <u>Prompts</u>:

   a. What information do you usually provide to this caregiver?

   b. How do you communicate this information?

   c. What would help you communicate information more effectively?

   d. What tasks does this caregiver do for your [person type]?

   e. Do other caregivers in your [person type]'s healthcare team record information in your home? What do they record?

   f. Where do they record this information? Who can see this information?

4. We're going to pivot a bit now to talk about Virtual Assistants, but before we do is there something else you wanted to mention about experience with your [person type]?

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Part 3 – Virtual Assistant Experience

5. Okay on to Virtual Assistants. Can you tell me what comes to your mind when you hear the words Virtual Assistant? [*ans. dialogue systems built into computers, e.g. Alexa, Siri, Google Assistant*]

    <u>Prompts</u>:

    a. Could you tell me a bit more about how you interact with Virtual Assistants in your home?

    b. Which assistant do you typically use? Why? What device(s) do you use it on?

    c. What makes you use a Virtual Assistant for these tasks?

    d. What would you least likely use a Virtual Assistant to do?

    e. Have you ever considered using a Virtual Assistant in the context of caring for your [person type]?

    f. Can you think of any tasks that a Virtual Assistant might be able to help you with when caring for your [person type]?

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Part 4 – Virtual Assistant Expectations in Home Care

6. Okay, now I'd like to talk about your expectations for potentially using a Virtual Assistant in home care. Let's pretend that you have an Alexa device that you can use for assisting you with home care. I'm going to read a few statements I'd like you to respond with a number from 1 to 7, where:

   1 – Strongly Disagree
   2 – Disagree
   3 – Somewhat Disagree
   4 – Neither Agree nor Disagree
   5 – Somewhat Agree
   6 – Agree
   7 – Strongly Agree

   Or, you can say skip to skip the question. Here's the first one:

   a. A Virtual Assistant should not have a personality.

      1 2 3 4 5 6 7

   b. A Virtual Assistant should not be able to remember details about my [person type]'s medical condition.

      1 2 3 4 5 6 7

   c. A Virtual Assistant should be able to record my [person type]'s health information for me when I ask it to.

      1 2 3 4 5 6 7

   d. A Virtual Assistant should be able to retrieve previously recorded health information for me.

      1 2 3 4 5 6 7

   e. A Virtual Assistant not be able to teach me how to effectively work with different medical technology in my home.

      1 2 3 4 5 6 7

   f. A Virtual Assistant should remind me about time sensitive tasks such as medications, treatments or therapies.

      1 2 3 4 5 6 7

   g. A Virtual Assistant should not be able to guide me through the steps required to perform tasks.

      1 2 3 4 5 6 7

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h. A Virtual Assistant should not be able to assist me in an emergency situation.

1 2 3 4 5 6 7

i. I would want to interact with A Virtual Assistant using full, completed sentences.

1 2 3 4 5 6 7

j. I would want to interact with A Virtual Assistant using specific words or queries.

1 2 3 4 5 6 7

k. A Virtual Assistant should not be able to listen for specific events that are occurring in the home, to support caregivers perform tasks specific to my [person type].

1 2 3 4 5 6 7

l. A Virtual Assistant should be able to listen for specific events that are occurring in my home, to remind caregivers to record the details of their tasks.

1 2 3 4 5 6 7

7. Before we go to the next part, is there something that you would like to comment on about your answers to these questions?

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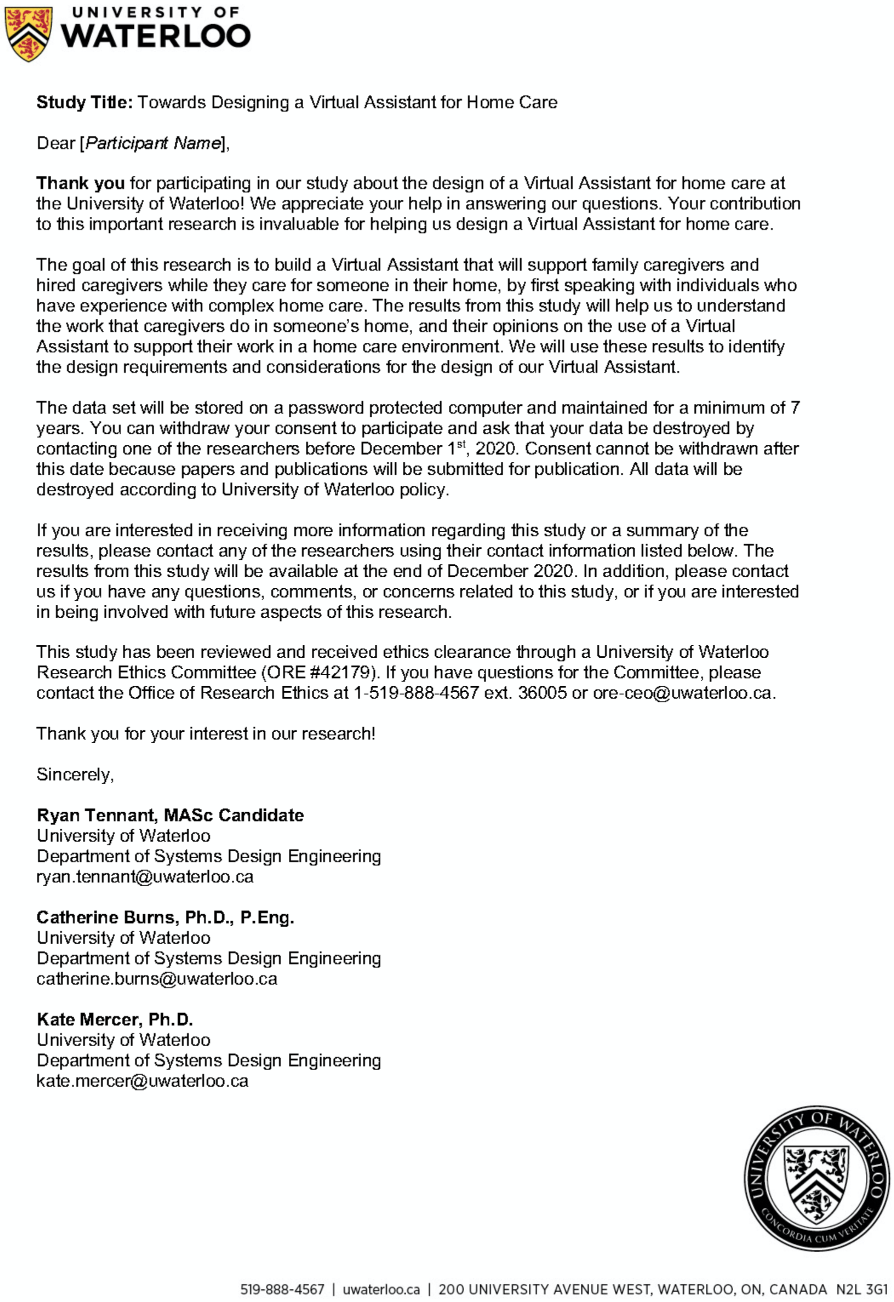
A.5 Appreciation Letter



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Study Title: Towards Designing a Virtual Assistant for Home Care

Dear [*Participant Name*],

Thank you for participating in our study about the design of a Virtual Assistant for home care at the University of Waterloo! We appreciate your help in answering our questions. Your contribution to this important research is invaluable for helping us design a Virtual Assistant for home care.

The goal of this research is to build a Virtual Assistant that will support family caregivers and hired caregivers while they care for someone in their home, by first speaking with individuals who have experience with complex home care. The results from this study will help us to understand the work that caregivers do in someone's home, and their opinions on the use of a Virtual Assistant to support their work in a home care environment. We will use these results to identify the design requirements and considerations for the design of our Virtual Assistant.

The data set will be stored on a password protected computer and maintained for a minimum of 7 years. You can withdraw your consent to participate and ask that your data be destroyed by contacting one of the researchers before December 1st, 2020. Consent cannot be withdrawn after this date because papers and publications will be submitted for publication. All data will be destroyed according to University of Waterloo policy.

If you are interested in receiving more information regarding this study or a summary of the results, please contact any of the researchers using their contact information listed below. The results from this study will be available at the end of December 2020. In addition, please contact us if you have any questions, comments, or concerns related to this study, or if you are interested in being involved with future aspects of this research.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42179). If you have questions for the Committee, please contact the Office of Research Ethics at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

Thank you for your interest in our research!

Sincerely,

Ryan Tennant, MASc Candidate
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