Exploring context of digital health intervention engagement of caregivers of people living with Alzheimer's and Related Dementia: Content analysis vs Topic modeling

By

Shanmugapriya (Priya) Loganathar

A dissertation proposal submitted in partial fulfillment of
requirements for the degree of

Doctor of Philosophy
(Industrial and Systems Engineering)

at the

UNIVERSITY OF WISCONSIN–MADISON
2024

Date of final oral examination: May 30th, 2024

The dissertation is approved by the following members of the Final Oral Committee:

John D. Lee, Professor, Industrial and Systems Engineering

Nicole E. Werner, Associate Professor, Wellness and Design

Anthony McDonald, Assistant Professor, Industrial and Systems Engineering

Beth Fields, Assistant Professor, Kinesiology

Dedication

To my அம்மா (mother),

This is dedicated to you, the woman who wears a gazillion hats. You run the world and our family, all while dedicating your life to taking care of us. Thank you for your endless love, strength, and sacrifices.

Acknowledgement

When I came to this country 10 years ago for my higher education, little did I know what life had in stock for me. I never imagined becoming an engineer, facing the hard realities of living in a different country, living through a pandemic, or doing a PhD. I have had profound opportunities to grow personally and academically, and to reassess and rebuild my culture and values. Many people were the rock I needed them to be through this difficult journey filled with many uncertainties. Without you all, I would not be completing this degree. I want to thank everyone in my life that continues to nurture me with love, support, and inspiration.

First, I have immense gratitude for my advisors, Dr. Nicole Werner, and Dr. John Lee. Their guidance not only cultivated a deep love for Human Factors Engineering in me, but also empowered me to navigate the challenges of my PhD journey. Nicole, if it weren't for you taking a chance on a HF newbie like me, I wouldn't be here today. Your unwavering patience, especially during the pandemic and the countless times I hit a wall, helped me navigate tough times and I owe it to you for learning the importance of setting realistic goals. John, your infectious enthusiasm for tackling new problems is truly inspiring. You were always generous with your time, and I appreciate you for not letting me give up. Thank you both for your unwavering support, for pushing me to be my best in your own ways, and for allowing me to find my own path within the field.

Thank you to my committee, Dr. Anthony McDonald, and Dr. Beth Fields, for your expert guidance. I appreciate your time in providing me valuable feedback and challenging questions that were instrumental in shaping my dissertation. Thank you to Christian Elliott, Matthew Zuraw, and CareVirtue for your support and partnership in my dissertation. Your support in facilitating access to the CareVirtue data and your invaluable insights were crucial to this dissertation. I would like to thank all the caregivers that participated in this study for your time and for trusting me in sharing the realities of your lived experiences. Your stories will undoubtedly have a significant impact on the fields of HFE and caregiving. I am honored to be an observer of your caregiving journey for a sliver of time.

I would also like to thank Dr. Justin Boutillier and Dr. Edmond Ramly for inspiring me and their role in shaping this dissertation. Your classes and the deeply enriching conversations played a role in shaping my work. Thank you to Dr. Karen Chen for introducing me to the wonderful world of Human Factors during my undergrad years and for showing me what research is like. Karen, it is safe to say I would not be here without you. Thank you to my mentors at the Department of Radiology, Dr. Scott Reeder and Dr. Matt Lee. I'm eternally grateful to you both for supporting me through a significant part of my dissertation. Thank you for introducing me to the practical aspects of where Human Factors can be applied and your patience with me as I was figuring it out alongside. I would also like to thank Dr. Sonya Makhni and Zachary WareJoncas for a wonderful summer at the Mayo Clinic Platform. Thank you for taking me on and showing me the realities of what it is like to do impactful work in industry settings.

My dissertation would be incomplete without thanking all the wonderful members of the two labs I've had the honor to be a part of. Thank you for creating a strong community to lean on through trying times, be it the pandemic, PhD, or just life. Rachel, Hanna, Hansol, Mengyao, Varshini, and Betsy — thank you for being my older research siblings. Your mentorship, advice, and countless laughs we have shared made this journey doable. Anna and Reid — thank you for all your support as we were cruising along our respective PhDs. To all the members that are embarking on their dissertation journeys— Vianney, Katharine, Morgan, Jah, and Sooyeon — I have enjoyed the chance to support each other during our time together. Finally, thank you to all the members of my research team I've had the privilege of mentoring and/or working with — Mehak, Zach, Jessica, Kiera, Anna J, Mengwei.

Madison wasn't just the place where I grew academically, it's also where I found love. Two doors down the hall, destiny brought Suyash into my life. We fell in love, got married, and became a part of each other's stories. Suyash, you are a part of all my successes and our PhD journey is our first professional milestone together. Thank you for being patient with me, for picking up all the things I dropped (literally and metaphorically), for embracing my quirks, and for humoring several conversations about the context of contexts. I'm excited to write our story together, and here's to many, many more milestones.

Thank you to my parents for supporting me in every way I needed them to. Appa, thank you for enabling me to pursue my passion in life and create my own path, even though I landed far away from yours. For the countless times I have joked about becoming the first "real" doctor in the family, I owe it to your passion and profession for making me as empathetic as I am today. Your passion for helping people inspired me to pursue a field that extends empathy to design of technologies. Amma, thank you for always just being a phone call away for the countless meltdowns I have had over the years and for being the iron lady you are for our entire family. My PhD is dedicated to you. This dissertation is a testament to your lived experience as a caregiver. I have immense respect, love, and gratitude for everything you do. Love you both a ton- I will only be doctor #3 in the family next to you both!

Lalithya aunty and Anu uncle — I can't thank you enough for being my family in Madison and now, wherever else life takes me. You've both, in your own ways, pampered me, yelled at me, and given me a kick whenever I needed it to finish this PhD. For that and for investing the time in our relationship, thank you and much love. Aunt Cheri and Uncle Senthil — thank you for helping me build a foundation and for nurturing my dreams during a crucial time in my life. You helped me find my footing in a new country and prepared me for the challenges that lay ahead. This PhD journey wouldn't have been possible without your unwavering support and love. Uncle Siva and Aunty Kala — thank you both for supporting me in your own ways in my pursuit of higher education in the US. Uncle Siva — I did become the first PhD family in our family, sorry not sorry :P But seriously, you are a huge inspiration to me and my generation in our family. Your dedication to excellence in everything you do has truly motivated us all to strive for our best. Meenakshi aunty and Sanjeev uncle — thank you both for your well wishes and the delicious food that kept me and Suyash fueled through the last few critical weeks of our PhD. Thank you for always being there for us.

Gazillion thanks to my Aachi and Thatha for helping me become the person I am today. I am proud to be your granddaughter and eternally grateful for your love and support. I am in awe of how much love you both have for me to keep yourself awake for all my late-night events – my wedding, my defense, and sometimes, our Duo video calls. Ramanujam thatha- while I have never had the pleasure of meeting you, I hope I make you proud. Your impact on the community to this date is what keeps the rest of us going.

Thank you to my best friends— Shirly, Sriya, Resh, Liz, Resh — for keeping me motivated, always making time for tea, and cheering me on. My younger siblings —Anuhya, Ved — for being my fierce protectors and allowing me to "akka" you both. My cousins— Sharika, Vig, Karthik, Maya, Arya, Sharanya, and Sharath — for the love from afar. Thanks to my dogs, or pup-a-dams as I lovingly call them, -— Jalebi and Buddy — for being in tune with my emotions, providing comic relief, and for getting me up and running every morning.

And finally, to my brother. Bro-bro, you are my biggest advocate. Thank you for always pushing me to reach for the stars. Your curiosity for anything and everything, our arguments about anything and everything has a role to play in shaping my life decisions. Safe to say, I would not have come to the US if it weren't for you, let alone a PhD. Love you bro-bro!

Abstract

Alzheimer's and related dementias (ADRD) are neurodegenerative diseases affecting 6.2 million adults in the US (“2023 Alzheimer’s Disease Facts and Figures,” 2023). Most of the care for those living with ADRD is provided by ADRD caregivers like family or friends who are often unpaid non-professional individuals that voluntarily assist with the delivery of care. ADRD caregivers are often under-supported in providing care which can lead to negative care-related outcomes such as stress, depression, and burnout. While Digital Health Interventions (DHIs) hold promise for supporting ADRD caregivers, these DHIs often do not properly integrate with the real-world settings of ADRD caregivers, resulting in various suboptimal engagement patterns with DHIs such as low usage, selective usage, or abandonment of DHI. This dissertation investigates the contextual factors associated with DHI engagement among ADRD caregivers. It also explores the potential of Structural Topic Modeling (STM)— a semi-automated text analysis technique— to support qualitative analysis in studying context of DHI engagement for ADRD caregivers.

The research identified three distinct DHI engagement patterns with a DHI to support communication and coordination of ADRD caregivers— CareVirtue: low and declining usage, moderate and consistent usage, and high and increasing usage. Each pattern was associated with specific contextual factors derived from the Patient Work System model. This highlights the varying context of ADRD caregivers and the need for heterogenous design of DHIs.

Furthermore, the study demonstrates that STM, when combined with manual qualitative analysis techniques like directed content analysis, can be a valuable tool to study context and provide (re)design insights for DHIs, especially when rapid results are needed to engage ADRD caregivers with DHIs. This approach reduces analysis time, produces distinct and complementary topics to manual qualitative analysis, and aids in understanding the complex work system of ADRD caregivers.

This work contributes to our understanding of DHI engagement for ADRD caregivers by proposing a conceptualization for studying DHI context using the caregiver journeys and suggesting a process-based view of DHI engagement. It also showcases the potential of STM to address limitations in traditional qualitative analysis methods, specifically the time and resource constraints. The findings inform the design of DHIs for ADRD caregivers by identifying unmet needs associated with different user groups and engagement patterns. Future research can build upon these findings to develop more effective and targeted DHIs for ADRD caregivers.

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1 Introduction

1.1 Problem statement

Alzheimer's and related dementias (ADRD) are neurodegenerative diseases affecting 6.2 million adults in the US ("2023 Alzheimer's Disease Facts and Figures," 2023). Most of the care for those living with ADRD is provided by ADRD caregivers like family or friends who are often unpaid non-professional individuals that voluntarily assist with the delivery of care. An estimated 16.1 million ADRD caregivers provide unpaid care valued at 256.7 billion US dollars.

Caring for those living with ADRD is complex and presents multiple challenges to caregivers (Alzheimer's Disease Facts and Figures, 2024; Goren et al., 2014a). The neurodegenerative progression of the disease presents a dynamic challenge for caregivers as they manage evolving behavioral and psychological symptoms like agitation, repetitive questioning, wandering, and delusions (Finkel et al., 1996). Those living with ADRD often are unable to perform activities of daily living and instrumental activities of daily living, leaving all responsibility of daily housekeeping tasks and hygiene tasks to the caregivers (Ponnala et al., 2020; Weiler, Lingg, Eagan, et al., 2022). Caregivers are often not equipped with adequate training and resources to handle the complex and dynamic symptoms (Brodaty & Donkin, 2009). Often, multiple caregivers are involved that presents a unique challenge in coordinating a diverse mix of caregiving activities such as medication management, providing companionship for the person living with ADRD (Ponnala et al., 2020; Rutkowski et al., 2021b).

While ADRD caregivers can experience positive outcomes related to caregiving such as family togetherness and family satisfaction, 30–40% of ADRD caregivers often face severe challenges in maintaining their personal health and well-being by experiencing burden, depression, burnout, decreased quality of life, and increased risk of other health problems, which ultimately also affect the health of the person living with ADRD ("2023 Alzheimer's Disease Facts and Figures," 2023; Alfakhri et al., 2018; Goren et al., 2014a). Additionally, these ADRD caregivers often also neglect their own health in taking care of the person living with ADRD, becoming the "hidden victims of ADRD" (Sallim et al., 2015).

To address these negative caregiver outcomes, the US National Institute on Aging has highlighted the development and testing of digital health interventions for caregivers of people living with ADRD as a key priority (Borson et al., 2016; *Recommendations from the NIH AD Research Summit 2015*, 2015). In response, many efficacious digital health interventions for supporting caregiver work, such as mobile and web applications that provide information, psychoeducation, task management, and social support have been developed to help improve caregiver outcomes (Deeken et al., 2019; Faieta et al., 2021; Godwin et al., 2013; Lee, 2015; Lorca-Cabrera et al., 2020). However, negative outcomes such as high caregiver stress and burden continue to persist among caregivers ("2023 Alzheimer's Disease Facts and Figures," 2023).

Inadequate engagement with existing digital health interventions in the real-world settings may be attributed as one of the many reasons for the mismatch between available interventions and negative outcomes. Engagement can be defined as "the extent and manner of use and a subjective experience characterized by attention, interest and affect" (O'Brien & Toms, 2008; Perski et al., 2017). While ideal engagement conditions such as use of the intervention in prescribed amounts is required to experience more positive outcomes, diverse engagement patterns of ADRD caregivers with digital health interventions in real-world settings exist, ranging from selective use of certain features of the interventions to abandonment of an intervention altogether.

The varying engagement patterns in real-world conditions can be attributed to the sensitivity of the intervention towards the complex ADRD caregiving contexts (Gitlin et al., 2015; Werner, Stanislawski, et al., 2017; Zhang et al., 2019). Context of engagement with digital health interventions has been defined as "any information that can be used to characterize the situation of an entity, where an entity is a person, place, or object that is considered relevant to the interaction between a user and an application, including the user and application themselves" (Dey & Abowd, 1999). Context of engagement with digital health interventions does not include the process of interaction between a user and the application or the benefits received from the interaction. For example, many current interventions such as mobile applications provide generalized passive information without considering the contextual factors like complexity of the tasks involved, the varying stage of ADRD and the specific needs of each stage for the caregiver, leading caregivers to disengage from digital health interventions (Rutkowski et al., 2021a; Werner, Brown, et al., 2022). However, specific contextual factors of ADRD caregivers and their influence on engagement remains less understood. Understanding contextual factors and how they influence engagement could help design interventions with which caregivers can meaningfully engage.

While many approaches to studying context exists (Beyer & Holtzblatt, 1998; Coles et al., 2020; Dourish, 2004; Duarte & Pinho, 2019; Kofod-Petersen & Cassens, 2006; Novotny & Bauer, 2017), the field of patient-engaged human factors provides a structured approach to identify and describe the complex context of ADRD caregivers in which digital health interventions are used (Carayon, Schoofs Hundt, et al., 2006; Holden et al., 2013, 2015). Patient-engaged human factors, defined as the "application of human factors theories and principles to study and improve work done by patients and families", helps model contextual factors of ADRD caregivers through the work-systems model. It conceptualizes context as a structured work system of interacting components such as people, tools and technologies, tasks, environment, socio-cultural, and organizational factors that influence processes to produce certain outcomes (Carayon, Schoofs Hundt, et al., 2006; Holden et al., 2013, 2015). This structured work system components could act as contextual barriers or contextual facilitators to the processes. By considering engagement with digital health interventions as a process, PEHF can be used to explore how contextual factors impede or facilitate engagement patterns. Hence, the work system of ADRD caregivers can be studied to understand how the complex contextual barriers and facilitators can influence engagement with digital health interventions.

CareVirtue is a multicomponent DHI for ADRD caregivers that is well-suited to explore DHI engagement patterns and the various contextual barriers and facilitators associated with each engagement pattern. Designed as a web application, CareVirtue supports the communication and coordination needs of ADRD caregivers by offering features such as a care journal, geolocated resources, and a shared calendar. Specifically developed with a person-centered care model for individuals living with ADRD and their caregivers, CareVirtue has been shown to be both acceptable and feasible in a previous study (Boutilier et al., 2022). This study demonstrated that caregivers exhibit diverse engagement patterns with CareVirtue, highlighting its suitability for investigating these patterns and their associated contexts.

Studying context and the mechanisms by which it influences engagement in DHIs such as CareVirtue often requires in-depth qualitative content analyses of observational data (Creswell et al., 2007; Dennison et al., 2013; Forman et al., 2008a; Valdez et al., 2017). Content analysis, a common method of analysis for qualitative data, involves immersion in the data to develop a general understand and then involves iterative coding or tagging the data to organize it into uncover and document links within and between concepts (Bradley et al., 2007). However, qualitative analyses can be challenging, time-consuming, and resource-intensive (Pope et al., 2000; Ziebland & McPherson, 2006).

Structural topic modeling (STM), a semi-automated text analysis technique, is a useful and ubiquitous tool that can be used to analyze qualitative data more efficiently (Roberts et al., 2013). STM uses rich textual data from a collection of documents, called corpus, to create topics or themes that arise from the corpus. Topics are a distribution of words from the corpus, with those words most related to the topic having higher probabilities of occurrence (Roberts et al., 2013). Additionally, STM allows for the addition of covariates or independent variables that affect the prevalence of a topic in a document or the variation of content for each topic across document (Roberts et al., 2013). There is a growing body of evidence that shows text analysis can support some aspects of qualitative data analysis such as identifying underlying themes and links between them (Alambeigi et al., 2020; Lee & Kolodge, 2020; Roberts et al., 2014). While STM can identify latent themes efficiently, it can also struggle to capture the richness and complexity of human experience due to its reliance on word frequency and co-occurrences. Additionally, the use of STM in exploring complex constructs, such as context of engagement with digital health intervention, in the field of Human Factors Engineering (HFE) is limited. Hence, there is a need to explore how STM can be leveraged in HFE to support qualitative research, specifically in understanding contexts of ADRD caregivers.

1.2 Research questions

1) How are contextual barriers and facilitators, defined by the work system model, of ADRD caregivers associated with various engagement patterns in a digital health intervention to support ADRD caregivers— CareVirtue?
    a) What are the various engagement patterns of ADRD caregivers in CareVirtue?

   b) What are the contextual barriers and facilitators of ADRD caregivers, defined by the work system model, that influence CareVirtue engagement?
   c) How are contextual barriers and facilitators to engagement associated with the various CareVirtue engagement patterns?
2) How does structural topic modeling support content analysis for identifying contextual factors of ADRD caregivers that influence engagement in a digital health intervention to support ADRD caregivers—CareVirtue?
   a) How efficient is STM in studying contextual factors of ADRD that influence CareVirtue engagement?
   b) How useful are the topics identified by STM in studying contextual factors of ADRD that influence CareVirtue engagement?

2 Literature review

2.1 Prevalence of ADRD and the Essential Role of ADRD caregivers

Alzheimer's and related dementias (ADRD) are progressive, neurodegenerative disorders that cause memory impairment, irreversible decline in cognitive functions such as thinking, and unpredictable behavioral and psychological symptoms such as aggression, agitation, and apathy (Geda et al., 2013). The progression of disease eventually interferes with a person's ability to perform daily tasks (Geda et al., 2013). The cause of ADRD is not fully understood and there is no evident cure or means of prevention, leaving disease management the only option. In 2019, Alzheimer's Disease International estimated that more than 50 million people live with ADRD worldwide, with an estimated increase to 152 million by 2050 (O'Connor, 2019). In the United States alone, 6.7 million adults are diagnosed with ADRD with an annual cost of $256.7 billion in disease management and treatment, making it the *most expensive disease* to manage in the US ("The Most Expensive Medical Diseases and Procedures | USC EMHA," 2023).

Due to the irreversible neurodegenerative progression of the disease, those living with ADRD heavily rely on their informal caregivers to help manage their symptoms and eventually carry out daily tasks (Finkel et al., 1996). Informal caregivers (thereby called ADRD caregivers) of those living with ADRD are family members or friends that are often unpaid, nonprofessional individuals who voluntarily assist with the delivery of care (Brodaty & Donkin, 2009; Reinhard et al., 2008). Over 16.1 million caregivers provide an estimated 18 billion hours of unpaid care value at $340 billion in 2022 in the United States, making informal caregiving a national crisis ("2023 Alzheimer's Disease Facts and Figures," 2023).

Providing care for those living with ADRD is a demanding experience. ADRD caregivers tend to provide care for an average duration of four years or more, with three-quarters of each day devoted to caregiving (Kasper et al., 2015). The amount of caregiving per day increases as ADRD progresses. With this huge commitment to caregiving, ADRD caregivers provide care for the following reasons: 1) desire to keep a family member or friend at home; 2) being close to those with ADRD; 3) having a perceived obligation to the person living with ADRD; and 4) love and sense of duty towards the person living with ADRD ("2023 Alzheimer's Disease Facts and Figures," 2023). While ADRD caregivers report positive outcomes from caregiving such as family togetherness and family satisfaction of helping others, 30-40% of caregivers also report negative outcomes (“2023 Alzheimer’s Disease Facts and Figures,” 2023; O’Connor, 2019). These negative outcomes include depression, burnout, decreased quality of life, and increased risk to other health disorders such as stroke, diabetes, cardiovascular disease, and ADRD, making ADRD caregivers the “hidden victims” of ADRD (“2023 Alzheimer’s Disease Facts and Figures,” 2023; Goren et al., 2014a; Sallim et al., 2015).

2.2 The complex context of ADRD caregiving

Caregiving occurs in a complex and dynamic context of providing care for a person living with ADRD. The context broadly includes an interplay of the following factors: 1) dynamic progression of the disease; 2) characteristics of the ADRD caregiver and the person living with ADRD; and 3) social and economic factors.

2.2.1 Dynamic progression of the disease

ADRD progresses through various disease stages that are characterized by unique symptoms, influencing the complexity and difficulty of caregiving tasks. Generally, there are three stages of the disease – mild cognitive impairment, mild AD, moderate AD, and severe AD (“2023 Alzheimer’s Disease Facts and Figures,” 2023). Each of these stages are associated with the corresponding disease progression as the person living with ADRD goes through very mild symptoms that may not interfere with everyday activities to symptoms that interfere with most everyday activities, changing the caregiving tasks carried out by the caregiver (Wilson, 1989). The symptoms of each stage of disease and the corresponding tasks and complexities in caregiving have been synthesized in the Table 2-1.

The first stage or the mild cognitive impairment requires ADRD caregivers to notice subtle symptoms and making sense of these symptoms through learning (Rasmussen et al., 2019; Wilson, 1989). The mild and moderate ADRD phases then requires caregivers to constantly learn new caregiving skills and perform new tasks for the person living with ADRD. Through the mild and moderate ADRD stages, caregivers perform a wide variety of tasks that have been broadly categorized as activities of daily living (ADL), instrumental activities of daily living (IADL), and maintenance (Katz, 1983; Lawton & Brody, 1969; Ponnala et al., 2020).

ADLs are defined as daily routine self-care activities. These tasks are further categorized as clinical (e.g., providing medication), functional (e.g., daily hygiene tasks), and cognitive (e.g., providing conversation and answering questions); IADLS are those that enable people to live independently in their communities and are further classified as decision making on behalf of or in consort with the person living with ADRD, house-keeping, information management activities, logistics around appointments, and transportation; maintenance activities are those that support ADLs and IADLs through emotional and mental support groups and include activities such as providing caregiver support to other caregivers, companionship to person living with ADRD, pet care, developing skills around caregiving, and being vigilant through supervising the person living with ADRD (Ponnala et al., 2020).

The difficulty and complexity of learning new skills and performing these tasks evolve through the mild AD and moderate AD stages as symptoms continue to decline for the person living with ADRD, such as close monitoring and surveillance of those living with ADRD as they develop more behavioral symptoms such as wandering and the loss in ability to recognize familiar faces and places. The mild–moderate stages are often associated with changes in family dynamics for ADRD caregivers as people living with ADRD are often unable to make decisions on their own due to the progression of the disease. These may result in conflicts with other members of the family as there maybe differences in beliefs around the symptoms of the disease, its seriousness, and making decisions on appropriate strategies for dealing with the symptoms (Pearlin et al., 1990). This puts the impetus on the primary ADRD caregiver to champion the decision-making process through conflicts (Kuhn, 1998).

Stages of ADRD	**Person living with ADRD symptoms ("2023 Alzheimer's Disease Facts and Figures," 2023)**	**Complexities in caregiving**
Mild cognitive impairment	Subtle symptoms such as problems with memory, language, and thinking.	Noticing subtle symptoms Discounting and normalizing symptoms as old age Becoming emotionally distant Suspecting larger problems Looking for answers (Rasmussen et al., 2019; Wilson, 1989)

Stages of ADRD	**Person living with ADRD symptoms ("2023 Alzheimer's Disease Facts and Figures," 2023)**	**Complexities in caregiving**
Mild AD	Takes longer to accomplish common daily tasks such as handling finances or paying bills	Dealing with the shock of diagnosis Lifestyle changes Learning new caregiving skills Planning for the future (Kuhn, 1998; Wilson, 1989)
Moderate AD	More problems with memory and language; gets harder to complete multistep tasks like bathing and dressing; personality and behavioral changes such as agitation and suspiciousness; recognizing people	Restriction in caregiver social life Change in family processes (conflict with other family members) Learning new caregiving skills Dealing with person with ADRD's other chronic conditions such as incontinence Economic difficulties Emotional changes such as frustration, decreased resilience and coping due to aggression from person living with ADRD) (Chenoweth & Spencer, 1986; Meek et al., 1998; Ozcan & Akyar, 2021; Wilks et al., 2011; Wilson, 1989)
Severe AD	Communicating verbally diminishes, movement becomes restricted to being bedbound, loses ability to swallow	Bereavement Transition to assisted living facilities. (Bonnel, 1996; Graneheim et al., 2014; Wilson, 1989)

Table 2-1 Different stages of ADRD, corresponding symptoms for the person living with ADRD, and the corresponding challenges and complexities in caregiving

2.2.2 Characteristics of the ADRD caregivers and those living with ADRD

The key characteristics of the ADRD caregivers and the person living with ADRD such as age, gender, ethnicity, relationship to the person living with ADRD, education, occupation, and economic attainments form a significant part of the ADRD caregiving context and play a role in influencing the level of negative outcomes ADRD caregivers experience such as stress (Pearlin et al., 1990).

Female caregivers are 1.53 times more likely to develop depression compared to male caregivers, likely due to the greater propensity to depression from gender roles in the society and a higher difficulty associated with providing care for males (Sallim et al., 2015). ADRD caregivers of males are 1.86 times more likely to develop depression, as males tend to exhibit a greater degree of certain behavioral and psychiatric symptoms of ADRD like misidentifying objects, people, and places (Sallim et al., 2015; Savva et al., 2009).

Over 30% of ADRD caregivers are ages 65 and over ("2023 Alzheimer's Disease Facts and Figures," 2023), and managing their own health conditions due to their age and underlying diseases can add to the complexity of caregivers of those living with ADRD (Pinquart & Sörensen, 2011). ADRD caregivers may have preexisting health conditions that require regular monitoring and treatment, such as hypertension or diabetes, which can make caregiving tasks more challenging (Brodaty & Donkin, 2009). Additionally, caregivers often neglect their own health needs while caring for their loved ones, leading to negative health outcomes such as fatigue, sleep disturbances, and increased risk of developing chronic health conditions. The combination of managing their own health conditions and caring for someone with ADRD can result in increased stress and burnout, which can negatively impact the quality of care provided to the individual with ADRD. ADRD caregivers may experience emotional distress and physical exhaustion, leading to decreased ability to provide adequate care, and potentially causing harm to both the caregiver and the person living with ADRD (Schubert et al., 2008).

The relationship between the ADRD caregiver and the person living with ADRD also poses its unique challenges in caregiving and forms an important part of the ADRD caregiving context. Spousal caregivers often experience more stress than adult children/children-in-law caregivers (Harris et al., 2021; Pinquart & Sörensen, 2011; Sallim et al., 2015). Spouses are often first in line to assume caregiving responsibilities, especially in American families and the behavioral changes from ADRD present unique challenges to spousal caregivers as ADRD often disrupts routines developed between spouses over several years (Bonnel, 1996; Pozzebon et al., 2016). Children and children-in-law caregivers, on the other hand, deal with conflicting responsibilities with caregiving such as their own careers and families (Pinquart & Sörensen, 2011).

2.2.3 Social and economic factors

ADRD can pose formidable strains on the economic and social conditions of ADRD caregivers. As household incomes reduce due to age and the disease, there is also a considerable increase in expenditure related to the management of ADRD, such as respite care, medications, and hospital visits (Deb et al., 2017; Pearlin et al., 1990). Social factors such as social networks, family dynamics, and cultural backgrounds can also influence ADRD caregiving as these can help in creating various coping mechanism for the ADRD caregivers (Hammad et al., 2024).

Social and economic disparities can significantly impact the context of ADRD caregiving. The availability of resources — respite care, digital health interventions, and support groups — often varies from one community to another, contributing to the negative outcomes and the differing context of ADRD caregiving. Economic disparities also limit access to information and knowledge that is needed for ADRD caregiving. ADRD caregivers report a significant information need for providing effective care (Hirakawa et al., 2011; Oberoi et al., 2016). However, obtaining this information is a complex process influenced by the goals and strategies of information seeking (Rutkowski et al., 2021a). Without adequate resources, caregivers may have limited opportunities to take breaks from caregiving responsibilities or receive assistance with tasks that are difficult to perform, leading to increased stress, burnout, and negative health outcomes (Goren et al., 2014a)

Hence, caregiving is a complex and multi-faceted process with multiple challenges. The interplay of biomedical, physical, emotional, social, and environmental factors of both the person living with ADRD and the caregiver along with the wide variety of tasks performed can make caregiving a dynamic and nuanced process with very little support. Caregivers overcome these challenges by carrying out multiple strategies like working with dementia care specialists, formal care providers, constantly modifying care routines for the person living with ADRD, upskilling themselves, and modifying their care environment (Weiler, Lingg, Wilkins, et al., 2022). Effective interventions that account for their complex contexts with multiple challenges are needed to support caregivers and overcome these constraints.

2.3 Current state of digital health interventions (DHI) for ADRD caregiving

2.3.1 Current DHI for ADRD caregiving show promise for improving caregiver outcomes

To address suboptimal caregiver outcomes, the US National Institute on Aging has highlighted the development and testing of digital health interventions as interventions for caregivers of people living with ADRD as a key priority (*Recommendations from the NIH AD Research Summit 2015*, 2015). Digital health interventions are "any advanced electronic equipment, which can be used to enhance support and care, act as a prompt for interventions by caregivers, monitor welfare and assist in communication and leisure activities for a person living with ADRD" (Sriram et al., 2019). For the purposes of this research, I will focus on digital health interventions that are designed to be used on computers, mobile phones, and/or tablets.

There are many types of DHIs, primarily used for communication and coordination with formal and informal care networks, supporting direct care, and information acquisition in the form of interactive mobile and web applications (Block et al., 2020). These mobile and web applications provide information, psychoeducation, task management, and social support that have the potential to help improve caregiver outcomes (Deeken et al., 2019; Faieta et al., 2021; Godwin et al., 2013; Lee, 2015; Lorca-Cabrera et al., 2020). DHIs offer some unique advantages to ADRD caregivers, such as their potential to be delivered remotely and their ability to provide caregivers with access to resources and support networks that may not be available in their local community (Godwin et al., 2013).

Many of the DHIs have been tested for efficacy, showing strong potential to help improve caregiver outcomes such as reduction of caregiver depression, anxiety, stress, and burden (Davies et al., 2020; Deeken et al., 2003; Gitlin, 2021; Godwin et al., 2013). Despite the availability of efficacious DHIs, negative outcomes such as high caregiver stress and burden persist (Christie et al., 2018a; Gitlin et al., 2015).

2.3.2 Limited evidence on engagement with DHIs for ADRD caregivers

User engagement, defined as "the extent and manner of use of a DHI and a subjective experience characterized by attention, interest and affect" (O'Brien & Toms, 2008; Perski et al., 2017), is one of the important factors for delivering the intended benefits of DHIs to ADRD caregivers (Berwick, 2003; Coulter, 2012; Gitlin et al., 2015; Kitsiou et al., 2021; O'Brien & Toms, 2008; Ramsey et al., 2020; Sawesi et al., 2016).

While current efficacy studies demonstrate a DHI's potential under controlled and ideal conditions for DHI engagement, real-world effectiveness often falls short due to the prevalence of various engagement patterns with DHI, such as low use, selective use of specific features, abandonment of intervention, etc. (Christie et al., 2018b; Eysenbach, 2005; Gitlin et al., 2015; Øksnebjerg et al., 2020; Raj & Iott, 2021). Additionally, research suggests that ADRD caregivers are also less likely to use technologies than the general population in real-world settings (Kim et al., 2017; Rathnayake et al., 2020).

Understanding the factors that influence these varying engagement patterns among ADRD caregivers in real-world conditions remains a critical gap in the literature. Nascent research focuses on exploring limited aspects of engagement such as usage time and the factors that may influence it such as intent to adopt, or acceptability. These studies highlight the importance of perceived usefulness for adoption (Mendez et al., 2021a) and the influence of factors like concerns about the care recipient, social norms, and access to online support networks on the acceptance of certain technologies, particularly surveillance-based ones (Xu et al., 2023). However, they don't fully explain the reasons behind engagement patterns after initial adoption.

Guisado-Fernández et al., 2019b identified broader factors influencing initial engagement with DHI for both caregivers and individuals with ADRD. These factors include attitudes towards technology, ethical concerns (privacy, data ownership), technology design and perceived usefulness, and the symptoms of ADRD itself. However, their study focused only on adoption, and the various engagement patterns that may exist after adoption. Additionally, it combined factors for both caregivers and care recipients, overlooking their distinct needs. Boutilier et al., 2022 explored the feasibility of DHI and identified factors associated with use, such as retirement status, higher income, and valuing features like coordination, privacy, and support. While this sheds light on user demographics and preferences, it doesn't delve into the underlying reasons for varying usage patterns.

Hence, current research lacks a deep understanding of why diverse engagement patterns with DHI emerge in real-world settings among ADRD caregivers. Existing studies often focus on single aspects of engagement, such as adoption or usage time, and do not fully capture the complex and multifaceted nature of caregiver engagement with DHI, such as the prevalence of various engagement patterns. This gap might be partially explained by the presence of multiple conceptualizations and operationalizations of “user engagement”.

2.4 Conceptualizations of engagement

User engagement is a complex multidimensional construct that has been conceptualized and defined in multiple ways. Several definitions characterize it as an outcome of interaction with a technology (Perski et al., 2017; Simblett et al., 2019), and as a process of interaction over time with a technology (Oakley-Girvan & Docherty, 2022; O'Brien & Toms, 2008). Conceptualizing engagement as an outcome has further divisions in how DHI engagement is operationalized. Conceptualizing and operationalizing engagement as a process during and after interaction with a technology has been less clear and difficult (Doherty & Doherty, 2019; O'Brien, 2018).

2.4.1 Engagement is an outcome of a user's interaction with technology

Engagement has been defined and measured as an outcome of a user's interaction with technology, such as their extent and manner of use. Conceptualizing engagement as an outcome has further divisions in how they are operationalized. One operationalizes engagement in digital health as subjective outcomes such as aesthetics and sensory appeal towards the intervention, motivation, and interest to use the intervention (O'Brien & Toms, 2008) whereas the other operationalizes engagement objectively through extent of usage (frequency, depth, duration) (Simblett et al., 2019).

The objective conceptualization of engagement allows for a standardized approach to measuring engagement in digital health technologies (O'Brien, 2018). This is especially important for evaluating the effectiveness of interventions or comparing engagement levels across different technologies or populations (Doherty & Doherty, 2019). However, it does not capture the subjective experience and perceptions of users such as the user's level of interest, satisfaction, acceptance, or motivation to use the technology (Perski et al., 2017). Users may continue to use a technology out of necessity or habit, even if they do not find it engaging or satisfying. Additionally, users' engagement with an intervention may be influenced by various subjective factors such as their emotional state, beliefs, values, and attitudes, which cannot be measured through objective usage metrics alone.

Subjective experience conceptualization considers the users' perceptions and experiences, which are essential for improved engagement in digital health technologies (O'Brien & Toms, 2008). Subjective measures of engagement can provide insight into how users engage with digital health interventions, what motivates them to use them, and what factors may hinder their engagement (Kelders et al., 2020). This information can be used to develop digital health interventions that promote engagement, leading to better health outcomes. However, subjective conceptualization alone may be insufficient because it is based solely on self-report measures, which may not always accurately reflect the actual engagement of a person in a digital health intervention (Doherty & Doherty, 2019).

2.4.2 Engagement is a process that occurs before, during, and after a user's interaction with technology

Engagement has been described as having three distinct phases in the context of DHIs: a beginning, a maintenance period, an end, and a possible reengagement or reinitiation (Oakley-Girvan & Docherty, 2022; O'Brien & Toms, 2008; Sidner et al., 2005). The users first become aware of the technology, then they decide to use the intervention, followed by a phase where the user is actively engaging with the technology according to their needs. Engagement models describe the components that influence each phase. The design of interface, intent to use, and knowledge about health and technologies of the user have been shown to influence the initiation of engagement; reinforcing behaviors of using the technological intervention reinforce and strengthen engagement; and stress management and nudges for adherence influence the maintenance of engagement (Oakley-Girvan & Docherty, 2022). Although these stages are defined as distinct there is no concrete method for operationalizing engagement as a three-stage process (Doherty & Doherty, 2019; O'Brien, 2018). Table 2-2 summarizes the definitions and the types of conceptualizations of engagement.

Type of conceptualization	Paper	Definition of engagement
Outcome	(O'Brien & Toms, 2008)	"Engagement is a category of user experience characterized by attributes of challenge, positive affect, endurability, aesthetic and sensory appeal, attention, feedback, variety/novelty, interactivity, and perceived user control."
Outcome	(Simblett et al., 2019)	"By engagement, we refer to the extent and manner in which people actively use resources."
Outcome	(Perski et al., 2017)	"Engagement is (1) the extent (e.g., amount, frequency, duration, depth) of usage and (2) a subjective experience characterized by attention, interest and affect."
Process	(Kelders et al., 2020)	"Engagement is predominantly seen as a state of being involved or occupied with an object, activity, or artifact, which usually results in a positive outcome. It is a multidimensional construct comprising behavioral, cognitive, and affective components."
Process	(Sidner et al., 2005)	"By engagement, we mean the process by which two (or more) participants establish, maintain, and end their perceived connection. This process includes initial contact, negotiating a collaboration, checking that other is still taking part in the interaction, evaluating whether to stay involved, and deciding when to end the connection"

Table 2-2 Type of conceptualization and definitions of engagement prevalent in literature

2.4.3 Factors influencing engagement with DHI among ADRD caregivers

While various engagement patterns with DHIs are under-explored, nascent suggests that low engagement with DHI among caregivers could be broadly due to the prevalence of low-quality, non-evidence-based interventions and insufficient research in bringing evidence-based interventions to practice.

Low quality interventions that do not consider the complex caregiving contexts of caregivers have the potential to be abandoned. For example, some technologies off-set their lack of information quality by providing more aesthetically appeasing interface (Werner, Brown, et al., 2022), which is not useful for a caregiver seeking information as they will often abandon the information behavior if they do not find information at the right time (Rutkowski et al., 2021a). Technologies are also not tailored to the stage of the disease of the person living with ADRD and the differing needs of caregivers, potentially causing poor engagement (Gitlin et al., 2015).

Studies have shown that while tested technologies are effective in the short term, their effect size reduces with time (Steffen & Gant, 2016). While research has been done to understand caregiver needs to create DHIs, less has been done to evaluate engagement with the developed technologies in real-life caregiving contexts (Matthews et al., 2015; Parker et al., 2023; Williams et al., 2013). Some research in translation of DHIs into real-life caregiving contexts has indicated that psychological characteristics of the caregiver such as expectation of use, acceptability, trust, autonomy, and motivation and usability of interface influence their engagement with technology (Bastoni et al., 2021; Christie et al., 2018a; Lin et al., 2020). However, complex factors such as sociocultural contexts and larger organizational contexts of caregivers on engagement have not been explored sufficiently (Bastoni et al., 2021; Christie et al., 2018a).

Limited evidence suggests that engagement, broadly studied as extent of usage, is influenced by contextual factors such as a person's social support, health status, perception of technology, which have been summarized in Table 2-3. However, studies have only explored factors that affect engagement in DHI that were already being used by caregivers such as timers, phone reminders, remote control television, or GPS trackers (Arntzen et al., 2016; Block et al., 2020; Wisniewski et al., 2019). These studies have found that although there is a willingness to adopt said technologies, barriers such as cost, lack of guidance and knowledge about interventions, how to use them, cultural relevance, and increased burden are some factors that negatively influence engagement with DHI (Boyle et al., 2022a; Wisniewski et al., 2019). While this is useful in informing design of DHIs, we do not know the complex factors that will lead to various engagement patterns with DHIs designed to address specific needs such as information management, or tracking/monitoring symptoms into practice. Understanding the contextual factors behind various engagement patterns with DHIs could help unveil the hidden needs of ADRD caregivers to target designing of interventions.

Hence, there is a need to identify the various engagement patterns and describe the contextual factors that influence engagement of ADRD caregivers with DHIs to design technologies that can improve positive outcomes. To do this, we must conceptualize the context of ADRD caregiving.

Paper	**Type of measure**	**Methods**	**Factors affecting engagement with DHI**
(Hardiker & Grant, 2011)	Extent of usage	Literature review on four types of eHealth service: health information on the Internet, custom-made online health information, online support, and telehealth	Characteristics of users including levels of motivation, experience with the internet and familiarity, trust; technological aspects – internet access and quality, features of the intervention; characteristics of the eHealth service – content; social aspects of use – being part of a group of individuals who were in a similar position to themselves
(Centi et al., 2019)	Extent of usage, Motivation	Nonrandomized pilot study; survey and use of technology among 30 participants	Goal setting, social support, and technology ownership
(Simblett et al., 2019)	Extent of usage	Qualitative analysis of interviews with 25 participants who had depression and used mHealth intervention	Health-related (e.g., symptom intensity, awareness, physical ability), user-related (technology acceptance, perceived costs, perceived utility), and technology-related (convenience, accessibility, intrusiveness) factors

Paper	Type of measure	Methods	Factors affecting engagement with DHI
(Zhang et al., 2019)	Extent of usage	Observational study of 5976 WeChat posts from three Chinese provincial CDCs	Content, time, frequency, and post type of information
(Böhm et al., 2020)	Extent of usage	Longitudinal observation study from 29643 users over a period of 6 months	Privacy concerns, user characteristics
(Lalloo et al., 2022)	Extent of usage	Randomized controlled trial of 56 participants assessing usage analytics, followed by content analysis of interview data	Goal setting, health, engagement of caregivers, ease of use

Table 2-3 Factors that influence engagement of users with DHIs for health management

2.5 Approaches for conceptualizing complex contexts

As ADRD contexts are complex, it is essential to explore how various frameworks have been used to conceptualize and elucidate these contexts for the purpose of designing or evaluating DHI for health management and caregiving. Several approaches have been used to conceptualize concepts in the fields of Human Factors and Human-Computer Interaction (HCI) for designing DHIs. These approaches are 1) the work systems models; 2) Unified Theory of Acceptance and Use of Technology model (UTAUT2); 3) contextual design; 4) activity theory; and 5) context-aware computing models.

2.5.1 The work systems approach

The work system approach is a macroergonomics approach that is a larger system perspective concerned with the study, design, and evaluation of work (Hendrick & Kleiner, 2002; Kleiner, 2008). The foundation for this approach is based on the Tavistock studies that evaluated the negative outcomes of technology in coal mines in the 1950s (Emery, 1993; Trist & Bamforth, 1951). Before the advent of technology, coal mining was done using what is called the 'handgot' method. The handgot method involved workers working in independent teams with autonomy. A new method called the “longwall” method that automated the process to improve system productivity. However, contrary to what was expected, the method lowered productivity, high absenteeism of workers, isolation, and distress among workers (Trist & Bamforth, 1951). With the longwall method, workers operated in shifts over very long distances, which established a need for hierarchy and thereby removed autonomy in work and causing greater isolation and distress among workers. This research revealed that there are larger social and organizational factors in play beyond just the technology affecting the overall outcomes of the work-system and that the implementation of a technology must consider these other factors of the system (Trist & Bamforth, 1951). The social and organizational factors affecting outcomes of the work-system make up a part of the context.

Later research further organized the work system as a structured system of interacting components — technology, organization, person, tasks, and environment, that makes up the larger context (Smith & Sainfort, 1989). This structured work system became the basis of the balance theory, which is used in the current work system models leveraged in design and evaluation of technologies for healthcare (Figure 2-1). The balance theory states there are multiple constraints in the work system that could cause negative outcomes such as stress to the individual. Although it may be difficult to remove all constraints in the work system to improve outcomes, the work system could be balanced by eliminating the negative aspects within the work system or by balancing the constraints in the work system with facilitators that can the counteract the effect of constraints. The work system can be balanced by either introducing new facilitators or by modifying existing components to reduce stress and the negative health consequences within the work system. The depiction of work system as a structured component with constraints and facilitators is useful in studying the complex caregiving context by providing a structured way to understand constraints and facilitators that affect engagement.

In recent years, the work system approach has been used to conceptualize caregiving activities as work as caregivers perform several tasks — providing medication, daily hygiene tasks, making decisions in consort with or on behalf of the person living with ADRD, housekeeping tasks, managing, and communicating information — to achieve outcomes like reduced burden, improved quality of life for both them and the person living with ADRD, etc. This work occurs within a complex work system involving several people, organizations, and environments that make up the context (Ponnala et al., 2020; Weiler, Lingg, Wilkins, et al., 2022; Werner, Malkana, et al., 2017). The work system here has been conceptualized as the context for caregiving processes and has been adapted in several frameworks described in following sections.

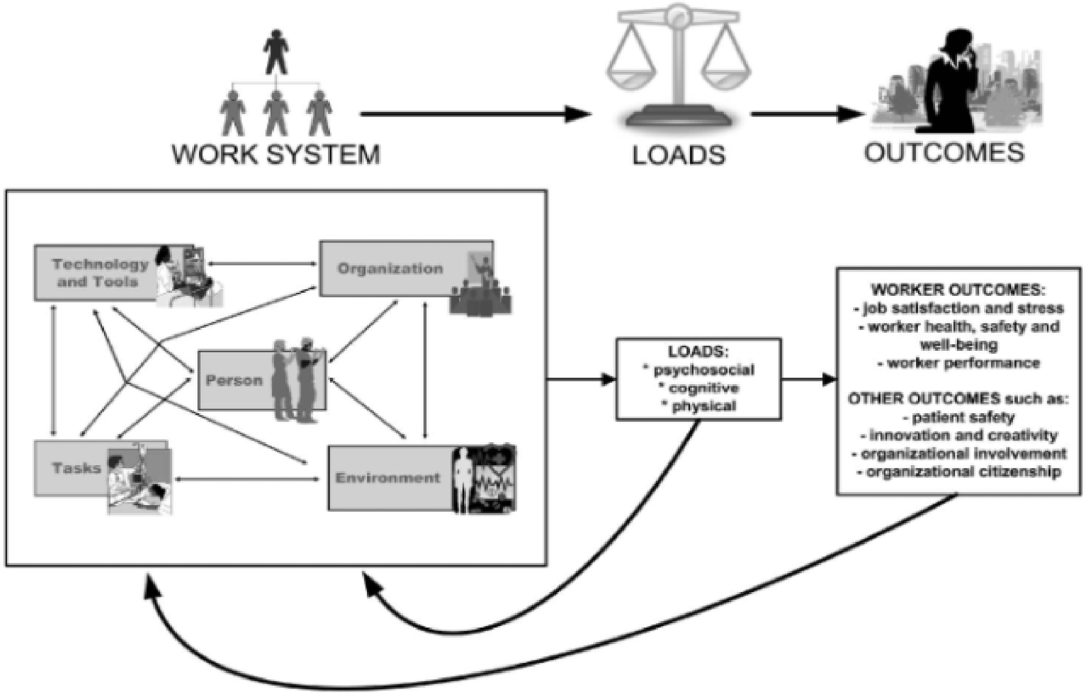

Figure 2-1 The Balance Theory for work system approaches. A structured work system, forming the context of where work takes place, has multiple constraints (or loads) that affect the outcomes of the system. The effect of the constrained can be "balanced" by changing the work system (Smith & Sainfort, 1989).

2.5.1.1 Systems Engineering Initiative for Patient Safety (SEIPS)

SEIPS is a work systems framework that was developed to understand work and performance in healthcare settings and its impact on patient safety (Carayon, Schoofs Hundt, et al., 2006). The SEIPS model integrates the work system model and a healthcare-related model, Donabedian model of quality (Donabedian, 2005), to create a relationship between the work system and outcomes. It uses a structure-process-outcome framework of the Donabedian model to guide the analysis and design of healthcare systems, where the structure is the work system as defined by the Balance Theory; the processes are care processes; and the outcomes are patient and employee outcomes Figure 2-1. The SEIPS model also includes feedback loops from the processes and outcomes back to the work system, indicating that the work system is always influenced and re-influenced by outcomes. Figure 2-2 provides a visual representation of SEIPS.

Context in SEIPS includes the work system and the care processes that occur within it. Poor processes and outcomes are triggers to the work system and SEIPS highlights opportunities for improved re-design of the work system. This concept is essential in understanding the engagement of caregivers with digital health interventions as the introduction of a technology will influence the work system and the care processes that may then influence outcomes. If the digital health intervention produced poor outcomes such as increased burden to use, the technology might not be engaged with, hence changing the work system with either reduced engagement or abandonment of technology. While the SEIPS model is comprehensive for professional healthcare contexts, it is limited in the focus on patients and caregivers.

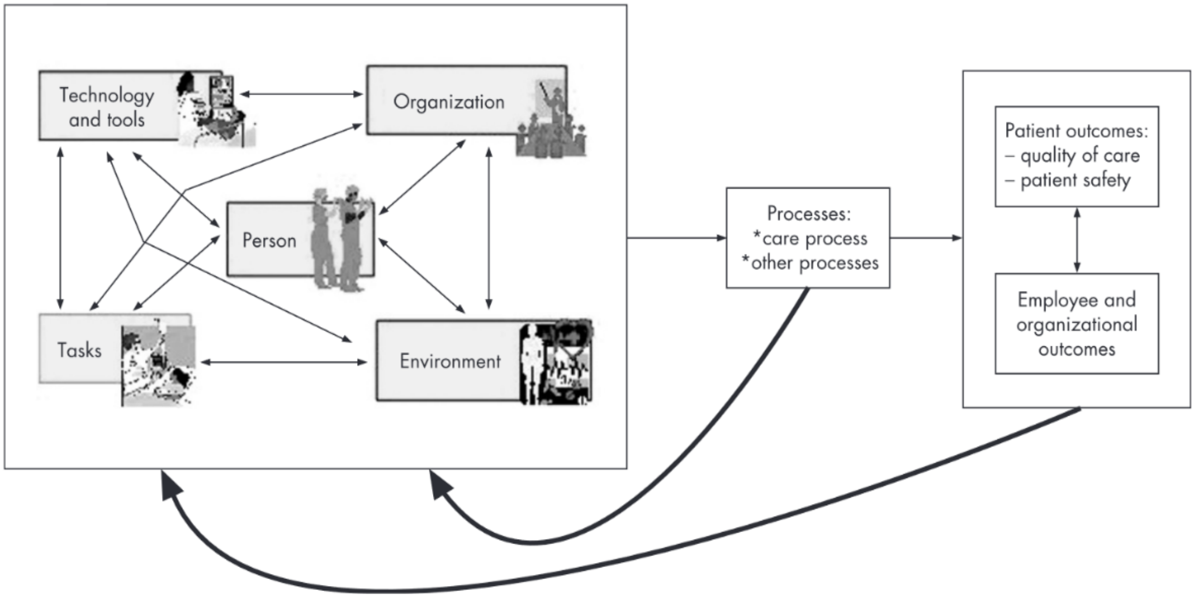

Figure 2-2 SEIPS uses the work system model and integrates it with a Structure-Process-Outcome model, where the context is the work system and the processes that occur within it (Carayon, Schoofs Hundt, et al., 2006). However, it remained necessary to capture the various care processes performed by patients and caregivers.

2.5.1.2 SEIPS 2.0

The SEIPS 2.0 model expands on processes based on who is actively performing work – healthcare workers, caregivers, and patients, or both. This expansion is based on the shift in focus on the field from patients and caregivers being passive recipients in healthcare to partners in care (Gorman et al., 2018; Valdez et al., 2015) and is important to consider when designing digital health interventions for caregivers (Valdez et al., 2015). Secondly, SEIPS 2.0 highlights the concept of configurations — while all components of the work system interact with each other as seen in SEIPS, only a subset of all interactions is relevant in each work process. The interaction(s) between the most influential components in a work system drives the outcomes (Holden et al., 2013). Thirdly, while SEIPS depicts the feedback loops, the SEIPS 2.0 model further expands on this by delineating between unintended vs intended, intermittent vs regular, and short vs long-lasting adaptations made to the system.

The context in SEIPS 2.0 is portrayed by the work system that influences the various processes done by professionals and patients, but an emphasis is placed on the most relevant work system components and their interactions that influence outcomes. Hence, context does not include the processes and the outcomes.

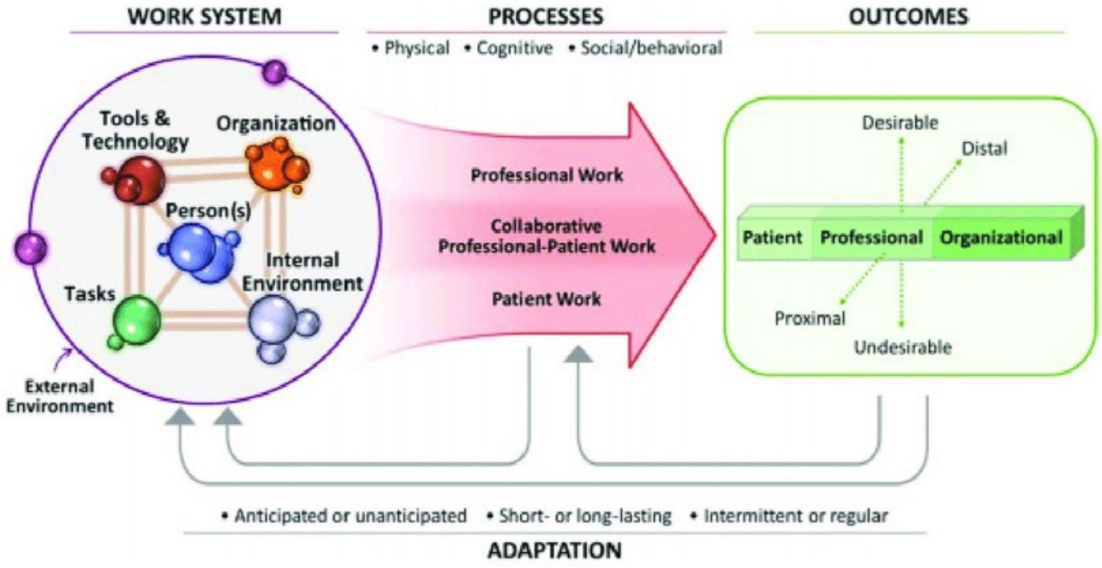

Figure 2-3 SEIPS 2.0 depicting context as the work system and the processes done by professionals and patients/caregivers that occur within it, with an emphasis on the most influential work system components (depicted by the larger bubbles in the work system) that affect outcomes *(Holden et al., 2013)*. However, there remained a need to elucidate context for non-professional patient and caregiver work in homes and communities.

2.5.1.3 Patient Work System (PWS) model

The PWS model presents an analysis of self-care performance constrints among elderly heart failure patients and their informal caregivers using the work system framework (Holden et al., 2015). It describes the work of non-professionals such as patients and informal caregivers doing work at non-professional settings such as home and community. This perspective of the work system is important as majority of work that happens in improving patient outcomes happens outside of professional healthcare settings (Holden et al., 2020) and this is important to identify and describe the work system components that can affect the engagement with caregiver-focused or patient-focused digital heatlh interventions. The PWS integrates the aging-specifc frameworks (Fisk et al., 2009) and healthcare-specifc human factors models (SEIPS and SEIPS 2.0). The integration of the aging-specific framework was performed to understand barriers to self-care performance for older adults with heart failure and their caregivers (Holden et al., 2015).

Figure 2-4 and Figure 2-5 provides an overview of the PWS and the specific elements associated with the work system components. The person(s) factors includes characterisitcs like demographics, biomedical, physical, affective, and cognitive traits of patients, caregivers, and healthcare professionals despite the model's focus on work done by non-professional in non-professional settings. The task factor describes tasks attributes that are carried out as part of the caregiving or patient work, such as the difficulty or complexity of the tasks. The tool factors encompass the usability and design, impact, and access to the tools used by nonprofessionals.

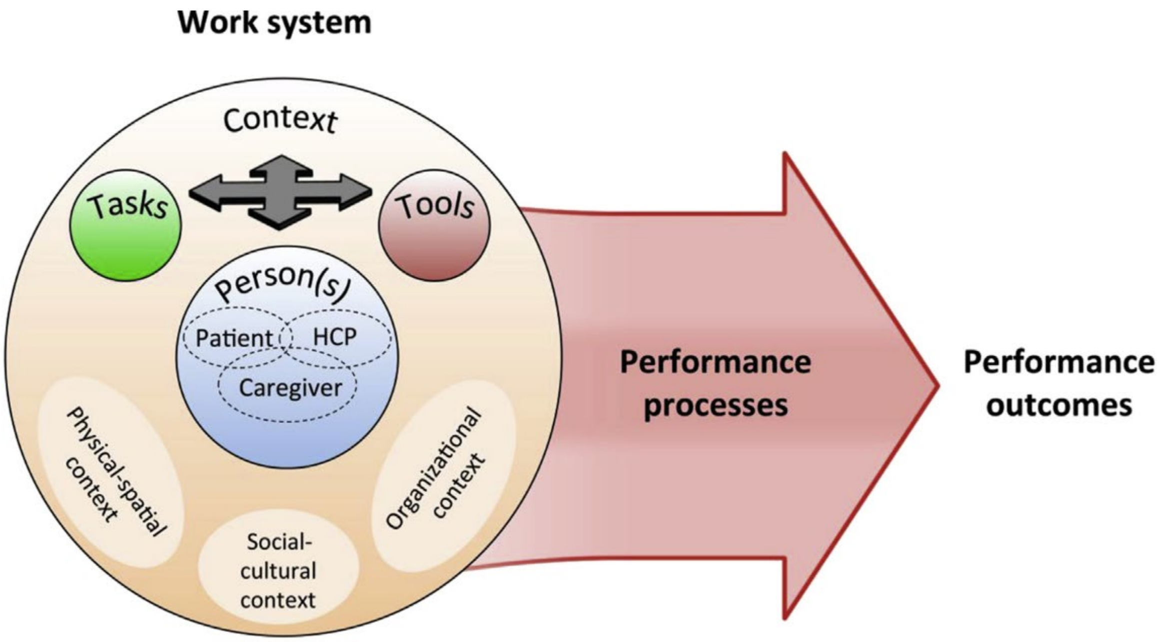

Figure 2-4 The PWS model describing context within the work system as social, organization, and physical context for patient/caregiver work in non-professional settings *(Holden et al., 2015)*.

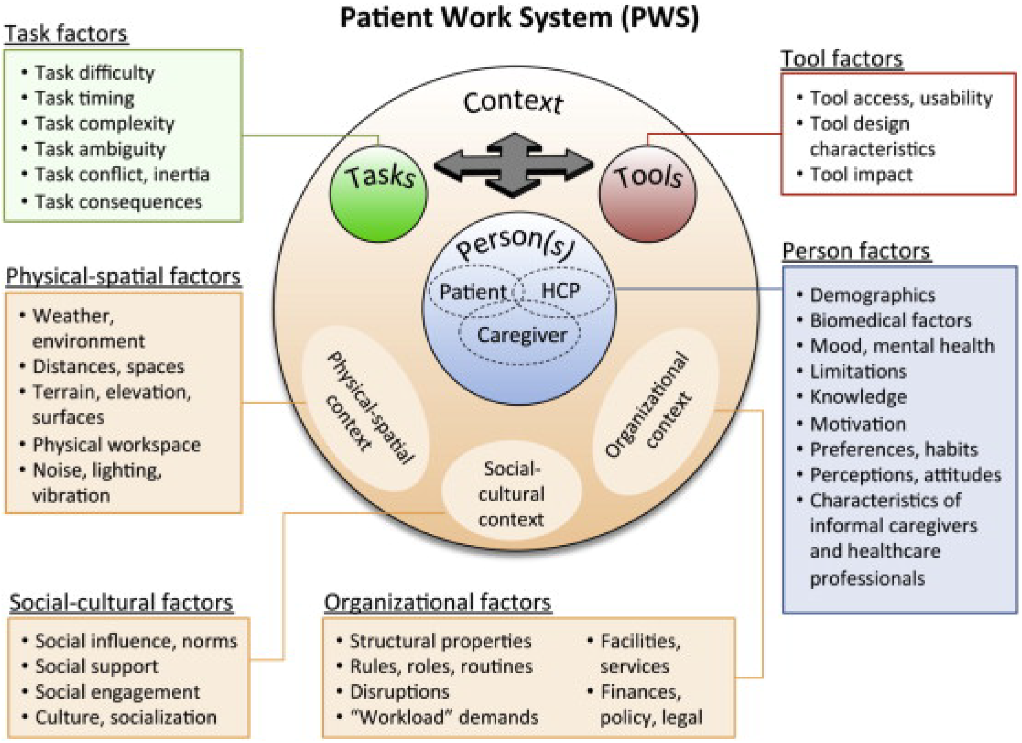

Figure 2-5 Work system components and elements of the PWS model (Holden et al., 2015)

While the SEIPS models implicitly define context as the entire work system, the PWS explicity describes context and places it within the work system. Context is further classified as socio-cultural, physical-spatial, and organizational contexts. Hence, the other componenets of the work system— person, tasks, and tools—are not considered context in this model. The three contextual factors were further explored in a later study that conducted a secondary analysis of the findings of PWS (Holden et al., 2017). The physical-spatial context refered to the weather, environment, geospatial distances between healthcare settings and home, and noise. Organizational factors refers to the rules, routines, and structural properties that are established within the context of patient care in nonprofessional setting. The social-cultural factor refers to social influence, normals, and support in the work system. The contextual factors are present in different levels – such as home and community. For example, if a household does not have the financial means to have computers at home (household organizational factor), the individual of the household would want to go to a library nearby (community physical-spatial factor) to seek health-information (Holden et al., 2017). These findings informed the creation of a macroergonomic patient work system model based on empirical evidence, visualized in Figure 2-6.

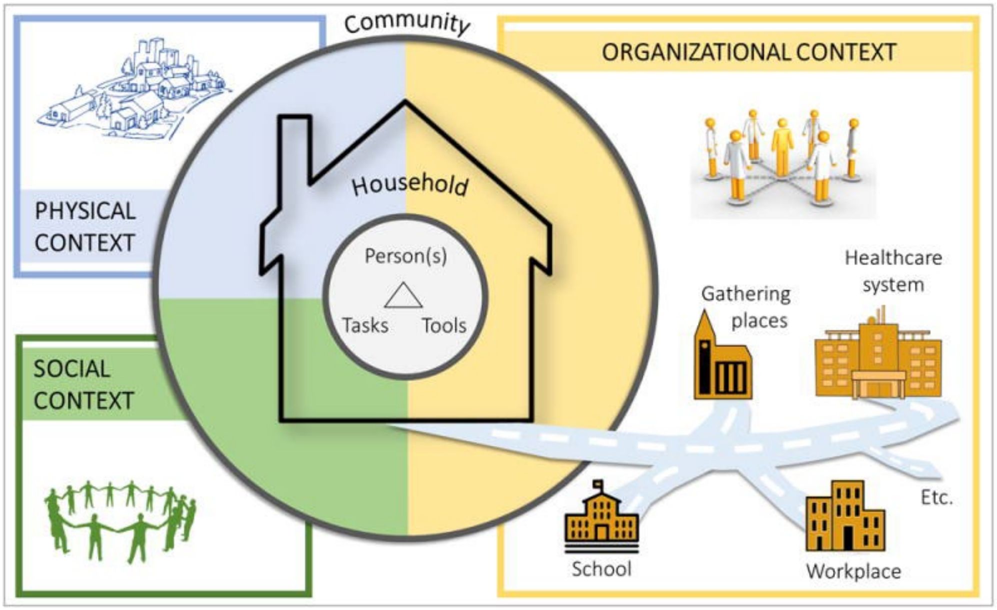

Figure 2-6 Description of context within the patient and caregiver work system (Holden et al., 2017)

While the model describes the factors that affects the performance of self-care and what constraints may be embbeded in the system that may affect self-care activities, it does not identify and describe the complex factors that would affect the engagement of caregivers with a newly introduced digital health interventions. There is also a need to expand the PWS model and define its factors for different patient groups and caregivers as it was based on information gathered specifically about elderly patients with heart failure and their caregivers in regards to self-care and medication management. The PWS framework (represented in Figure 2-4, Figure 2-5, Figure 2-6) could be used for further research in identifying factors within the work system that will affect engagement of informal caregivers of those living with ADRD with digital health interventions.

From these work system models, context of DHI engagement for ADRD caregivers can be defined as a structured system of interacting components impeding or facilitating DHI engagement such as person, tools and technologies, organizational-factors, socio-cultural factors, physical-spatial, and task factors that influence DHI engagement to create outcomes.

2.5.2 Unified Theory of Acceptance and Use of Technology 2 (UTAUT2)

The unified technology acceptance and use model (UTAUT2) is a theoretical framework that was developed to predict behavior intention and use behavior in the specific context of consumers (Venkatesh et al., 2012). The model states that the factors 1) performance expectancy, which is the degree to which an user will be benefitted from using the technology, 2) effort expectancy, which is the degree of ease associated with using technology, 3) social influence from others in using technology, 4) facilitating conditions such as perception of resources, support to use technology, 5) hedonic motivation, which is the joy in using, 6) price value, and 7) habit, which is the performance of behaviors automatically influence the behavioral intention to use technology, which in turn affects the use behavior. The factors hedonic motivation, price value, facilitating conditions, and habits are moderated by age, gender, and experience in using technology of the user. The model is depicted in Figure 2-7.

The context in this model is implicitly provided by social influence, person factors such as age, gender, experience, motivation, habits, and facilitating conditions as predictors of technology use beyond just the perception of the person. This model does not describe the situational context of technology such as the physical environment, the tasks involved and their characteristics, or groups of people that may be involved in performing a task. The UTAUT2 has been used in understanding predictors of use for mobile health technologies and wearable technologies in the healthcare settings (Duarte & Pinho, 2019; Schomakers et al., 2022). Contextual factors such as cultural differences, privacy, trust, and perception of disease as a threat have also had some influence on behavioral intent (Binyamin & Hoque, 2020; Dwivedi et al., 2016; Schomakers et al., 2022; Zhang et al., 2019).

The UTAUT2 is specifically developed for consumer technologies and can be applied towards digital health interventions for patients and caregivers to understand their use behavior, one of the constructs of engagement. It also can describe the effect size and the directionality of relationships between different factors. However, UTAUT2 has a few limitations for conceptualizing context to understand engagement with digital health interventions for caregivers of those living with ADRD. First, UTAUT2 has not been validated for the ADRD caregiving context and there are disagreements over the validity of constructs for mobile health applications. Secondly, while the UTAUT2 can predict directionality and effect size of constructs, the constructs are not comprehensive, specifically for the context of informal caregivers of those living with ADRD and mechanisms of how these constructs influence use behavior are not thoroughly explored.

Although the UTAUT2 does not explicitly define context of DHI engagement, it can be gleaned as the interplay between social influence, individual characteristics (age, gender, experience), and facilitating conditions that influence technology use beyond just a user's perception. In other words, context in UTAUT2 emerges from a combination of social and individual factors surrounding the technology use.

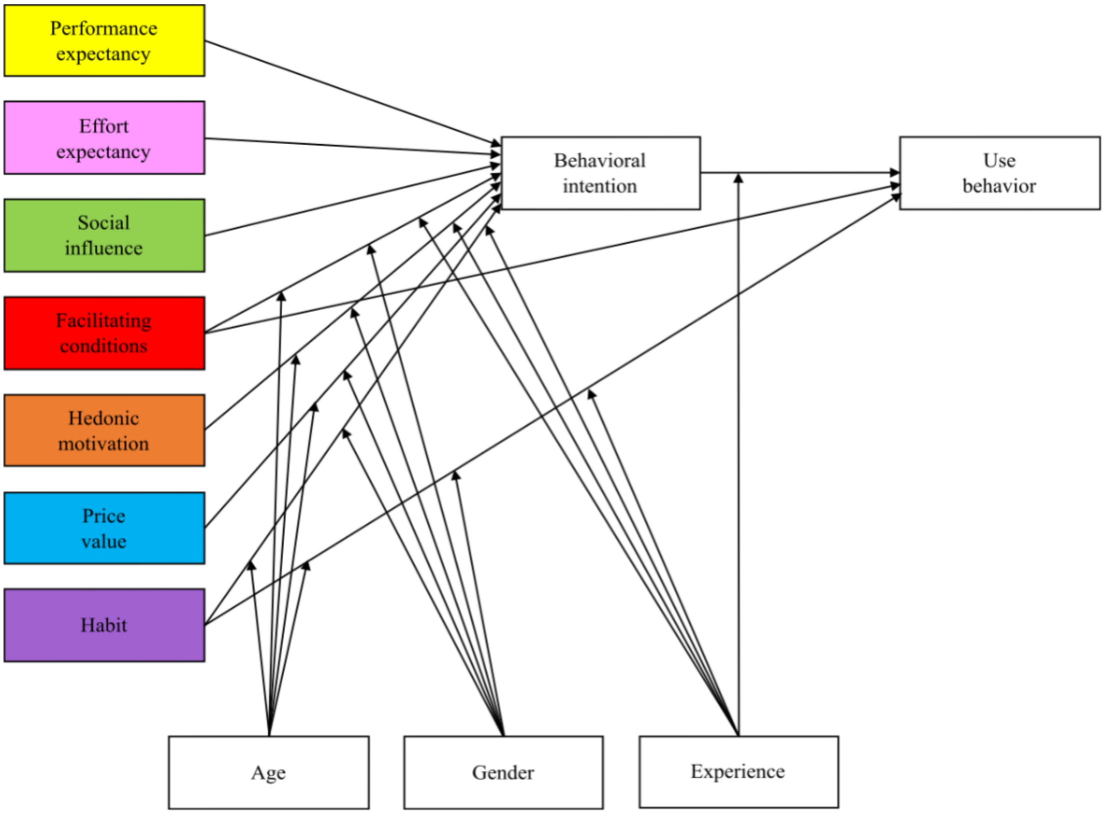

Figure 2-7 The Unified Theory of Acceptance and Use of Technology. Context is implicated as the social influence, facilitating conditions and habits *(Venkatesh et al., 2012)*

2.5.3 Contextual Design

Contextual Design is a user-centered design approach that emphasizes the importance of understanding the user's context in the design process. It involves observing and analyzing the user's behavior, needs, and goals in their natural environment to uncover insights that inform design. This approach focuses on the user experience and how it is influenced by the user's context, such as their physical and social environment. Contextual Design is particularly useful for designing complex technologies that require a deep understanding of the user's needs and behaviors (Beyer & Holtzblatt, 1998). Contextual Design, unlike the other frameworks described here, is an approach to design for creating a technology, with the aim of going into wherever the user is and seeing what they do to uncover why people do what they do (Beyer & Holtzblatt, 1998). Although contextual design suggests many steps and methods to creating an intervention, this section will focus on how the approach conceptualizes context.

Contextual Design provides ten different models for conceptualizing contexts to understand human behavior and experience. They are the flow model, cultural model, physical model, sequence model, artifact model, the day in the life model, identity model, relationship model, collaboration model, and sensation model.

1. The flow model depicts how multiple individuals coordinate and assume various roles and responsibilities during a work process facilitated by technology.
2. The cultural model highlights the various factors that influence a person, group, or organization, unveiling the cultural context in which the product must thrive.
3. The physical model outlines the arrangement and progression of actives as they are observed in each space, encompassing the layout, tolls used, and paths taken in carrying out the activity.
4. The sequence model illustrates the individual steps and intentions behind the activities to be supported, akin to a task analysis.
5. The artifact model displays the design and usage pattern of an object used during the activity.
6. The day-in-the-life model how behaviors are different in various situations in the user's life.
7. Identity models show how the core identity of the user, such as pride, self-esteem, and value, and how they have the potential to affect an activity.
8. The relationship model shows the important relationships in the user's life and how a user interacts with the relationships in the context of the activity being studied.

9. Collaboration model how collaboration with others helps achieve the activity being studied.
10. Sensation model shows the visceral experience the technology should manifest in the user's life.

According to Contextual Design, context is an ongoing experience surrounding a user's activity that influences their behavior and experience with a technology. These factors can be social (cultural model, relationship model, collaboration model), physical (physical model), temporal (day-in-the-life model), or internal (identity model) and can be explored through various lenses using the ten contextual models.

Contextual Design provides flexibility for researchers and designers to use any combination of models to conceptualize context, according to their research or design goals. While each of these models describe context in a simplified way, the use of all 10 models may be more elaborate and complicated.

2.5.4 Activity theory

Activity theory, also called cultural-history activity theory, is a descriptive sociotechnical theory that frames how people achieve goals through the mediation of artifacts such as tools, societal rules, division of labor, and community (Engeström, 2000). It suggests that an activity is composed of a subject (a person or group) that engages in an activity to achieve an objective mediated by artefacts such as tools in a social and cultural context. This theory further describes activities as a collection of actions that are performed consciously. Actions are further composed of operations that are performed non-consciously, thereby helping understand the unity of consciousness, activities, and the context in which an activity occurs. A common representation of an activity is Engeström's triangle, with the subject, object (or objective of the activity), and artefacts (tools) as part of the upper triangle. The base of the triangle is the social context of the activity and includes the rules that a subject act by, the community or the other individuals, and the division of labor among the members of the community. This interaction leads to an outcome such as health and wellness of a patient or caregiver.

While activity theory does not explicitly suggest what context is, context models have been developed using the activity theory as a framework. Studies have mapped the components of activity theory to explicit taxonomy of context. A model by Kofod-Petersen and Cassens maps the components of activity theory to five contextual components – environmental context such as users surroundings, tools, services, people, and information accessed by the user; personal context that describes that mental and physical information about that user; social context that describes social aspects, such as information regarding the various roles a user can assume in a society; task context that describes what the user is doing; and spatial-temporal context that describes attributes such as time, location, and the community (Kofod-Petersen & Cassens, 2006). This model suggests that the goal and the activities done by the subject are not part of the context.

Activity theory and the context models that arise from activity theory recognize that context is not explicitly identifiable and that there are no sharp boundaries for context. Hence, activity theory uses the activity performed by the subject to define the boundaries of the context.

From activity theory and related context models, it can be gleaned that context is composed of the environmental context, personal context, social context, task context, and spatial-temporal context in which the activity of DHI engagement takes place. This context collectively shapes and is shaped by the activity.

2.5.5 Context-aware computing models

Context-aware computing is a field that is concerned with the design of technologies that "uses context to provide relevant information and/or services to the user, where relevancy depends on the user's tasks" (Dey & Abowd, 1999). The field of context-aware computing presents various conceptualizations of context, ranging from positivist to phenomenological perspectives (Dey & Abowd, 1999; Dourish, 2004; Schmidt, 2000; Winograd, 2001).

Positivist approaches to context view it as a kind of knowable information that can be captured and represented by technology. This stems from the belief that context remains stable throughout an activity. Within this perspective, there are different definitions. Brown et al. focus on environmental factors like location, user identity, time, and season (Brown et al., 1997). Dey and Abowd take a broader view, defining context as any information that characterizes the situation, including people, places, objects (like tools), and even the user and application themselves. This latter definition goes beyond "environment" to encompass all potentially relevant factors. Positivists also propose a categorization scheme, dividing context into primary and secondary categories. Primary context includes core aspects like location, user identity, time, and the current activity (Dey & Abowd, 1999). The secondary context then encompasses additional details that are attributes of these primary factors.

In contrast to positivist approaches, phenomenological perspectives (Dourish, 2004) define context as a relational property that emerges from the interaction between objects and activities. Context is not simply a collection of data to be programmed, its relevance hinges on its connection to a specific activity. Furthermore, phenomenology argues that activity shapes context, rather than an independent context shaping activity. Context, then, is an emergent property of interaction, not a stable, objective set of features. Meaning and relevance arise from the relationship between these contextual properties and established practices – those purposeful actions surrounding tools and information that imbue them with significance for users. Systems can display their own context, offering users transparency into their decision-making processes. This visibility becomes the context within which users can then make informed actions.

Combining the positivist and phenomenological perspectives in context-aware computing reveals that context can be both a set of stable, knowable information and an emergent, relational property shaped by interactions and activities. Although these perspectives lie at opposite ends of the epistemological spectrum, they necessitate a pragmatic approach to defining context that supports the design of DHIs in a manner that is both comprehensive but also simplified in communicating the complexity of context for the purpose of design.

A summary of all approaches and their conceptualization of context is described in Table 2-4.

Definition of context of DHI engagement

From the various perspectives of context across the epistemological spectrum, the context of DHI engagement can be effectively defined using the patient work system (PWS) model. The PWS framework, rooted in pragmatic epistemology, conceptualizes context as a dynamic system of interacting components. These components include the person, tasks, characteristics of the DHI under study, other tools and technologies used, social factors, organizational factors, and physical-spatial factors, all of which influence DHI engagement to create outcomes.

The PWS model provides a comprehensive and holistic approach to understanding context by examining how these components interact to produce outcomes. At the same time, it simplifies the complexity of context by categorizing it into distinct components, enabling theoretical advancement of context and communication of context to key stakeholders for design of DHIs.

Within this model, the dynamic system of interacting components can act as barriers or facilitators to the process of DHI engagement. While outcomes resulting from DHI engagement can further impede or facilitate engagement, they are not considered part of the context at a single point in time. Additionally, components of the dynamic system that do not influence DHI engagement at a given moment are not regarded as part of the context for that specific point in time.

Approach	**Framework**	**Purpose**	**Conceptualization of the context**	**Gaps in conceptualization of context for studying engagement in ADRD caregiving**
Work systems	SEIPS	Study, design, and evaluate work and supporting technologies in healthcare settings	The structured work system of interacting components	Limited focus on patient and caregiver contexts
	SEIPS 2.0	Study, design, and evaluate work and supporting technologies in healthcare settings with a delineation among professional, collaborative, and patient work	The structured work system of interacting components with an emphasis on the most relevant interactions between work system components that lead to outcomes	The context for nonprofessional patient and caregiver work in nonprofessional settings such as homes and communities needs to be clarified.
	PWS	Study, design, and evaluate the work and supporting technologies of patients and caregivers in nonprofessional	Physical, organizational, and socio-cultural context explicitly placed	Work system is defined only for elderly patients that perform self-care activities;

Approach	Framework	Purpose	Conceptualization of the context	Gaps in conceptualization of context for studying engagement in ADRD caregiving
		settings such as home and community	within the patient work system	limited focus on informal caregivers
UTAUT2		To predict behavioral intention and use of consumer technologies	Facilitating conditions, habits, and social influence that affect behavioral intent and use of consumer technologies	Contextual factors have not been validated for ADRD caregiving – there may be other contextual factors
Contextual design		To understand needs and design technologies	A user's natural environment and how it helps or constraints specific tasks the user needs to accomplish	Does not provide insights into larger systems or context beyond the user's immediate surrounding that may affect ADRD caregiving or engagement with digital health interventions
Activity theory		To understand the unity of consciousness and activity	Context consists of environment, personal, social, task, and spatio-temporal sub contexts	Complex to apply for design of technologies; sub-contexts are subjective and not well-elucidated to apply in various settings
Context-aware computing approaches	Positivist	Posits context as information for design of technologies	Context consists of any information in a situation that is relevant to interaction between a user and an application	Requires knowing and providing technologies with context before establishing what is relevant and irrelevant context; additionally it only includes the immediate context surrounding an interaction with technology

Approach	**Framework**	**Purpose**	**Conceptualization of the context**	**Gaps in conceptualization of context for studying engagement in ADRD caregiving**
	Phenomenological	To posit context as a relational property that holds between objects and activities	Context is dynamic and arises from activity	Dynamic and comprehensive contexts are difficult to model

Table 2-4 Summary of different approaches to conceptualizing context and their gaps

2.6 Methods of analysis for identifying and describing contexts in Human Factors Engineering

In identifying and describing contextual factors that affect engagement, the goal of the research is usually discovery-oriented to understand the processes and mechanisms that underly phenomenon (Forman et al., 2008a). The most common research methods used to describe an account of the factors that could lead to an action are qualitative in nature (Creswell et al., 2007).

Qualitative research helps advance the field of healthcare HFE by providing insights into user behavior and actions in ways traditional quantitative approach alone cannot (Hancock & Szalma, 2004; Hignett & Wilson, 2004; Valdez et al., 2017). First, qualitative research can help offer a systems-perspective of highly complex environments of healthcare (Vicente, 1999). It can help explore complex cognitive and behavioral processes embedded within complex physical, organizational, and social contexts of healthcare that can be otherwise difficult to quantify (Carayon, 2006; Hancock & Szalma, 2004; Hignett et al., 2013). Second, it is well suited for understanding phenomena within their contexts, uncovering links to concepts and behaviors, thereby generating and refining healthcare HFE theory (Bradley et al., 2007; Glaser & Strauss, 2017). Third, it serves as a means of gaining a deeper understanding of health professional, patient and caregiver work for the purposes of improving work environments, such as through design of technologies (Beer et al., 2014; Carayon, 2006; Rutkowski et al., 2021b; Werner, Stanislawski, et al., 2017). Fourth, it has the capability to support quantitative research in multiple ways. It can offer explanatory reasons behind quantitative findings or act as an exploratory tool, helping identify relevant variables for quantitative studies. It can also shed light on the underlying meaning behind results of quantitative data analysis. (Carayon et al., 2015; Christian et al., 2006; Rochais et al., 2013). Additionally, quantitative methods are also often insufficient for a number of necessary stages of product development such as identifying needs of various populations and translating these needs to design (Wixon et al., 1990).

Qualitative research methods such as semi-structured interviews, observation studies, and focus groups have been predominantly used in Human Factors Engineering to study complex constructs like contexts (Holden et al., 2017; S. Valdez & Brennan, 2017; Valdez & Brennan, 2015; Werner, Stanislawski, et al., 2017). The use of qualitative methods yields a thick description of qualitative data. Thick description of qualitative data often entails a detailed account of human activities and the context in which these activities take place. This description can be useful in studying abstract concepts like context.

Despite the various benefits of qualitative research, qualitative research poses challenges to analysis requiring manual, time-intensive, and resource-intensive analyses. Unlike quantitative data with structured numerical values, qualitative research generates a vast amount of raw, unstructured data such as verbatim notes, transcribed recordings of interviews or focus groups (each transcript ranging from 10 pages to 40 pages of single-spaced text), and the researcher's reflective notes made during the research. Organizing and analyzing this voluminous data is labor-intensive and time-consuming (Creswell & Poth, 2007; Pope et al., 2000). Maintaining qualitative rigor further adds to the time and resource demands. Triangulation, a key principle to improving the credibility of research, involves incorporating multiple data sources, researchers, and methods that add layers of complexity to the analysis (Valdez et al., 2017).

The following are the common analysis techniques for identifying themes and patterns in qualitative data.

2.6.1 Manual analysis methods

2.6.1.1 Content analysis techniques

Content analysis is a widely used research method that involves the systematic analysis of qualitative data to identify patterns and themes in the data (Hsieh & Shannon, 2005). The method is used to analyze a wide range of textual and visual materials, including documents, media content, and social media data, among others. Content analysis involves systematically analyzing and categorizing textual or visual data to identify patterns and themes. This process helps to identify overarching patterns or themes that may not have been immediately apparent during content analysis. One of the key benefits of content analysis is its flexibility, allowing researchers to adapt the method to suit their specific research questions and data characteristics. Hsieh and Shannon (2005) outline three different approaches to qualitative content analysis: conventional, directed, and summative. The conventional approach involves an inductive analysis of data, the directed approach involves a deductive and inductive analysis based on pre-existing categories in literature, and the summative approach is a quantitative method that involves the use of numerical counts and statistical analysis of word frequencies in the data. Despite the different approaches, all three involve a rigorous and systematic process of identifying and categorizing patterns and themes in the data. These techniques allow the researcher to determine the relationships between concepts.

Content analysis often involves coding the data for specific patterns based on specific research questions. A code is "most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data" (Saldana, 2015). Coding starts with either using existing frameworks to identify patterns in the data or looking for specific instances based on the research question (Saldana, 2015). These initial codes were then categorized multiple times until the codes were segregated, grouped, and relinked to consolidate meaning (Saldana, 2015). Content analysis is also often augmented with techniques such as affinity diagramming to further group identified categories and identify themes. After the content analysis is completed, affinity diagramming is used to group the identified categories or themes into clusters based on their similarities or relationships. Affinity diagramming is a method used in qualitative research to organize and synthesize data gathered through content analysis. Affinity diagramming can be a helpful tool in qualitative research because it allows researchers to identify patterns and relationships in large amounts of data, and to organize the data in a way that facilitates further analysis and interpretation.

Manual qualitative analysis techniques can be conceptually challenging, time-consuming, and resource intensive (Pope et al., 2000). Researchers often spend time familiarizing themselves with the data, iteratively identifying themes drawn directly from the data or from a preexisting model or framework and engaging in member-checking to ensure findings align with reality (Valdez et al., 2017). Current literature suggests that analysis time using content analysis techniques can take anywhere from 300 minutes to 400 minutes for a 60-minute transcription of one interview (Neal et al., 2015; Taylor et al., 2018).

2.6.1.2 Rapid approaches to qualitative analysis

Several rapid approaches to qualitative analysis have been developed and used to reduce the time and cost of qualitative analysis while simultaneously improving the ability to collect more data (Hamilton, 2013; Taylor et al., 2018; Vindrola-Padros & Johnson, 2020). These techniques mainly focus on eliminating the need to create transcripts, speeding up the process of transcription, or by adapting qualitative methods to only focus on deductive analysis, where themes are identified from the data using pre-existing frameworks.

Eliminating the need for creating transcripts requires researchers to simultaneously collect data and analyze data using techniques like mind mapping or by coding data directly from the audio or visual source. While these techniques reduce cost of analysis and have been evaluated for their reliability in identifying codes through inter-rater reliability scores (Gravois et al., 1992), they often compromise on the rigor of the analysis by limiting the natural pace of group discussions that are required in qualitative coding and the potential loss of details in coding while collecting data (Valdez et al., 2017; Vindrola-Padros & Johnson, 2020). Transcripts provide a verbatim record of everything said, allowing researchers to revisit specific points and nuances later. Direct coding can miss these subtleties, especially for complex ideas or technical jargon. Furthermore, skipping transcripts can disrupt the natural flow of group discussions in interviews or focus groups. Researchers focused on coding in real-time may not be able to fully engage with participants or ask follow-up questions as readily.

Another method is expediting the creation of transcripts using voice recognition software or employing scribes (Vindrola-Padros & Johnson, 2020). This approach is especially valuable for slow typists or researchers with disabilities, but it adds a financial burden to the project. Both methods offer distinct advantages. Speeding up transcripts allows for faster analysis compared to skipping them entirely, and it provides a more faithful record of the data for in-depth analysis.

One additional method created by the U.S. Department for Veteran Affairs (Hamilton, 2013), offers a more structured approach to qualitative analysis for rapid transmission of findings to healthcare settings. This process involved developing templated summaries of each data collection event such as interviews or focus groups using templated with pre-determined domains. The template is then tested to ensure it is easy to use and it captures the necessary information. The data from each transcript is summarized in the template and the summaries are organized in a matrix to identify patterns and trends across the data. While this method significantly reduces the time involved in qualitative analysis (Taylor et al., 2018), it cannot be used for exploratory qualitative analysis research that aims to discover and understand a new concept that is not well-defined like context.

2.6.2 Semi-automated analysis

2.6.2.1 Epistemic Network Analysis

Epistemic Network Analysis (ENA) is a method used to analyze the structure and dynamics of knowledge and learning in complex systems (Shaffer et al., 2009). It is based on the idea that knowledge is not just a collection of discrete facts, but rather a complex network of concepts and relationships that evolve over time. ENA uses mathematical models and network analysis techniques to study how knowledge is constructed and how it changes over time. The basic premise of ENA is that knowledge is represented as a network of nodes and links, where nodes represent concepts or ideas, and links represent the relationships between those concepts. By analyzing the structure of the network, ENA can reveal patterns of learning and knowledge acquisition, as well as identify areas where knowledge may be incomplete or incorrect. However, the focus of ENA is to represent qualitative data as how they are connected to one another and co-occur, but not necessarily to identify themes or topics from a dataset.

2.6.2.2 Topic modeling

Topic modeling is a semi-automated text analysis technique used in natural language processing and machine learning to identify and extract topics from a large collection of text data. The goal of topic modeling is to discover the underlying themes or topics in the text data and to group similar pieces of text based on the topics they address.

The most used algorithm for topic modeling is Latent Dirichlet Allocation (LDA), which is a generative statistical model that is based on Bayesian probability theory (Blei et al., 2001). The model assumes that each document in the collection is a mixture of topics, and that each word in the document is drawn from one of those topics. It uses rich textual data from a collection of documents, called a corpus, to create topics or themes that arise from the corpus. Topics are a distribution of words from the corpus, with those words most related to the topic having higher probabilities of occurrence (Roberts et al., 2013). The algorithm iteratively assigns topics to each word in the corpus and updates the probabilities of each topic based on the words that are associated with it. Typically, a researcher will choose a set number of topics to extract from the data, and then examine the words and documents associated with each topic to interpret what it represents. Topic modeling can be a useful tool for analyzing large, unstructured datasets like semi-structured interviews. However, it has limited ability to model relationships between different topics.

Structural Topic Modeling (STM) is a type of topic modeling that allows for the incorporation of covariates (independent variables) into the topics. Covariates are independent variables that are often additional metadata that can influence how frequently topics appear across the documents (topic prevalence) and the various words used to discuss each topic (topic content) through a standard regression analysis (Roberts et al., 2013, 2014). Covariates might play a crucial role in enhancing the understanding of concealed patterns and variations such as correlated topics which proves particularly valuable in the qualitative analysis of data. Researchers have leveraged covariates to systematically explore large text data, leading to a more nuanced and insightful qualitative understanding (Lee & Kolodge, 2020; Lester et al., 2019; Loganathar et al., 2023; Rutkowski et al., 2021b). For example, Loganathar et al., 2023 used a STM model to find that high users of a digital journaling platform for caregivers of people living with ADRD discussed positive experiences about their caregiving more frequently, while low users expressed negativity regarding their caregiving experiences through their interview responses using STM. The number of journal posts of each participant was added as a covariate to interview data in this study. This helped reveal this difference in user engagement, providing a deeper understanding of how user engagement with the journal influenced the topics discussed in the interviews.

While covariates have been used to identify how the topics are correlated and how the prevalence of topics changes with respect to the covariate, current research has not explored using existing frameworks or deductive coding to identify topics (Roberts et al., 2013). This is an important gap that needs to be addressed if semi-automated approaches are used for content analysis for exploring factors, such as context, that use pre-existing conceptualizations.

2.6.3 Automated qualitative analysis

Recently, there has been an increased attention to the use of Large Language Models (LLMs), such as ChatGPT (Generative Pre-trained Transformer), for qualitative analysis (Morgan, 2023; Schiavone et al., 2023; van Manen, 2023). These LLMs are trained on massive amounts of text data to communicate and generate human-like text in response to a wide range of prompts and questions.

ChatGPT is a straightforward chatbot interface where data can be uploaded into the chatbot and multiple queries regarding the data can be posted. Major software packages for qualitative analysis such as ATLAS.ti and MAXQDA have developed partnerships with the developers of ChatGPT to summarize various aspects of the data and provide automatic coding of data (Morgan, 2023). Various preliminary studies have been conducted to evaluate ChatGPT's ability to produce similar results as that of manual qualitative coding, yielding mixed results. While ChatGPT is agreed upon as a way to reduce the time required to perform manual qualitative coding and a reliable method to identify broad themes, its ability to identify subtle, interpretive themes is underexplored and in-question (Morgan, 2023; Schiavone et al., 2023). Additionally, traditional coding usually involves multiple cycles of coding, where a researcher goes from identified initial set of codes that are closer to the original data and the subsequent cycles of coding work with the previous set of codes to locate more conceptual patterns and links within the data (Saldana, 2015). However, ChatGPT prioritizes identifying general themes in the data initially. This "broad to specific" approach might not be ideal for inductive research, which often starts with specific observations and builds towards broader conclusions. Researchers aiming to explore new ideas from data may find this order of analysis restrictive. Further complicating matters is the potential for "hallucination" – the generation of inaccurate or nonsensical responses by the model. Since each response builds on the context of previous interactions, a single misstep can snowball, leading to misidentified themes and subthemes in the data analysis. In essence, while ChatGPT can be a helpful tool for finding broad themes, its limitations in inductive research and potential for introducing errors require careful consideration.

Analysis method	**Limitations**
Content analysis	Conceptually challenging, resource-intensive, and time-consuming (Pope et al., 2000)
Rapid approaches	Inability to produce nuanced themes; reduces rigor of research; and can only be used for explanatory research
ENA	Relies on pre-defined categories or concepts to construct interactions but cannot generate themes
LDA	Limited ability to model relationships between topics; Lack of consideration of covariate effects; No ability to use existing frameworks to guide analysis (Roberts et al., 2013)
STM	Unknown ability to explore deductive and inductive approaches to qualitative analysis using existing frameworks
Automated approaches	Hallucinations and inability to produce nuanced, interpretive themes

Table 2-5 Common methods used to analyze qualitative datasets and their limitations

3 Research questions

As discussed in Chapter 2, despite the prevalence of efficacious digital health interventions for ADRD caregivers, negative outcomes continue to persist. One factor identified as the cause for prevalence of negative outcomes is the inadequate engagement of ADRD caregivers with digital health interventions (DHIs). We know from Chapter 2 that engagement is influenced by contextual factors, but the contextual factors of ADRD caregivers that influence engagement are underexplored. Therefore, I propose using the Patient Work System model to conceptualize the context and explore the contextual barriers and facilitators to DHI engagement of ADRD caregivers. As defined in Chapter 2.5, context of DHI engagement can be defined as a dynamic system of interacting components such as person, tasks, the characteristics of DHI under study, other tools and technologies used, social-factors, organizational factors, and physical-spatial factors that influence DHI engagement to create outcomes. The dynamic interacting components could act as contextual barriers or facilitators to DHI engagement. This dynamic context of DHI engagement has not been fully explored for ADRD caregivers and limits our current understanding of how ADRD caregivers engage with DHIs.

Additionally, as discussed in Chapter 2.6, methods to analyze and explore complex contexts are qualitative in nature and can be resource and time intensive. Semi-automated techniques such as Latent Dirichlet Allocation (LDA) do not provide any means for using existing conceptual frameworks to guide findings and answer specific research questions such as contextual factors affecting engagement. I propose to use structural topic modeling, a type of topic modeling that allows for addition of covariates or variables that that influence the prevalence of a topic within the data. I will use DHI engagement and the components of PWS as a covariate to identify how the PWS components influence the presence of contextual factors in the data.

3.1 Research question 1: Contextual factors behind DHI engagement

RQ1: How are contextual barriers and facilitators, defined by the work system model, of ADRD caregivers associated with the various digital health engagement patterns in a digital health intervention (DHI) designed to support care coordination among ADRD caregivers?

As discussed in Chapter 2, DHI engagement can be defined as "the extent and manner of use and a subjective experience characterized by attention, interest and affect" (O'Brien & Toms, 2008; Perski et al., 2017). Many contextual factors such as cultural relevance, habits, trust in technology have been shown to impede or facilitate DHI engagement. Understanding the contextual factors and how they impede or facilitate DHI engagement for ADRD caregiving can help with redesign of digital health interventions to improve meaningful DHI engagement and thereby improve outcomes for ADRD caregivers.

I propose to use the PWS model to conceptualize context and identify the work system elements, hereby understood as contextual factors, that influence engagement with digital health interventions through content analysis. Further, I propose to investigate how these contextual factors impede or facilitate DHI engagement and how these barriers and facilitators are associated with the various DHI engagement patterns. Only few studies have explored engagement among caregivers of those living with ADRD, such as extent of use, intent to adopt, and acceptability of DHIs (Boutilier et al., 2022; Mendez et al., 2021b). While these studies provide insights into who uses digital health interventions the most and the least, the complex factors such as stage of disease, range of caregiving tasks, cultural relevance, and personal characteristics that may lead to the varying levels of engagement (e.g., high extent vs use or low extent of use) are poorly understood.

3.2 Research question 2: Structural Topic Modeling for Qualitative Analysis

RQ2: How does structural topic modeling support content analysis, both inductive analysis and inductive-deductive analysis, for identifying contextual factors of ADRD caregivers that influence engagement in a digital health intervention for ADRD caregivers?

As mentioned in Chapter 2.6, understanding contextual factors involves using qualitative methodologies that generate rich qualitative data. Manual data analysis methods, such as content analysis, are generally used in discovery-oriented research questions for describing an account of factors that lead to an action, such as engagement (Forman et al., 2008a). Manual qualitative analysis techniques can be conceptually challenging, time-consuming, and resource intensive (Pope et al., 2000). Researchers often spend time familiarizing themselves with the data, iteratively identifying themes drawn directly from the data or from a preexisting model or framework (Valdez et al., 2017). Although semiautomated techniques such as Latent Dirichlet

Allocation, a topic modeling technique, could help with this, they are limited in their ability to model relationships between themes and existing frameworks cannot be used to guide analysis (Roberts et al., 2013).

I propose to use Structural Topic Modeling (STM), a type of topic modeling, that allows for the addition of covariates or independent variables that affect the prevalence of a topic in a document or the content of topics across documents and combine it with manual qualitative analysis (Roberts et al., 2013). I propose a combined STM-manual qualitative approach to identifying contextual factors of ADRD caregivers that influence DHI engagement. I will first manually code the interview transcripts using the PWS components. I will then run STM on these codes using the PWS components as a covariate and identify how PWS components influence the presence of STM-identified topics. I will compare the results of the combined STM-manual qualitative analysis and evaluate its time-efficiency and usefulness and understand if STM can support qualitative analysis.

4 Researcher's worldview

To perform research, a researcher makes decisions on their research methods and methodologies from a plethora of choices. The researcher can justify their choice and use of methods and methodologies based on their worldview (Diesing, 1966). The researcher's paradigm or worldview encompasses their beliefs about theories of existence (ontology), theories of knowledge that explore the relationship between the researcher and the researched (epistemology), and theories of how knowledge can be produced (methodology) they choose for their research proposal (Creswell, 2009).

The range of worldviews can be conceptualized on a continuum ranging from objectivism, where a researcher believes there is one objective reality outside of human perception and uses quantitative methodologies, to subjectivism, where a researcher believes that knowledge is subjective to the each individual and there is no ultimate truth and uses interpretive and critical inquiry methodologies (Diesing, 1966). Each of these worldviews have their corresponding beliefs about ontology, epistemology, and methodology.

As a researcher, I identify as a pragmatic, which lies somewhere middle on the spectrum of worldviews between objectivism and subjectivism (Barkin, 2003). I assume a constructivist epistemology (knowledge is provisional and contingent, derived from practical consequences and implications), and a pragmatic set of methodological procedures that involves using both qualitative and quantitative methods where necessary (Lee, 2012).

Operationally, I tend to use a variety of qualitative and quantitative research methodologies to understand the experiences and perspectives of individuals influenced by their varying contexts, including me as a researcher and quantitative research methods to complement my research in constructing knowledge. For example, in the case of qualitative methods such as interviews, this could mean asking broader and general questions about a situation as well as documenting my perception of how my place as a researcher influences the participants. In the case of quantitative methods, it could mean using surveys or questionnaires to gather data on individual beliefs or experiences and interpret the data in a way that recognizes the subjective nature of these beliefs and the context in which they were formed.

My affinity towards pragmatism stems from an inherent belief that reality is complex and dynamic and is constantly being influenced by human actions and interactions, and it is my responsibility as a researcher to uncover these dynamics in complex contexts to construct knowledge that is actionable. Given the rapid evolution of generative machine learning models and their increasingly collaborative role with the researcher in Human Factors research in uncovering people’s experiences, I believe that a pragmatic approach to knowledge where the researcher influences and is influenced by machine learning models that can be fed with an abundance of varying perspectives is necessary to properly interpret people's experiences and construct knowledge that has practical consequences.

5 Overview of Parent Study

This dissertation is conducted on the data obtained from the CareVirtue (R41) project supported by grants (R41AG069607 and P30AG062715) from the NIH National Institute on Aging. In this chapter, I outline the details of the CareVirtue (R41) project.

5.1 CareVirtue – a web application to support ADRD care networks

CareVirtue is a progressive web application developed in React to support and connect ADRD care networks that can be accessed via a web browser on any device with a data connection. CareVirtue was initially developed as a platform for caregivers to store and share information with members of their care network to address the unmet needs for tools to support coordination from caregivers in an online support group community. It aims to address the current gaps in existing caregiver-specific support technology for ADRD to support coordination, communication, and connection between care networks. CareVirtue's design honors the person-centered care model for people living with ADRD and their caregivers by accounting for the following: 1) treating people living with ADRD as those with unique needs; 2) seeing the world from their perspective; 3) creating a positive social environment in which people living with ADRD can experience relative well-being and quality of life. At the time of the study, CareVirtue possessed the following features: 1) CareVirtue dashboard, 2) journal, 3) care guide, 4) care team management, 5) shared calendar, and 6) geolocated resource list, elaborated in *Table 5-1*.

Features	Description
CareVirtue dashboard	A centralized hub to document and share important information with the team. It provides an easy access to the journal where caregivers can document, communicate, and coordinate about events, upcoming events such as appointments and attending care network members, a list of current and pending care team members
Journal	The journal feature provides a place for the care team to document, communicate, and coordinate daily caregiving activities and shared experiences about the person living with ADRD. CareVirtue prompts every journal entry posted by the care team for the entry's general mood/feelings and a category such as behavior note, medication note, activities & hobbies, etc. The care team has the option of searching and filtering to explore trends and insights about the person living with ADRD's needs. The selected portions or the entire care journal can be exported as PDF to share as necessary.
Care guide	Includes a template that the care team can tailor specifically to the needs of the individual person living with ADRD. It has a focus on both practical and individual quality of life needs such as Activities of Daily Life (ADL) capabilities, food and drink preferences, favored hobbies and activities, and personal grooming needs for any person on the care team to understand the person living with ADRD as a whole person.
Care team management	The ability of primary caregivers to invite care network members to use the account with security permissions assigned at each invitation.
Shared calendar	Supports scheduling and sharing recurring events with selected members of the care team.
Geo-located resources list	A hub for all resources related to ADRD. During the time of this study, resources were limited to Alzheimer's Association 24X7 helpline, contact details for CareVirtue support, and the research team. Care team members were able to add their own list of resources with the corresponding contact details.

Table 5-1 Features of CareVirtue and their description

5.2 Parent study objectives

This project is guided by two objectives. The first objective is to demonstrate the feasibility of using CareVirtue to record and document daily care interactions between members of the care network and people living with ADRD. To achieve this aim, the research team conducted a usability and feasibility study to assess the acceptability of CareVirtue. The second objective is to establish the utility of the data set produced by CareVirtue as a data source for an AI enabled intelligent caregiver assistant application. To achieve this objective, the research team is using natural language processing and machine learning techniques to analyze and generate insights about care networks and people living with ADRD interactions with the text data obtained through CareVirtue.

5.3 Parent study design and procedures

The research team conducted a feasibility study over a period of eight weeks with 41 care networks of people living with ADRD. Participants were recruited between February and June 2021 through multiple community sites in Wisconsin and Southern California as well as through the Wisconsin Alzheimer's Disease Research Center by advertising in email, social media, and newsletters. Interested individuals who contacted the research team by phone or email were scheduled for a phone screening for the following eligibility criteria: self-identified primary caregiver of a person living with ADRD, at least 18 years of age, English speaking, daily Internet access, and shares caregiving information/responsibility with other caregivers. Eligible participants were scheduled for a one-hour enrollment via Zoom. During the enrollment, a research team member obtained informed consent from the primary caregiver and the associated person living with ADRD if the person living with ADRD had decisional capacity. If the person living with ADRD did not have decisional capacity, the primary caregiver could consent on their behalf if they were the legally authorized representative. The participants were then given a demographic survey and the research team provided a virtual tour of CareVirtue, explaining the different features of the platform. The research team helped the primary caregiver create their account and invite other members of their care network that the primary caregivers selected. Once other members of their care network (secondary caregivers) were invited, they were contacted by email to obtain their informed consent electronically. Participants were asked to use CareVirtue for eight weeks following the enrollment visit.

During this use period, the research team administered a weekly questionnaire to the primary caregivers starting one week after enrollment. The weekly questionnaire measured confidence in using CareVirtue, caregiver workload, other resources caregivers use, their experience with CareVirtue, and changes they would make to CareVirtue. The research team also collected data on eight CareVirtue platform usage metrics across the study period: number of logins, journal posts, journal post replies, calendar events, secondary caregiver invites sent, secondary caregiver invites accepted, care guide sections created, and resources accessed. At the completion of the eight weeks, the research team conducted a post-trial visit virtually for an hour with the primary caregivers. The visit included a post-trial interview that was conducted using a semi-structured interview guide and a post-trial questionnaire that measured usability and usefulness of CareVirtue. The interview guide was developed to broadly understand how CareVirtue was used and to understand caregivers' experiences with CareVirtue during the study period. Participants were asked about how useful CareVirtue was to them, the features they liked the most and least, how their routines had to be changed to use CareVirtue, and how they used CareVirtue for interacting with their care network. These interviews were audio recorded and transcribed. Then, all transcripts were deidentified. Following the completion of the post-trial visit, the primary caregivers were provided with a US$150 e-gift card. Secondary caregivers contacted the research team if they were interested in participating in the post-use survey and interview. Secondary caregivers received US $15 for completion of the post-use survey and US $25 for completion of the 30-minute post-use interview.

5.4 Data sources

Demographic data

The research team collected primary caregiver characteristics including age, gender, race and ethnicity, income, education, marital status, location, and employment. The research team also collected demographics for the person living with ADRD including age, gender, ethnicity, living situation, and relationship to the primary caregiver. Demographic data were not collected from secondary caregivers.

Weekly questionnaire

The weekly questionnaire was used to measure usability using weekly confidence in using CareVirtue, usefulness with caregiver workload, other resources caregivers use, their experience with CareVirtue, and changes they would make to CareVirtue. This data was collected only from primary caregivers. The weekly confidence survey was measured with a single question: "rate your confidence in using CareVirtue on a scale from 1 (not at all confident) to 10 (very confident)". Caregiver workload was measured using the National Aeronautics and Space Administration-Task Load Index (NASA-TLX), which consists of a six-item subscale with a 100-point range with five-point steps (0=very low to 100=very high) (Hart, 1986). Other resources used by caregivers, their experience with CareVirtue, and changes they would make to CareVirtue were assessed using the corresponding single questions: 'What other resources/tools do you use?', 'How would you describe your experience with CareVirtue so far?', and 'What changes would you make to CareVirtue?'.

CareVirtue use metrics

The research team also collected data on eight CareVirtue platform usage metrics across the study period: number of logins, journal posts, journal post replies, calendar events, secondary caregiver invites sent, secondary caregiver invites accepted, care guide sections created, and resources accessed. Data were obtained from primary caregivers and secondary caregivers.

Post-trial interview

The interview data were collected from 41 primary caregivers (female = 38, age: average = 60.3, standard deviation = 9.8) that completed the study and 3 secondary caregivers that opted in to do the interviews. The interview was conducted to obtain more context of the surveys and CareVirtue use data. A semi-structured interview consisting of two sections was conducted with each participant post-trial for an hour via Zoom. The first section focused on obtaining feedback on CareVirtue in understanding how useful CareVirtue was in daily caregiving, how it fit into a caregiver's day-to-day life, and how care networks interacted using CareVirtue. The research team members asked follow-up questions for clarification and additional context. Example interview questions included "what parts of CareVirtue did you use daily? What made you return to using CareVirtue? What made you feel confident in using CareVirtue? What made you less confident". The second section included questions that attempted to understand the lived experiences of caregivers further with questions on how they make decisions to obtain respite and financial support and was only posed to primary caregivers. The entire interview guide is in Appendix Interview guide for post-trial interviews.

Post-trial questionnaire

The post-trial questionnaire measured primary caregiver perceptions of usability and usefulness of CareVirtue. These measures were obtained from all primary caregivers that completed the interviews and secondary caregivers that opted in to complete the questionnaire. Usability was measured using the System Usability Scale (SUS) (Bangor et al., 2008), which includes 10 statements (e.g., "learning to use CareVirtue was quick for me") with a five-point response scale (1 = strongly disagree to 5 = strongly agree). Usefulness was measured using the Behavioral Intention Scale (Asan et al., 2018; Holden & Karsh, 2009) and the perceived usefulness scale (Davis, 1989). The Behavioral Intention Scale included four statements (e.g., "If it were up to you, to what extent would you want to use CareVirtue?") with a five-point response scale (1 = not at all to 5 = a great deal). The perceived usefulness survey included 4 statements (e.g., "using CareVirtue would make it easier to perform my caregiving role") with a five-point response scale (1 = strongly disagree to 5= strongly agree).

Table 5-2 summarizes the data that has been collected and the data that will be the focus of my present work.

Data	Primary caregiver	Secondary caregiver
Demographic data	51 primary caregivers (female - 38/51, 75%)*	N/A
Weekly questionnaire	Confidence in using CareVirtue Caregiver workload Open-ended questions on other resources used and experience with CareVirtue	N/A
CareVirtue use	8 CareVirtue platform metrics - (number of logins, journal posts*, journal post replies*, calendar events*, secondary caregiver invites sent*, secondary caregiver invites accepted*, care guide sections created*, and resources accessed*)	5 CareVirtue platform metrics - (number of logins, journal posts, journal post replies, calendar events, and resources accessed)
Post-trial interviews	41 primary caregivers with Section 1 (CareVirtue feedback)* and Section 2 (lived experiences)	3 secondary caregivers with CareVirtue feedback
Post-trial questionnaire	41 primary caregivers with SUS*, Behavioral Intention*, perceived usability*	12 secondary caregivers with SUS, Behavioral Intention, perceived usability

*Indicates data I will use for my present work

Table 5-2 Data collected from the parent study

6 Exploring engagement of ADRD caregivers with a digital health intervention to support care coordination— CareVirtue

This chapter is prepared as a manuscript for Journal of Medical Internet Research (JMIR)

6.1 Introduction

Alzheimer's and related dementias (ADRD) impact 6.2 million adults in the US and the long-term care of people living with ADRD is often provided by ADRD caregivers— i.e., unpaid family or friends (Alzheimer's Disease Facts and Figures, 2024). With an estimated 16.1 million ADRD caregivers contributing unpaid care valued at $256.7 billion US dollars, their efforts often come at significant physical, emotional, and economic costs (Alzheimer's Disease Facts and Figures, 2024).

Caring for those living with ADRD is complex and presents multiple challenges to ADRD caregivers (Alzheimer's Disease Facts and Figures, 2024; Goren et al., 2014a). The neurodegenerative progression of the disease presents a dynamic challenge for ADRD caregivers as they manage evolving behavioral and psychological symptoms like agitation, repetitive questioning, wandering, and delusions (Finkel et al., 1996). Over time, those living with ADRD often become unable to perform activities of daily living and instrumental activities of daily living. This requires the ADRD caregivers to take the majority of responsibility for these activities such as daily housekeeping and handling finances (Kunkel & Applebaum, 1992; Lawton & Brody, 1969; Ponnala et al., 2020). ADRD caregivers are often not equipped with adequate training and resources to handle the complex and dynamic symptoms (Brodaty & Donkin, 2009). Often, multiple caregivers are involved that presents a unique challenge in coordinating a diverse mix of caregiving activities such as medication management and providing companionship for the person living with ADRD (Holden et al., 2018; Ponnala et al., 2020; Rutkowski et al., 2021b; Tang et al., 2018).

ADRD caregiving is often associated with suboptimal mental, physical, and economic outcomes for the caregivers (Alzheimer's Disease Facts and Figures, 2024; Annerstedt et al., 2000; Goren et al., 2014a). Although ADRD caregivers can experience positive outcomes related to their caregiving such as family togetherness and family satisfaction of helping others, 30–40% of ADRD caregivers report negative outcomes such as adverse mental health outcomes, strain, decreased quality of life, and burnout (Alzheimer's

Disease Facts and Figures, 2024; Sallim et al., 2015). Additionally, ADRD caregivers report greater negative outcomes such as depression and anxiety than caregivers of those living with non-ADRD health conditions (Sallim et al., 2015; Thunyadee et al., 2015).

To address these negative outcomes, the US National Institute on Aging and other national advisory panels have made it a priority to support design and dissemination of digital health interventions (DHI) for ADRD caregivers (Borson et al., 2016; National Plan to Address Alzheimer's Disease, 2024; *Recommendations from the NIH AD Research Summit 2015*, 2015). In response, various DHIs for supporting ADRD caregivers, such as mobile and web applications for information, education, support, and task management, have demonstrated efficacy to improve caregiver outcomes (Deeken et al., 2019; Faieta et al., 2021; Godwin et al., 2013; Hopwood et al., 2018). Despite this growing suite of ADRD caregiver DHIs, negative outcomes persist (Alzheimer's Disease Facts and Figures, 2024).

Inadequate engagement with DHIs in the real-world settings may be attributed as one of the many reasons for the mismatch between available DHIs and negative outcomes (Christie et al., 2018; Gitlin 2021; Mendez et al., 2021; Rathnayake et al., 2020). DHI engagement can be defined as "the extent and manner of use and a subjective experience characterized by attention, interest and affect" (Perski et al., 2017, p. 258). While reasons such as prevalence of low quality DHIs and lack of access could be attributed as some of the reasons for the prevalence of negative outcomes for ADRD caregivers, DHI engagement is agreed upon as a critical step to reap the benefits of DHI (Christie et al., 2018a; Edney et al., 2019; Werner, Brown, et al., 2022). Many studies show that ADRD caregivers that engage with DHIs in prescribed doses experience greater positive outcomes such as lowered anxiety, higher mastery of caregiving skills, and improved quality of life (Boyt et al., 2022; Deeken et al., 2019; Etxeberria et al., 2021; Shin et al., 2022). For example, efficacy studies suggest that ADRD caregivers who use DHIs for the prescribed amounts (e.g., one-hour every month for five months, one-hour every week for three months, 32 minutes or higher, etc.) experience more positive outcomes than those ADRD caregivers that use the interventions less frequently (Beauchamp et al., 2005; Boyt et al., 2022). However, these prescribed amounts for engaging with DHIs are often not followed in the real-world settings

(Christie et al., 2018a; Etxeberria et al., 2021; Gitlin, 2021; Gitlin et al., 2015; Mendez et al., 2021c; Meyerowitz-Katz et al., 2020).

Emerging research suggests that when ADRD caregivers use DHIs in real-world settings, they exhibit diverse engagement patterns (Eysenbach, 2005; Øksnebjerg et al., 2020; Raj & Iott, 2021). These patterns include high usage of specific features of a DHI (Boutilier et al., 2022; Øksnebjerg et al., 2020), moderate usage of all features (Boutilier et al., 2022), abandonment of the DHI altogether (Meyerowitz-Katz et al., 2020), and reversing decisions to engage with the DHI (Meyerowitz-Katz et al., 2020). While some patterns like abandonment and disengagement could be attributed to the prevalence of non-evidence based, low-quality DHI (Choi et al., 2020; Werner et al., 2022; Wozney et al., 2018), reasons behind other DHI engagement patterns remain unclear.

DHI engagement patterns in real-world settings are known to be influenced by the context in which DHI engagement takes place (Centi et al., 2019; Christie et al., 2018a; Guisado-Fernández et al., 2019b; Hardiker & Grant, 2011; Lalloo et al., 2022; Xu et al., 2023). Context of DHI engagement has been defined as "any information that can be used to characterize the situation of an entity, where an entity is a person, place, or object that is considered relevant to the interaction between a user and an application, including the user and application themselves" (Dey & Abowd, 1999, p. 3). Contextual factors of ADRD caregivers including the size of caregiving network, disease stage of the person living with ADRD, and the ADRD caregiver's relationship with the person living with ADRD have been known to facilitate or impede DHI engagement and could explain some DHI engagement patterns like highly selective usage of some features of a DHI among some caregivers (Boyt et al., 2022; Christie et al., 2018a; Xu et al., 2023). But specific contextual factors and the mechanisms through which they impede or facilitate DHI engagement, potentially leading to various DHI engagement patterns, remains less understood (Bastoni et al., 2021; Boyle et al., 2022b; Christie et al., 2018a). Understanding these contextual factors comprehensively and how they influence DHI engagement could help identify various needs for different sub-populations of ADRD caregivers and could aid design of DHIs with which ADRD caregivers can meaningfully engage. *Hence, there is a need to understand the complex contexts of DHI engagement patterns to design appropriately for supporting ADRD caregivers.*

Patient-engaged human factors provides an approach to identify and describe the contexts of ADRD caregivers in which DHIs are used. Patient-engaged human factors is defined as “the application of human factors theories and principles to study and improve work done by patients and families” (Holden et al., 2020, p. 1). One specific Patient-engaged human factors approach, *the work systems model*, helps in modeling contextual factors of ADRD caregiving such as the persons involved, technologies and tools used, tasks involved, social and organizational factors, and environments that influence processes to produce certain outcomes (Carayon, Schoofs Hundt, et al., 2006; Holden et al., 2013, 2015; Ponnala et al., 2020; Valdez et al., 2015). These contextual factors can occur as barriers or facilitators to DHI engagement. Barriers are those contextual factors that make it impossible, difficult, or unsatisfied to engage with a DHI, whereas facilitators are those contextual factors make it possible, easy, or satisfactory to engage with a DHI (adapted from Holden et al., 2015). By considering engagement with DHI as a process, patient-engaged human factors can be used to explore how contextual barriers and facilitators influence engagement patterns.

Hence, our objective is to identify the varying DHI engagement patterns of ADRD caregivers and explore how contextual barriers and facilitators influencing DHI engagement of ADRD caregivers are associated with various DHI engagement patterns in an ADRD caregiver DHI to support communication and coordination among ADRD care networks— CareVirtue.

6.2 Methods

This study is a secondary analysis that builds upon a broader primary study to assess the feasibility of a web-based DHI called CareVirtue (R41AG069607) (Boutilier et al., 2022). The University of Wisconsin-Madison Institutional Review Board (IRB) approved this study.

CareVirtue is a progressive web app designed to support and connect ADRD care networks that can be accessed via a web browser on any device with a data connection. CareVirtue aims to address the current gaps in existing ADRD caregiver-specific support technology to support coordination, communication, and connection between care networks. At the time of the study, CareVirtue included the following features: 1) dashboard, 2) care journal, 3) care guide, 4) care team management, 5) shared calendar, and 6) geolocated resource list, elaborated in Table 6-1.

Features	**Description**
CareVirtue dashboard	A centralized hub to document and share important information with the team. It provides an easy access to the journal where caregivers can document, communicate, and coordinate about events, upcoming events such as appointments and attending care network members, a list of current and pending care team members
Journal	The journal feature provides a place for the care team to document, communicate, and coordinate daily caregiving activities and shared experiences about the person living with ADRD. CareVirtue prompts every journal entry posted by the care team for the entry's general mood/feelings and a category such as behavior note, medication note, activities & hobbies, etc. The care team has the option of searching and filtering to explore trends and insights about the person living with ADRD's needs. The selected portions or the entire care journal can be exported as PDF to share as necessary.
Care guide	Includes a template that the care team can tailor specifically to the needs of the individual person living with ADRD. It has a focus on both practical and individual quality of life needs such as Activities of Daily Life (ADL) capabilities, food and drink preferences, favored hobbies and activities, and personal grooming needs for any person on the care team to understand the person living with ADRD as a whole person.
Care team management	The ability of primary caregivers to invite care network members to use the account with security permissions assigned at each invitation.
Shared calendar	Supports scheduling and sharing recurring events with selected members of the care team.
Geo-located resources list	A hub for all resources related to ADRD. During the time of this study, resources were limited to Alzheimer's Association 24X7 helpline, contact details for CareVirtue support, and the research team. Care team members were able to add their own list of resources with the corresponding contact details.

Table 6-1 Features of CareVirtue and their description

6.2.1 Primary study design and procedures

The research team conducted a feasibility study over a period of 60 days with 51 ADRD caregivers. Participants were recruited between February and June 2021 through multiple community sites in Wisconsin and Southern California as well as through the Wisconsin Alzheimer's Disease Research Center by advertising in email, social media, and newsletters with the following eligibility criteria: self-identified primary caregiver of a person living with ADRD, at least 18 years of age, English speaking, has daily Internet access, and shares caregiving information/responsibility with other caregivers. Participants were enrolled via an hour-long meeting over video conferencing software in which their informed consent was obtained. During enrollment, participants also completed a socio-demographics survey and were provided with an orientation to CareVirtue's features. In addition, the research team helped the primary ADRD caregiver create their account and invite other members of their care network. Participants were asked to use CareVirtue for 60 days following the enrollment visit. During this use period, the research team collected data on five CareVirtue platform usage metrics across the study period: number of journal posts, journal post replies, calendar events, secondary caregiver invites accepted, and resources accessed.

At the completion of the 60 days, the research team conducted a post-trial meeting with primary ADRD caregivers via an hour-long meeting over video conferencing software. The visit included a semi-structured interview and an electronic questionnaire with validated measures of usability and usefulness.

The semi-structured interview guide was developed through multiple iterations by the study team to broadly understand how CareVirtue was used and to understand caregivers' experiences with CareVirtue during the study period. The study team had expertise in engineering, caregiving, product development, technology commercialization, and qualitative research. Participants were asked specific questions about their experience with CareVirtue (e.g., "What features did you like the most and the least, and why?", "What changes did you make to your existing routine to use CareVirtue?"). These interviews were audio recorded, transcribed verbatim by a professional transcription service, and deidentified.

Finally, the team administered an electronic questionnaire to assess primary ADRD caregiver perceptions of usability and usefulness of CareVirtue. Usability was measured using the System Usability Scale (SUS) (Bangor et al., 2008), which includes 10 statements (e.g., "learning to use CareVirtue was quick for me") with a five-point response scale (1 = strongly disagree to 5 = strongly agree). Usefulness was measured using the Behavioral Intention Scale (Asan et al., 2018; Holden & Karsh, 2009). The Behavioral Intention Scale included four statements (e.g., "If it were up to you, to what extent would you want to use CareVirtue?") with a five-point response scale (1 = not at all to 5 = a great deal). Following the completion of the post-trial visit, the primary caregivers were provided with a US$150 e-gift card.

Out of the 51 participants in the study, ten participants dropped out of the study and are not included in the current study.

6.2.2 Current study analysis

We used a descriptive, concurrent mixed methods analysis approach (Creswell, 1999), in which qualitative and quantitative analysis were integrated to provide a comprehensive analysis.

We performed the analysis in three steps: 1) quantitative analysis to identify various engagement patterns of 41 participants using a clustering technique on CareVirtue platform usage data; 2) qualitative analysis to identify contextual barriers and facilitators influencing CareVirtue engagement of ADRD caregivers using directed content analysis on 41 interview transcripts; and 3) integration of the quantitative analysis from step 1 and qualitative analysis from step 2 to explore how contextual barriers and facilitators influencing CareVirtue engagement of ADRD caregivers are associated with various engagement patterns.

For the purposes of this study, we defined engagement with CareVirtue as the "extent and manner of use and a subjective experience characterized by attention, interest and affect" (Perski et al., 2017). We operationalized the extent and manner of use as the number of times a feature of CareVirtue was used (e.g., journal, calendar). We captured the subjective experience through the analysis of qualitative interviews, where a participant described their interest and experience using CareVirtue.

6.2.2.1 Quantitative analysis: identifying CareVirtue engagement patterns

To identify the varying patterns in engagement, we used the clustering technique, which is a statistical technique used for grouping similar data points together (Jain et al., 1999). Analysis was conducted in R (version 4.2.2) using the *cluster* package (Maechler et al., 2023).

To prepare the data for clustering, we first extracted CareVirtue platform usage metrics for each of the 41 participants across different features of CareVirtue (number of journal posts, journal post replies, calendar events, and resources created). To explore how engagement patterns might evolve over time, we then split the platform usage metrics for each participant over two time periods: the first 30 days and the second or last 30 days of the study. Finally, to ensure all platform usage metrics contributed equally to the clustering process, we scaled all variables to the range (0,1) across features for each participant. This scaling accounted for potential differences in the scale of each metric, such as the number of journal posts compared to the number of resources posted.

To identify the varying engagement patterns with CareVirtue (i.e., clusters), we employed a multi-pronged approach to identify the appropriate clustering technique and number of clusters. First, we evaluated the internal validity and stability qualities of k-means, k-medoids, and hierarchical clustering techniques for cluster numbers ranging from three to six. K-means clusters data points based on closest distances of datapoints to centroids. It is a robust and fast clustering technique. K-medoids clusters based on closest distances to an actual point in the data that is most-centrally located. This technique creates tighter clusters and handles outliers better. Hierarchical clustering merges data points based on their proximity, creating hierarchical clusters, making it easy to identify any hierarchical relationships. Internal validation measures (e.g., silhouette coefficient, Calinski-Harabasz index) helped quantify how distinct the clusters were, while stability measures (e.g., average distance between means, average proportion of non-overlap) helped assess how resilient the clusters were to small data perturbations (Rendón et al., 2011). We then visualized all participants in a reduced-dimensional space using the three clustering techniques and the four cluster numbers (k = 3, 4, 5, 6). We carefully considered both approaches – internal/stability validation and visual exploration – in tandem. This comprehensive evaluation informed our final decision regarding the optimal clustering technique, k-medoids, and cluster number, k = 6. See Chapter 11: Appendix: Clustering results for more details.

Within each cluster, we examined the differences in participants' CareVirtue engagement patterns between the first and second 30-day periods (e.g., average number of journal posts in the first 30-days and average number of journal posts in the second 30-days, etc.).

6.2.2.2 Qualitative analysis: identifying contextual barriers and facilitators influencing DHI engagement

Conceptual framework

The Patient Work System (PWS) framework (Holden et al., 2015) was used to guide this analysis. The PWS describes the work of non-professionals such as patients and informal caregivers doing work in non-professional settings (e.g. the home). This framework organizes the patient and caregiver context as a structured work system of six interacting components including people, tools and technologies, tasks, organizational factors, socio-cultural factors, and physical-spatial factors in which care processes occur to create outcomes (Holden et al., 2015). Each of the six work system components is further broken down into elements that describe specific characteristics of the component. For example, the person component consists of elements such as motivation, biomedical characteristics, and demographic characteristics of the patient that affect their care activities. These PWS elements were described as contextual factors in this study and can act as barriers or facilitators to CareVirtue engagement.

Context of DHI engagement, hence, can be defined as a dynamic system of interacting components such as person, tasks, the characteristics of DHI under study, other tools and technologies used, social-factors, organizational factors, and physical-spatial factors that influence DHI engagement to create outcomes. The context consisting of the dynamic system of interacting components can act as barriers or facilitators to the process of DHI engagement. Outcomes resulting from DHI engagement can further impede or facilitate DHI engagement but are not included as context at single point in time. Other components of the dynamic system that do not directly influence DHI engagement are not context at a given single point in time.

For this study, contextual barriers (henceforth also called barriers) were defined as any work system property or condition that makes it impossible, difficult, or unsatisfied to engage with CareVirtue (adapted from Holden et al., 2015); contextual facilitators (henceforth also called facilitators) were defined as any work system property or condition that makes it possible, easy, or satisfactory to engage with a DHI (adapted from Holden et al., 2015). Our study was from the perspective of the primary ADRD caregiver. Primary ADRD caregiver was defined as the person that provides the most care to the person living with ADRD and secondary ADRD caregiver(s) were defined as the person(s) that help the primary ADRD caregiver in their care responsibilities (Ponnala et al., 2020). Processes were the physical, cognitive, and social-behavioral activities that are aimed at accomplishing a health-related goal or outcome (Holden et al., 2013, 2015). Outcomes were the states or conditions resulting from processes (Holden et al., 2013, 2015). In this study, we considered the act of engaging with CareVirtue as a process. Outcomes were those that result from this DHI engagement and were considered barriers or facilitators if they influenced CareVirtue engagement.

Directed content analysis

We performed a directed content analysis guided by the PWS framework to identify the contextual barriers and facilitators that influenced engagement with CareVirtue (Hsieh & Shannon, 2005). This involved two stages of coding – first, to identify the PWS components and second, to identify the contextual barriers and facilitators that influenced DHI engagement. Interview transcripts were coded in NVIVO 13.

Stage 1coding to identify PWS components

First, I, the lead author (PL) trained three other analysts (MO, KM, ZW) with experience in Human Factors Engineering on the definitions of the PWS components, outcomes, barriers, and facilitators over a course of three one-hour meetings. Then, as members of the coding team, we (PL, MO, KM, ZW) performed the first stage of coding by identifying passages with PWS components and outcomes acting as barriers and facilitators influencing DHI engagement in each transcript. In this stage, we ensured the passages identified were PWS components that influenced engagement with CareVirtue and not those components that were influenced by the engagement with CareVirtue. To establish reliability, we (PL, MO, KM, ZW) collaboratively coded two randomly selected transcripts in two meetings. We then dually coded each transcript and met weekly during the coding process to discuss any discrepancies through consensus and ensure rigor (Barry et al., 1999). We transferred the resulting coded passages to an Excel document. This document had the coded passage, participant identifier, and the corresponding PWS component/outcome in each row. We identified and eliminated any unintended duplicates that arose during the export process from NVIVO 13. This involved carefully reviewing the Excel sheet, line by line, and using the *sort* function on the coded passages. However, we retained other duplicates resulting from coincident coding (e.g., passage coded as both Person and Organization factors) as separate rows to ensure all relevant coding was captured for further analysis. After eliminating duplicates, 474 coded passages were retained.

Stage 2 coding to identify contextual barriers and facilitators to DHI engagement

We conducted the second stage coding focused on identifying the contextual barriers and facilitators to DHI engagement from the 474 coded passages.

We first sorted the Excel document by each component (e.g., person, organizational factors, outcomes). Three members of our coding team with an expertise in Human Factors Engineering (PL, MO, AJ) performed a deductive and inductive analysis guided by the PWS elements. This entailed identifying those contextual barriers and facilitators influencing DHI engagement for each PWS component. We (PL, MO, AJ) met bi-weekly to resolve any discrepancies in the identified contextual barriers and facilitators. We brought any contextual barriers and facilitators that were inductively identified in the coding process to a senior researcher (NW) and refined the codebook over several hourly meetings until a final codebook was converged on.

I (PL) then applied the codebook to the coded passages in the Excel sheet. This involved assigning the most relevant contextual barrier, facilitator, or outcome influencing DHI engagement to each coded passage. We reviewed and discussed these codes with a senior researcher (NW) and a research team member (AL) over several weekly team meetings to ensure consistency and address any discrepancies. We confirmed that ten percent of all codes were reviewed and discussed with the research team (NW, AL, PL) as a final check to ensure consistency.

The resulting Excel sheet consisted of all coded passages in each row with the corresponding unique identifier for participants, and the contextual barrier or facilitator.

6.2.2.3 Integrating quantitative and qualitative: exploring contextual barriers and facilitators associated with CareVirtue engagement patterns

To explore the contextual barriers and facilitators associated with each CareVirtue engagement pattern, we first prepared the data by creating a linked data file with all the engagement patterns, the corresponding participants, and the coded passages with contextual barriers, facilitators, and outcomes in R statistical software.

Then, we identified the occurrence of each contextual barrier and facilitator associated with the engagement patterns. Using R's *count* function, we identified the presence or absence of these factors for each engagement pattern. We also summarized the demographic characteristics of participants belonging to each engagement pattern to provide any additional context for the contextual barriers and facilitators.

Next, we developed a description of the contextual barriers and facilitators associated with each engagement pattern. For each engagement pattern, we identified the coded passages that described the contextual barriers and facilitators influencing engagement. Then, we examined the coded passages for each contextual barrier and facilitator and selected illustrative quotes that effectively capture the nature and influence of the contextual barrier and/or facilitator on engagement to develop a description. While not every contextual barrier and facilitator present within a engagement pattern was described with illustrative quotes to ensure conciseness and clarity, we carefully chose quotes that effectively represented the range of contextual barriers and facilitators influencing engagement for each engagement pattern. These descriptions were reviewed by the research team, including a senior researcher (NW, AL). To ensure the description of each engagement pattern was rigorous, we looked at negative cases (instances where the identified descriptions did not hold true) by going back to the transcript for each participant and consolidated the description for each group (Valdez et al., 2017).

Throughout the analysis we also documented key insights, questions, and data analysis activities using Birks et al.'s mnemonic analytic memos (Birks et al., 2008).

6.3 Results

We identified three CareVirtue engagement patterns (Figure 6-1), 22 contextual barriers and facilitators influencing CareVirtue engagement, and 8 outcomes influencing engagement. The three patterns were: 1) Low and declining usage; 2) moderate and consistent usage; and 3) high and increasing journal usage. The contextual barriers and facilitators consisted of five person factors, six tool factors (three in CareVirtue and three in other tools), three socio-cultural factors, five organizational factors, one physical-spatial factor, two task factors, and eight outcomes. A detailed definition and examples of the 30 contextual barriers and facilitators are presented in Appendix: Contextual barriers and facilitators of ADRD caregivers influencing DHI engagement.

For each engagement pattern, we present the summary of the platform metrics, demographics of the participants within each engagement pattern, and a description of the contextual barriers and facilitators with corresponding illustrative quotes.

6.3.1 What were the CareVirtue engagement patterns?

The three engagement patterns identified were low and declining usage, moderate and consistent usage, and high and increasing journal usage. Three outliers were excluded from analysis. The platform usage metrics for each DHI engagement pattern is summarized in Table 6-2.

Characteristic	**Low and declining usage (n = 17)**	**Moderate and consistent usage (n = 16)**	**High and increasing journal usage (n = 5)**
Platform usage summary			
Journal posts in first half, mean (SD)	5.77 ± 4.15	20.56 ± 5.94	27.8 ± 8.17
Journal posts in second half, mean (SD)	1.65 ± 2.45	17.37 ± 9.46	80.80 ± 32.78
Journal replies in first half, mean (SD)	0.41 ± 0.87	4.25 ± 4.37	5 ± 3.39
Journal replies in second half, mean (SD)	0	2.62 ± 3.6	30.66 ± 9.8
Calendar events created in first half, mean (SD)	3.93 ± 0.94	3.75 ± 3.26	9.8 ± 10.76
Calendar events created in second half, mean (SD)	0.94 ± 2.56	2.69 ± 7.25	5.2 ± 8.40
Resources created in first half, mean (SD)	0.23 ± 0.56	1.00 ± 2.60	0.40 ± 0.89
Resources created in second half, mean (SD)	0	0.25 ± 1	0
Number of secondary caregivers on CareVirtue, median (IQR)	1 (0, 2)	2 (1, 3.25)	3 (2, 4)

Table 6-2 Summary of engagement patterns

Figure 6-1 indicates the lowest usage across all features throughout the study period for the low and declining usage pattern. DHI engagement further declined in the second half for all features except the calendar for this pattern. In contrast, the moderate and consistent usage pattern maintained relatively consistent engagement across all features throughout the study, albeit a slight decrease in the second half. The high and increasing journal usage pattern exhibited the highest use of journal and calendar, followed by an increase in journal usage in the second half of the study.

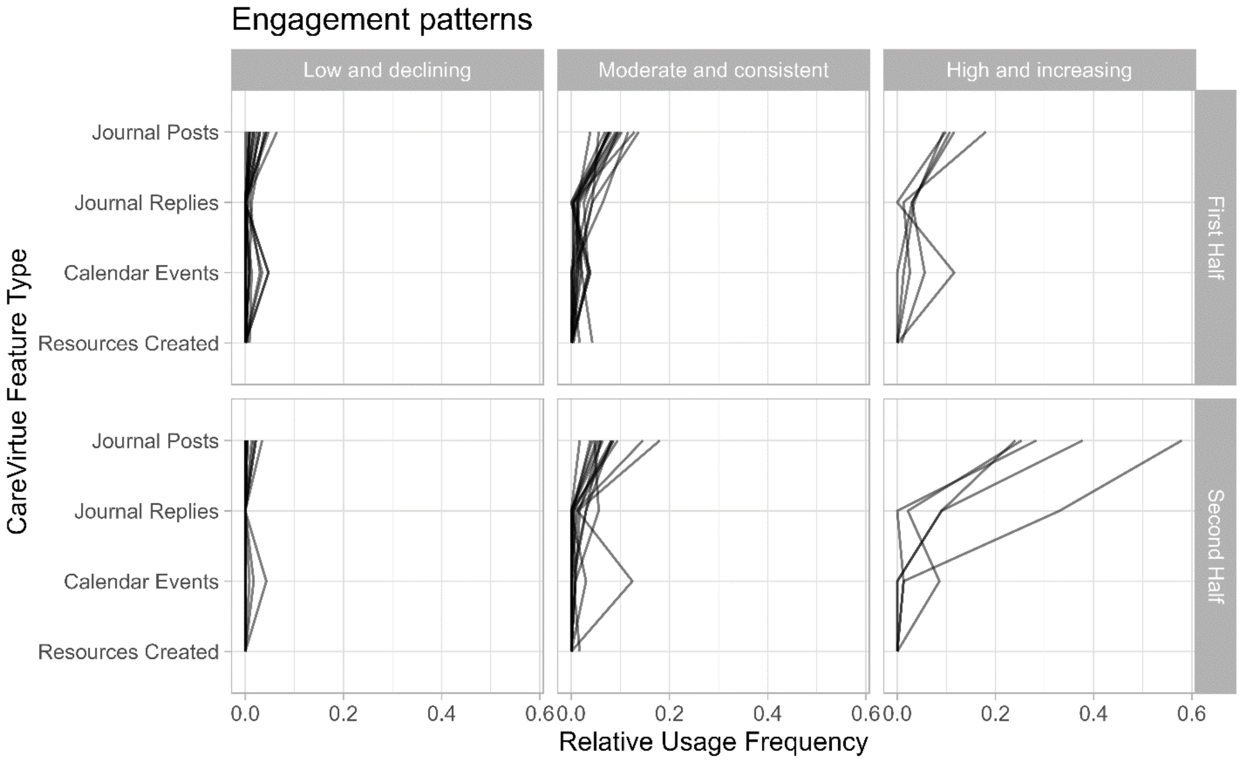

Figure 6-1 Engagement patterns in CareVirtue: The y-axis represents the type of feature in CareVirtue – the first and second half indicate the first 30 days of the study and the second 30 of the study respectively. The x-axis represents the usage frequency scaled across features. Three patterns are identified: low and declining usage across all the features through the entire study, 2) moderate and consistent usage through the entire study for most of the features, and 3) high and increasing journal usage from the first 30 days of the study.

6.3.2 How are contextual barriers and facilitators influencing CareVirtue engagement of ADRD caregivers associated with the engagement patterns?

The demographics of participants belonging to each engagement pattern is summarized in Table 6-3. The presence or absence of each contextual barrier and facilitator for each DHI engagement pattern is summarized in Table 6-4.

Table 6-4 suggests that 22, 19, and 7 contextual and outcome-related barriers were present within the low and declining usage, moderate and consistent usage, and high and increasing usage patterns respectively. Additionally, 18, 20, and 15 contextual and outcome-related facilitators were present within the low and declining usage, moderate and consistent usage, and high and increasing journal usage patterns respectively.

Characteristic	**Low and declining (n = 17)**	**Moderate and consistent (n = 16)**	**High and increasing (n = 5)**
Sex, female, n (%)	11 (65)	11 (69)	3 (60)
Age (years), mean ± SD	57.62 ± 11.27	60.69 ± 9.31	65.8 ± 4.09
Age of person living with ADRD, mean ± SD	77.59 ± 10.02	80.75 ± 12.33	73.2 ± 13.1
Living situation, n (%)			
Primary caregiver lives with person living with ADRD	8 (47)	12 (75)	5 (100)
Person living with ADRD in a separate home, nursing home, retirement community, or other assisted living facility	9 (53)	4 (25)	0 (0)
Relationship to person living with ADRD, n (%)			
Spouse/partner	8 (47)	6 (37)	4 (80)
Parent or in-law	9 (53)	10 (63)	1 (20)
Employment, n (%)			
Full-time	8 (47)	7 (44)	0
Retired	3 (18)	7 (44)	4 (80)
Part-time	4 (23)	1 (6)	1 (20)
Not working	2 (12)	1 (6)	0
Location type, n (%)			
Urban	13 (76)	14 (88)	4 (80)
Rural	4 (24)	2 (12)	1 (20)
Hours spent caregiving per day, mean ± SD	11.65	16.35	19.63
Perceived usefulness of CareVirtue (Behavioral Intention), median (IQR)	2.87 (1.12, 3.44)	3.75 (3.0, 4.12)	4.5 (4.0, 5.0)
Usability of CareVirtue (System Usability Scale), median (IQR)	76.43 (68.12, 86.25)	85.17 (81.25, 91.25)	86.5 (72.5, 97.5)

Table 6-3 Summary of primary ADRD caregiver demographics for each engagement pattern

		Presence of barriers			Presence of facilitators		
Work System Component	**Contextual barriers and facilitators**	**Low and declining (n = 17)**	**Moderate and consistent (n = 16)**	**High and increasing (n = 5)**	**Low and declining (n = 17)**	**Moderate and consistent (n = 16)**	**High and increasing (n = 5)**
Person	Psychological well-being of primary caregivers	X	X		X	X	
	Psychological well-being of secondary caregivers	X	X	X			
	Technology attitude and literacy of primary caregivers	X	X		X	X	X
	Technology attitude and literacy of secondary caregivers	X	X	X			
	Biomedical characteristics of primary caregivers	X					
Tools	CareVirtue's versatility		X			X	X
	CareVirtue's access and usability	X	X	X	X	X	X
	CareVirtue's privacy and trustworthiness	X	X		X	X	
	Integration of existing tools with CareVirtue	X	X	X		X	
	Satisfaction with using other existing tools	X		X	X		
	Access to internet	X					
Tasks	Complexity of caregiving tasks	X	X	X	X	X	
	Conflicts with self-care tasks		X				
Socio-cultural	Social support	X	X			X	X

		Presence of barriers			**Presence of facilitators**		
Work System Component	**Contextual barriers and facilitators**	**Low and declining (n = 17)**	**Moderate and consistent (n = 16)**	**High and increasing (n = 5)**	**Low and declining (n = 17)**	**Moderate and consistent (n = 16)**	**High and increasing (n = 5)**
	COVID	X	X				
	Existing social and personal values	X	X			X	X
Organizational	Formal care network characteristics	X	X		X	X	
	Informal care network characteristics	X	X			X	X
	Workload	X	X	X			
	Routines	X			X		X
	Distribution of care settings	X	X		X		X
Physical-spatial	Workspaces	X					
Outcomes	Emotional catharsis				X	X	X
	Caregiving appraisal				X	X	X
	Caregiving reappraisal				X	X	X
	Interpersonal influence		X		X	X	X
	Information management among informal care network and hired helpers	X	X		X	X	X

		Presence of barriers			Presence of facilitators		
Work System Component	**Contextual barriers and facilitators**	**Low and declining (n = 17)**	**Moderate and consistent (n = 16)**	**High and increasing (n = 5)**	**Low and declining (n = 17)**	**Moderate and consistent (n = 16)**	**High and increasing (n = 5)**
	Information management with healthcare professionals and associated empowerment	X			X	X	
	Care coordination and planning				X	X	X
	Monitoring care recipient				X	X	X

Table 6-4 Presence or absence of contextual/outcome-related barriers and facilitators across CareVirtue engagement patterns: 'X' indicates the presence of a barrier or facilitator.

Low and declining usage

The 'low and declining usage' engagement pattern consisted of ADRD caregivers with a mean age of 57.62 years (SD = 11.27), with a majority (53%) providing care for parents or in-laws. Notably, 70% of these ADRD caregivers were employed full-time or part-time. Furthermore, 53% of ADRD caregivers in this group provided care for persons living with ADRD residing separately, either in a care facility or in another residence (Table 6-3).

The low and declining engagement pattern was associated with more contextual and outcome barriers than contextual facilitators. The description of the contextual barriers and facilitators for this engagement pattern is described below.

Barriers to engagement with CareVirtue. This engagement pattern was associated with the presence of the contextual barrier *workload* or the demand placed on the care network's cognitive resources to carry out tasks within a specified amount of time, as a barrier to using CareVirtue. One participant described resistance to using CareVirtue with other commitments in their life such as family:

> "see if I didn't have the kids here and life wasn't as hectic, I could certainly use it a whole lot better." (P291).

This engagement pattern was also associated with *informal care network characteristics* such as the size, composition, geographic distribution, and the role of the care network acting as a barrier to engaging with CareVirtue. One participant indicated a lack of connection with their family members that led them to refrain from sharing CareVirtue with other family members:

> "[My family is] totally, they're really, really disconnected. And so I did not invite them, yeah. It just would've caused more chaos, more phone calls, more, it wouldn't have been helpful." (P273).

Additionally, participants also described that their *satisfaction with using existing tools* deterred them from using CareVirtue. One participant described that they preferred to use their phone calendar as it provides reminders regarding appointments:

> “I utilized my phone more. Also, again, because of the reminder feature, right? My phone pops up, oh, you know, Dad has PT this afternoon at 2:30.” (P251).

Participants in this group indicated that their *physical well-being* negatively influenced engagement with CareVirtue as one participant described that their back issues prevented them from engaging in CareVirtue through a computer or mobile device:

> "It's difficult for me to do it, yeah [..] I have some health issues with my back that doesn't require me, it's hard for me to function and do it" (P233).

Access to internet also negatively influenced engagement as one participant’s family lived in a rural area:

> “while I have my laptop on most of the time, she barely does because she’s up there in the middle of nowhere Wisconsin, and so Internet for her is even a challenge.” (P222).

The participants in this engagement pattern had *workspaces* that are outside of the primary ADRD caregiving environment that also negatively influenced their engagement with CareVirtue:

> “there are days where I'm just never home or . . . night and I don't think about jumping on the computer at that time. So if I would have thought to put it through on my phone, I would have used it more” (P232).

Information management with healthcare professionals impeded engagement with CareVirtue as one participant described that the tool’s inability to share relevant notes and action items to their care team as a barrier:

> “I think it would be a cool, you know, tool if you could work with your physicians on this kind of thing. Because, you know, it would be easy to send them updates that way that occasionally, you know, we got a new prescription for [the care recipient] and it would have been nice to, you know, communicate via this tool” (P271).

Facilitators to engagement with CareVirtue. This engagement pattern was also associated with some contextual and outcome facilitators that influenced engagement. *Information management among informal care network and hired* *helpers* occurred as a facilitator as participants used CareVirtue to bring members of the care network more involved in care:

> "my main goal was to get my brothers more involved and be able to communicate with them about what's going on with my father. And so that was kind of nice to have" (P271).

The usability and access to support when navigating the interface was described as a facilitator by some participants:

> "Honestly, it was like when I had a question, I just hit the little blue bubble and it sent a note. And in absolutely no time somebody got back to me and answered the question or told me how to do what I was, needed to do" (P283).

Participants belonging to this engagement pattern also described positive outcomes from using CareVirtue like *care coordination* that helped elevate the care provided by others in the network through communication of specific care needs:

> "So being able to put [person living with ADRD's] specific preferences next to [specific tasks], it just bumped the next person's care level up for [person living with ADRD] (P232)".

For some, the lack of *satisfaction with existing tools* facilitated engagement with CareVirtue.

One participant described that the lack of privacy and security in other communication tools facilitated engagement with CareVirtue:

> "sometimes we use Messenger, not just for my, for her care, you know, but for anything family. [..] which is not necessarily a secure, you know, thing, and this one is. So, yeah, it has just created something that was specifically and exclusively for her care" (P234).

Moderate and consistent usage

The 'moderate and consistent usage' engagement pattern consisted of ADRD caregivers with a mean age of 60.69 years (SD = 9.31), with a majority (63%) providing care for parents or in-laws. 50% of these ADRD caregivers were employed full-time or part-time whereas the remaining 50% were not working. 75% of the

ADRD caregivers with this engagement pattern lived with the person living with ADRD they were providing care for (Table 6-3).

The 'consistent usage' engagement pattern was associated with 19 contextual barriers and 18 contextual facilitators to engagement with CareVirtue. The description of contextual and outcome barriers and facilitators for this engagement pattern is described below.

Barriers to engagement with CareVirtue. This engagement pattern was associated with the contextual barrier—*complexity of caregiving tasks*. One participant described that the stage of ADRD of the person living with ADRD did not require the coordination that CareVirtue supports:

> "The caregiving that I'm doing with a person with somewhat mild dementia doesn't need all the kind of coordinating through different providers that this software seems to kind of focus on" (P215).

Another participant described that the *versatility of CareVirtue,* specifically, that of accessing a web-app was more difficult than accessing a mobile app:

> "for people like me that aren't real technologically savvy, if I can just get the icon app on my phone, that's easier to me than, you know, actually going to a website and then logging in and whatever" (P264).

The *workload* of the care network also impeded engagement with CareVirtue as one participant described their hesitancy in sharing it with others in the care network due to the busy lives of the secondary ADRD caregivers:

> "I think I hesitated many times [sharing CareVirtue] just because they have their own lives, and, you know, one of them has young children, and, I mean, they're both are very busy people and taking care of a lot of other people." (P203).

Another barrier associated with the 'moderate and consistent usage' engagement pattern is the perception of engaging with CareVirtue as a *conflict with a primary caregiver's self-care tasks.* One participant described often prioritizing the person living with ADRD relative to themselves. This participant emphasized the need for features in CareVirtue that would specifically address the challenge of balancing caregiving responsibilities with their own personal self-care tasks:

> "to actually have something that said, okay, I took my medicine today and put an X on my square. And that way, she took her medicine, and I took mine. We get so focused on her stuff, that we forget about other stuff" (P211).

Facilitators to engagement with CareVirtue. This engagement pattern was associated with an outcome facilitator, *information management among informal care networks.* Managing information among informal network such as the nurses schedule was perceived as a facilitator to engaging with CareVirtue:

> "But the calendar was there because it was, again, useful for my sister to look at. It said, oh, yeah, the nurse's aide came today. I wonder how that went. Or her nurses are there today, I wonder what's going on. So, yeah, so that was useful also" (P206).

A contextual facilitator that was associated with the 'consistent usage' pattern was *CareVirtue's access and usability.* The ease of learning how to use CareVirtue and teach others on how to use it was described as a facilitator by one participant:

> "So in the beginning, it was a little awkward, but with just repeated usage, it got really easy, and I was able to instruct multiple caregivers on how to use it" (P202).

The contextual facilitator, *complexity of caregiving tasks,* also influenced engagement in this group. CareVirtue helped some participants keep track of managing complex caregiving activities such as managing medication and other daily activities:

> "I just would make an entry like grandma's grass was cut today. So then, you know, instead of trying to remember, [..] now when did the grass have to be cut? When do I need to redo the medications? I could just kind of keep that, you know, keep that logged" (P274).

CareVirtue's integration with existing tools was described as a facilitator to engagement as participants could copy data from their Electronic Health Records into their personal CareVirtue dashboard:

> "I think it worked really well with, I would go, I mean, I can have a couple of windows open, and I would have her, MyUnityPoint up, and then I would just, basically, you know, copy over any PT, any doctor's appointments, you know, when she needed a blood test" (P243).

High and increasing journal usage

The 'high and increasing journal usage' engagement pattern consisted of ADRD caregivers with a mean age of 65.8 years (SD = 4.09), with a majority (80%) providing care for spouses or partners. 80% of these caregivers with this engagement pattern retired from employment. Furthermore, 100% of these caregivers lived with the person living with ADRD they were providing care for (Table 6-3).

This engagement pattern was associated with a presence of more contextual and outcome facilitators to engagement than barriers. The description of the contextual factors as barriers and facilitators for this engagement pattern is described below.

Barriers to engagement with CareVirtue. The 'high and increasing journal usage' engagement pattern was associated with the presence of the contextual barrier, *workload.* One participant described that the secondary ADRD caregivers in their care network have a high workload and did not have the time to engage with CareVirtue:

> "And [secondary caregiver] never, he never opened them. I've looked at it and that doesn't, the other one is at a camp where he's got, you know, kids in his cabin all the time. And he's been busy this whole time" (P264).

Another participant described that the *complexity of caregiving tasks* varied over time and hence, decided it would take too much time to use the in-built calendar in CareVirtue:

> "I used it mainly for [care recipient]'s medical things that were going on, but I really didn't use it for everything that goes on because, you know, we have some weeks that are very packed, and it just didn't feel like, you know, it would take up too much time making too many calendars" (P242).

Satisfaction with existing tools also negatively influenced use for this engagement pattern. One participant described that they filled out the whiteboard every morning to plan out the day instead of using CareVirtue:

> "Well, I mean, every morning I have to fill out that whiteboard, so it's pretty, you know, this is kind of, I got used to this when I was in the Navy when I was a teenager [...] And I've sort of patterned [caregiving planning] after that" (P260).

Facilitators to engagement with CareVirtue. Participants with this engagement pattern described that the *versatility of CareVirtue* in being able to use it across devices facilitated their DHI engagement:

> "I don't like doing things on the phone, and my phones are not very good. So, it was on my computer" (P260).

Personal and social values of participants such as compassion for the person living with ADRD and respect for their boundaries facilitated CareVirtue engagement. One participant described CareVirtue as their "silent partner" that allowed them to share information without hurting the person living with ADRD and/or affecting their relationship with the person living with ADRD:

> "I don't want to embarrass [person living with ADRD]. I don't know what he can hear, what he can't hear. I know he can't hear most times, but sometimes when you're talking to people, people don't always understand how much he can or can't. Or I just didn't want anything to come between our relationship. And its key, and [CareVirtue] is a silent partner" (P264).

Caregiving appraisal, or the evaluation of the experience of caregiving, including the challenges and rewards, through CareVirtue was described as a facilitator:

> "So it, it also gave me a record that I could go back and look at. Because, you know, I know in years to come, you know, when I am grieving, I will be able to say, hey, you know, this or that" (P264).

6.4 Discussion

Our mixed-methods study explored ADRD caregiver engagement with CareVirtue — an ADRD caregiver DHI to support communication and coordination among ADRD care networks. Specifically, we identified the various engagement patterns of ADRD caregivers with CareVirtue and the contextual barriers and facilitators of ADRD caregivers influencing engagement associated with each engagement pattern. We uncovered three engagement patterns: low and declining usage, moderate and consistent usage, and high and increasing journal usage. We then identified a range of contextual barriers and facilitators influencing engagement of ADRD caregivers, informed by the Patient Work System model, that were associated with each engagement pattern.

Many prior studies have applied work systems models to understand barriers and facilitators to the care processes of clinicians, patients, and caregivers (Rutkowski et al., 2021b; Walker & Carayon, 2009; Werner, Malkana, et al., 2017; Wooldridge et al., 2017). However, we applied a work system model to study barriers and facilitators to the process of DHI engagement of ADRD caregivers. This is an important innovation as researchers increasingly acknowledge that DHI engagement is a multi-dimensional construct that extends beyond some form of usage to a social, behavioral, and cognitive process (Perski et al., 2017; Yardley et al., 2016). DHI engagement can therefore be studied using various ergonomics concepts and methods such as the work systems. The approach of studying engagement patterns through work-systems models, as shown by our findings, can offer a method to systematically assess DHIs by discerning a DHI's alignment with user needs. Furthermore, it can enable the identification of areas for improvement to redesign DHIs to meet user requirements.

A key finding of our study is that each engagement pattern was associated with a distinct configuration of contextual barriers and facilitators that influenced DHI engagement among ADRD caregivers. In other words, different contextual barriers and facilitators might be behind varying engagement patterns. These engagement patterns and their associated contextual barriers and facilitators highlight the diverse needs of ADRD caregivers and have implications for the design of DHIs that support ADRD caregivers.

6.4.1.1 Beyond the primary caregiver factors for design of DHI

By taking a systems approach, our findings not only confirm but extend prior research on barriers and facilitators of ADRD caregivers to DHI engagement. Many studies have identified primary ADRD caregiver factors and DHI-related factors influencing DHI engagement, but fewer studies have documented task, socio-cultural, organizational, and physical-spatial factors that influence DHI engagement of ADRD caregivers (Christie et al., 2018b; Duggleby et al., 2019; Werner, Stanislawski, et al., 2017). For example, Christie at al., 2018's review of 46 studies that explored implementation of DHIs for ADRD caregivers identified that 57% of 204 factors that influenced engagement tested were associated with the DHI (e.g., usability) and 34% of the factors were associated with the ADRD caregivers such as workload, technology literacy, access to internet, and psychological state. While our findings confirmed that these factors influence DHI engagement, we found contextual barriers and facilitators around integration of the DHI with other tools being used, existing social support, routines, and the distribution of care workspaces that should be taken into consideration for design of DHIs to support ADRD caregivers.

We also found that DHI engagement of the primary ADRD caregiver was influenced by the care network such as secondary ADRD caregivers, formal caregivers, and healthcare professionals. Previous studies have highlighted the importance of the structure and nature of relationships in a care network and their influence in the use of DHIs for ADRD caregivers (Christie et al., 2018a; Linden et al., 2022; Ponnala et al., 2020). Our findings deepened the understanding of the care network's influence in engagement by highlighting secondary caregiver factors such as role conflicts, workload, and psychological well-being, and the nature of familial relationship with the primary ADRD caregiver. These factors, in turn, influenced the primary caregivers' engagement with DHIs. Our findings suggest that DHIs, specifically those designed to support communication and coordination among care networks, should consider the needs of primary and secondary caregivers, and the routines involving formal caregivers.

6.4.1.2 Redesign of DHI through systems approach

Studying DHI engagement patterns through a systems-approach can provide a systematic method to evaluate and redesign a DHI. Through the identification of contextual barriers and facilitators associated with each engagement pattern, we identified system imbalances (i.e., contextual barriers to DHI engagement that are not mitigated by the contextual facilitators influencing DHI) (Carayon, 2009). These distinct imbalances for each engagement pattern can help with the identification of unmet ADRD caregiver needs, guiding DHI redesign efforts. This insight can inform redesign for tailoring design features specific to ADRD caregivers or for identifying ADRD caregiver subgroups that could benefit from the targeted DHI and marketing strategies.

Across the engagement patterns, we identified contextual barriers and facilitators that were common (shared among engagement patterns) and unique (not shared with other patterns) that could be further used to inform redesign. Although our study did not compare these contextual barriers and facilitators, notable patterns emerged. For some contextual barriers, the overarching barrier could manifest differently. For example, 'moderate and consistent usage' pattern highlighted task complexity as too high to be supported by the DHI whereas the 'low and declining usage' pattern indicated a low task complexity. This divergence in contextual barriers signals an opportunity for design customization, by incorporating ADRD caregiver input on task complexity to tailor functionalities accordingly.

6.4.1.3 Sustained DHI engagement among ADRD caregivers through feedback

Our study indicates that contextual factors may play a role in how ADRD caregivers assess outcomes and subsequently (re)engage with DHIs. By observing engagement patterns over time, our findings indicate that ADRD caregivers may evaluate the benefits of using DHIs in relation to their context, informing their subsequent usage decisions. Depending on how the outcomes align with their context-influenced goals, ADRD caregivers may adjust their DHI engagement levels accordingly. This finding is consistent with existing research highlighting caregivers' goal-oriented care activities and adjustment of care processes based on outcomes (Rutkowski et al., 2021b; Werner, Rutkowski, et al., 2022). Our study extends this conceptualization of adjustment or feedback for sustained DHI engagement of ADRD caregivers. While many previous studies on DHI engagement have explored factors of ADRD caregivers influencing adoption of DHI (Guisado-Fernández et al., 2019a; Mendez et al., 2021a), our study adds to the limited research on understanding sustained DHI engagement of ADRD caregivers. This finding could be used to (re)design DHIs by incorporating self-evaluation tools for ADRD caregivers or by leveraging Internet of Things measures to track ADRD caregiver outcomes. Based on the tracked caregiver context and outcomes, DHIs could offer personalized support. This might include adjusting task reminders, providing targeted educational resources, or suggesting additional support services based on the caregiver's needs and challenges.

Our study provides preliminary insights into contextual factors that may influence how ADRD caregivers re-engage with DHIs following their DHI outcome assessment. Prior research indicates that ADRD caregivers employ various coping strategies, including emotion-focused (managing one's emotional responses to stress) and problem-focused (practical steps to removing stressors) approaches, to navigate the challenges of caregiving (Monteiro et al., 2018; Murfield et al., 2021; Robinson-Lane et al., 2021; Sabo & Chin, 2021; Waligora et al., 2019). Our study suggests that caregivers in the 'low and declining' engagement pattern, which mainly consisted of adult children or children-in-law with professional occupations living separately from the person living with ADRD, may prioritize problem-focused solutions to managing caregiving, such as managing information with healthcare professionals, as evidenced by presence of barriers to this outcome. Consequently, their engagement with the DHI may have decreased over time as the DHI (CareVirtue) was not designed to support this goal at the time of this study. Conversely, caregivers in the 'high and escalating' engagement pattern, primarily comprising of spouses and those respecting the boundaries of the person living with ADRD, may prioritize emotion-focused coping strategies such as caregiving appraisal, leading to an increase in their DHI usage over time as the DHI may have aligned with their coping strategies through journaling. While our study's sample size limited our ability to confirm these findings and identify significant differences, it highlights a potential divergence in coping strategies among different caregiver groups. Future research should explore and validate these findings to inform the development of DHIs tailored to the specific needs of ADRD caregivers to promote sustained DHI engagement.

6.4.1.4 Design implications

This study underscores the importance of recognizing and accommodating the distinct needs of different ADRD caregiver groups and can be used to inform the design of future caregiving support technologies in several ways (Table 6-5). The different patterns of engagement and the contextual factors of ADRD caregivers associated with each pattern provide a framework for identifying the varied challenges experienced by caregivers and how the existing features met or did not meet their needs. Additionally, our study also helps designers and developers to identify their target population within caregivers and design specific tools for the differing needs of the caregivers. For example, the distribution of care work settings between home and hospice, workload within the care team, and interpersonal dynamics between informal caregivers significantly contribute to low engagement with CareVirtue. Coordinating with disengaged team members for hospice visits and documenting care decisions at the hospice emerged as primary needs for this group. Hence, caregiving support technologies should include extensive documentation of care decisions while the care recipient is in hospice, and remote monitoring features should be explored for this group.

Similarly, personal values, such as respecting care recipient boundaries, and navigating social stigma associated with ADRD create a supportive environment in CareVirtue for venting and enhancing engagement among the high journal usage group. However, spouses, the predominant composition of this group, struggle with their children accepting the diagnosis of dementia for their parents and struggle with engaging their secondary caregivers in caregiving support technologies. Hence, design should include tailoring interventions to address the unique challenges faced by secondary caregivers - mental health resources for dealing with a parent's dementia, providing support groups for secondary caregivers.

Further, the consistently engaged caregiver group experiences a balanced mix of barriers and facilitators across contextual factors. Managing personal medication and doctor appointments, in addition to caring for the recipient, poses unique challenges to this group. Coordinating care among multiple hired helpers positively influenced engagement. Hence, design should include role-based dashboards, task-delegation tools for the care team, and self-care tools for the primary caregiver.

Previous studies have shown that there is a high turnover in web-based interventions if the intervention focused on a singular feature, such as education for behavioral symptoms or journaling as opposed to having multiple design features (Grossman et al., 2018). Our study provides insights and design implications for different types of caregivers and what their specific needs are for interventions to be made adaptive with multiple features.

Contextual factors	Design implications
Low and declining usage	
Distribution of care work settings between hospice and home Workload of care network Strained interpersonal dynamics among care network Low technology literacy among care network	Robust features for extensive documentation of care decisions Calendar scheduling features such as automated scheduling that integrates with hospice providers' scheduling systems Remote monitoring features Alternative communication channels besides mobile or web apps for less tech-savvy family members such as SMS reminders or phone call notifications
Moderate and consistent usage	
Conflicts with self-care tasks such as managing medication Structure of hired helpers (formal care network characteristics)	Role based dashboards Self care check-ins and resources for primary caregivers Task prioritization tools that allow caregivers to prioritize critical tasks first and schedule less urgent tasks around their own needs Delegation tools that facilitate task delegation within the care network Dashboards that provide workload trends for the caregiver over time to help identify periods of increased stress
High and increasing journal usage	
Personal and social values (e.g., respecting care-recipient's boundaries) Psychological needs of secondary caregivers	Educational resources and self-care for secondary caregivers Support groups for secondary caregivers Features to facilitate communication with secondary caregivers

Table 6-5 Design implications for future digital health interventions for ADRD caregivers

6.4.1.5 Limitations and future work

Certain limitations of this study should be considered. First, although our study was diverse in terms of education and rurality, the study was conducted with mostly white participants. Future work should include a diverse range of perspectives to ensure that caregiver support tools are effective for a broad base of users. Secondly, our study was a secondary analysis. While members of this study were involved in the design and data collection of the primary study (PL, AL, NW), the nature of questions asked from the interviews (e.g., what features did you like the most and why?) may have resulted in a disproportionate presence number of barriers and facilitators for our study. Future studies should conduct primary research with carefully designed interview questions that avoid biasing the participants. Thirdly, clustering was done with available website usage metrics. While reasonable judgement was used to exclude some metrics like login information as participants may have stayed logged in, there is a risk to construct validity. Future studies should explore alternative methods to enhance construct validity and provide a more comprehensive analysis. Fourth, clustering as a data analysis method comes with inherent risks of assuming homogeneity within clusters. While the mixed methods design of our study mitigates this risk, future studies explore more robust techniques to clustering. Fifth, the length of the study was only 60 days to identify substantial engagement patterns temporally. Additionally, the work system approach used here only depicts the time unit of 60 days, potentially obscuring the DHI's influence on context. Despite efforts to minimize the identification of contextual factors influenced by DHI engagement, future research should consider longer longitudinal study designs, incorporating pre- and post-interviews. This approach would provide a more precise representation of the contextual barriers and facilitators influencing DHI engagement. Finally, interviews were only conducted with primary caregivers, hence future studies should explore the perspectives of secondary caregivers to obtain a holistic view of how care networks are important for engagement with caregiver support technologies.

6.5 Conclusion

To explore various engagement patterns and the contextual factors associated with the engagement patterns, we analyzed the use of a shared communication and coordination platform for ADRD caregivers. We identified three distinct engagement patterns (low usage, consistent usage, and high surge in journal usage) and the associated contextual factors impeding and facilitating engagement using the PWS framework. Our analysis revealed that a diverse interplay of contextual factors underly each engagement pattern. For example, caregivers with limited social support networks and those living with ADRD that live away from the primary caregiver may exhibit low usage patterns, while caregivers juggling their own health needs alongside caregiving responsibilities may demonstrate consistent usage patterns. Additionally, caregivers seeking emotional support and appraisal may show a high surge in journal usage. These findings highlight the importance of considering the unique circumstances of each caregiver when designing and implementing digital health interventions. Future research efforts should explore interventions tailored to address the specific needs and contexts of caregivers across different engagement patterns. By understanding this complex interplay of contextual factors, we can create more effective digital health interventions that support ADRD caregivers and ultimately, enhance the quality of life for both caregivers and those living with ADRD.

7 Qualifying the Quantitative: Can Structural Topic Models deliver timely, valid findings for design of digital health interventions?

This chapter is prepared as manuscript for Applied Ergonomics

7.1 Introduction

Qualitative research is a seminal research method and methodology used in healthcare Human Factors and Ergonomics (HFE) to understand, design for, and evaluate various complex patient care contexts such as homes, emergency departments, surgical rooms, in-patient settings, and radiology reading rooms (Carayon et al., 2015; Obradovich & Woods, 1996; Valdez et al., 2017; Wiegmann et al., 2021). Qualitative research typically refers to an inquiry process for exploring a social phenomenon that ultimately leads to the development of hypotheses, models, and theories. It helps researchers build a complex and holistic picture of a social or human problem (Creswell & Poth, 2007; Forman et al., 2008b). It entails studies that predominantly generate and analyze non-numerical data (e.g., words, audios, pictures, videos) using data collection methods such as interviews, focus groups, and observations (Creswell et al., 2007; Creswell & Poth, 2007; Valdez et al., 2017). Data analysis methods used in qualitative research often include time-intensive and resource-techniques like inductive analysis (where themes for the analysis are drawn directly from the data), deductive analysis (where themes for the analysis are drawn from a pre-existing model or framework), or a mixture of both (Creswell et al., 2007; Valdez et al., 2017).

Qualitative research helps advance the field of healthcare HFE by providing insights into user behavior and actions in ways traditional quantitative approach alone cannot (Hancock & Szalma, 2004; Hignett & Wilson, 2004; Valdez et al., 2017). First, qualitative research can help offer a systems-perspective of highly complex environments in healthcare (Vicente, 1999). It can help explore complex cognitive, physical, social, and behavioral processes embedded within complex organizational contexts of healthcare that is often difficult to quantify (Carayon, 2006; Hancock & Szalma, 2004; Hignett et al., 2013). Second, it is well suited for understanding phenomena within their contexts, uncovering links to concepts and behaviors, thereby generating and refining healthcare HFE theory (Bradley et al., 2007; Glaser & Strauss, 2017). Third, it serves as a means of gaining a deeper understanding of health professional, patient and caregiver work for the purposes of improving work environments, such as through design of technologies (Beer et al., 2014; Carayon, 2006; Rutkowski et al., 2021b; Werner, Stanislawski, et al., 2017). Fourth, it has the capability to support quantitative research in multiple ways. It can offer explanatory reasons behind quantitative findings and act as an exploratory tool to help identify relevant variables for quantitative studies (Carayon et al., 2015; Christian et al., 2006; Rochais et al., 2013).

Despite the various benefits of qualitative research, qualitative research poses challenges to analysis requiring manual, time-intensive, and resource-intensive analyses (Hamilton, 2013; Pope et al., 2000; Taylor et al., 2018). Unlike quantitative data with structured numerical values, qualitative research generates a vast amount of raw, unstructured data. This includes verbatim notes, transcribed recordings of interviews or focus groups (each transcript ranging from 10 pages to 40 pages of single-spaced text), and the researcher's reflective notes made during the research. Organizing and analyzing this voluminous data is labor-intensive and time-consuming and usually informs some form of content analysis (Creswell & Poth, 2007; Pope et al., 2000). Content analysis, a common approach to data analysis in healthcare HFE, involves multiple steps (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Valdez et al., 2017). Multiple researchers must first familiarize themselves with the raw data to identify initial codes or analytical categories that describe and explain phenomena (Bradley et al., 2007; Malagon-Maldonado, 2014; Pope et al., 2000; Valdez et al., 2017). This process could be inductive coding (codes emerging from the data), deductive coding (codes driven by a preexisting theory or framework), or a combination of both inductive and deductive coding, also called directed content analysis (Braun & Clarke, 2006; Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Often, many of these identified codes have subcodes or subcategories, creating a complex taxonomy of relationships that requires meticulous line by line coding, documentation of reflexivity, and ongoing discussions within the research team, and goes through multiple iterations (Barry et al., 1999; Birks et al., 2008; Saldana, 2015). Maintaining qualitative rigor further adds to the time and resource demands. Triangulation, a key principle to improving the credibility of research, involves incorporating multiple data sources, researchers, and methods that adds layers of complexity to the analysis (Valdez et al., 2017).

Structural topic modeling (STM), one of the many rapid approaches to qualitative analyses, is being increasingly used in healthcare HFE to address the time and resource limitations of manual qualitative research (Lester et al., 2019; Loganathar et al., 2023; Rutkowski et al., 2021b). Referred to as a "form of automated inductive content analysis" (Lester et al., 2019), STM is a semi-automated topic model that analyzes large amounts of textual data from a collection of documents (e.g., interview transcripts) to uncover latent thematic structures, called topics (equivalent to codes in manual qualitative analysis), from the data (Roberts et al., 2013). STM has the potential to support qualitative analysis by overcoming the time constraints of qualitative analysis, especially within areas of healthcare where rapid results are needed.

STM leverages a statistical framework to identify topics. Initially, documents are converted into a numerical representation using techniques like Bag-of-Words (BoW) and Term Frequency-Inverse Document Frequency (tf-idf) (Manning et al., 2008). While BoW creates a simple word count matrix, Tf-idf refines this by considering both a word's frequency within a document and its rarity across the entire set of documents (Manning et al., 2008). This helps identify keywords that are particularly informative for a specific document's content. Following document representation, STM employs statistical techniques like Bayesian inference and multinomial distributions to perform topic inference (Blei et al., 2001; Blei & Lafferty, 2007; Mimno et al., 2011; Roberts et al., 2013, 2014). This process analyzes word co-occurrence patterns within documents and assigns words to topics and models the probabilistic nature of topic assignment.

Beyond topic identification, STM can also incorporate covariates (independent variables) into the documents (Roberts et al., 2013, 2014). Covariates are independent variables that are often additional metadata that can influence how frequently topics appear across the documents (topic prevalence) and the various words used to discuss each topic (topic content) through a standard regression analysis (Roberts et al., 2013, 2014). Covariates might play a crucial role in enhancing the understanding of concealed patterns and variations such as correlated topics which proves particularly valuable in the qualitative analysis of data. Researchers have leveraged covariates to systematically explore large text data, leading to a more nuanced and insightful qualitative understanding (Lee & Kolodge, 2020; Lester et al., 2019; Loganathar et al., 2023; Rutkowski et al., 2021b). For example, Loganathar et al., 2023 used a STM model to find that high users of a digital journaling platform for caregivers of people living with ADRD discussed positive experiences about their caregiving more frequently, while low users expressed negativity regarding their caregiving experiences through their interview responses using STM. The number of journal posts of each participant was added as a covariate to interview data in this study. This helped reveal this difference in user engagement, providing a deeper understanding of how user engagement with the journal influenced the topics discussed in the interviews. This information, identified inductively by STM, could help inform the design and implementation of such technologies to better target user needs rapidly without the time-constraints of a traditional qualitative analysis alone.

While research has explored the use of STM to support inductive analysis, it has not been fully explored as an approach to support combined deductive and inductive analysis. Directed content analysis, a commonly used deductive and inductive approach to qualitative data analysis in healthcare HFE, leverages pre-existing theoretical frameworks to guide data analysis (Hsieh & Shannon, 2005; Valdez et al., 2017). Depending on the complexity of the theoretical framework being used, several stages of qualitative coding of data may take place. For instance, the Patient Work Systems (PWS) framework is a model that describes the barriers among elderly heart failure patients and their informal caregivers in performing self-care to manage their health at non-professional settings like the home. Specifically, the model demonstrates how system components such as individuals (e.g., patients, caregivers, healthcare professionals), tools, tasks, organizational, physical-spatial, and socio-cultural factors interact with each other to shape performance processes and outcomes. The PWS has been leveraged to study barriers to self-care and caregiving in other settings such as those of Alzheimer's and Related Dementias (ADRD) caregivers (Holden et al., 2015, 2017; Weiler, Lingg, Wilkins, et al., 2022). The qualitative analysis using this type of framework usually entails an initial stage of deductive coding to identify the system components (e.g., tools, tasks, etc.) and any interactions between the work system components. Then, subsequent stages of inductive and deductive coding are performed to identify subcategories to these components (e.g., the individual factors include demographics, motivation to perform self-care, biomedical factors, etc.) and any interactions between these subcategories (Holden et al., 2015; Wust

McBroom, 2023). STM has not been applied to directed content analysis of such frameworks that involves several stages of coding with inductive and deductive approaches. Therefore, understanding how STM can support multiple stages of inductive and deductive content analysis may help with improving limitations of qualitative analysis such as the time demands. Specifically, there is a need to explore how manual deductive coding from an initial stage of coding (e.g., system components) can be leveraged as covariates to perform the subsequent stages of coding with STM.

We explore the utility of STM in supporting a directed content analysis for identifying contextual factors influencing ADRD caregiver engagement with a digital health intervention (DHI) for ADRD caregivers—CareVirtue— using the Patient Work System framework. ADRD, a neurodegenerative disease that impacts 6.2 million adults in the US, presents unique challenges for ADRD caregivers who provide essential support for people living with ADRD ("2023 Alzheimer's Disease Facts and Figures," 2023). These ADRD caregivers often navigate the dynamic complexities of ADRD progression and its associated symptoms like agitation, repetitive questioning, wandering, etc. while managing their own lives (Finkel et al., 1996; Goren et al., 2014b). Caregivers are often not equipped with adequate training and resources to handle the complex and dynamic symptoms of ADRD (Brodaty & Donkin, 2009). Although ADRD caregivers can experience positive outcomes from caregiving such as family togetherness and family satisfaction of helping others, 30–40% of ADRD caregivers report negative outcomes such as adverse mental health outcomes, strain, decreased quality of life, and burnout (Alzheimer's Disease Facts and Figures, 2024; Sallim et al., 2015).

While many efficacious digital health interventions (DHI) have been designed for supporting ADRD caregivers, these DHIs often experience varied engagement patterns such as low utilization, abandonment, or selective usage of specific features, potentially leading to unrealized benefits. Recent research suggests that the varying patterns of DHI engagement among ADRD caregivers might be due to a lack of consideration for the specific contexts in which the DHIs are used. Context in which DHI engagement occurs has been defined and conceptualized in many ways. Some describe it as an information such as "any information that can be used to characterize the situation of an entity, where an entity is a person, place, or object that is considered relevant to the interaction between a user and an application, including the user and application themselves" (Dey & Abowd, 1999, p. 3), while others describe it as a knowledge that is an emergent from the interaction between users, objects, and activities and is always dynamic (Dourish, 2004). Combining the two perspectives, context of DHI engagement can be defined as a dynamic system of interacting components such as person, tasks, the characteristics of DHI under study, other tools and technologies used, social-factors, organizational factors, and physical-spatial factors that influence DHI engagement to create outcomes (Holden et al., 2015). The dynamic interacting components could act as contextual barriers or facilitators to DHI engagement. This context of DHI engagement has not been fully explored for ADRD caregivers and limits our current understanding of how ADRD caregivers engage with DHIs.

Many DHIs designed to support ADRD caregivers may offer generic educational resources without considering the context in which DHIs are used such as phase of ADRD, preferred themes of education, or presentation of out-of-date content leading to varied DHI engagement patterns such as abandonment (Boyt et al., 2022; Christie et al., 2018b; Werner, Brown, et al., 2022). There is a limited understanding of how the context of ADRD caregivers influences DHI use among ADRD caregivers. To address this gap, we identified 30 contextual factors of ADRD caregivers such as workload, social and personal values and how they influenced DHI engagement with a digital health intervention to support communication needs of ADRD caregivers— CareVirtue—in a parallel study (Loganathar et al, *In Progress*). However, like many qualitative research studies, the analysis alone exceeded over 200 hours, highlighting the need for more efficient methods to analyze qualitative data. Therefore, we propose using STM to support deductive and inductive analysis such as directed content analysis using the PWS framework to efficiently identify contextual factors influencing caregiver engagement with CareVirtue.

The PWS is a work system model that describes the work of non-professionals such as patients and informal caregivers doing work at non-professional settings like the home. The PWS framework organizes the patient and caregiver context as a structured system of interacting components such as people, tools and technologies, tasks, organizational factors, socio-cultural factors, and physical-spatial factors (Holden et al., 2015). Further, each of these components are composed of work system elements (e.g., organizational factors include rules and roles, routines, disruptions, etc.). This structured conceptualization of context makes the PWS framework a well-suited framework using which the utility of STM can be explored in supporting directed content analysis.

We propose conducting an STM-supported directed content analysis in two stages: first, a manual deductive coding of interview data to identify the PWS components and second, using the initial codes from the manual analysis as a covariate for subsequent coding with STM. The use of covariates can help identify topics that are particularly influenced by the presence of specific PWS components and hence, reveal complex relationships within the data. Hence, our objective is to explore how STM can support content analysis for study the contextual factors of ADRD caregivers that influence their engagement with CareVirtue — a web-based platform for ADRD caregivers. To do this, we aim to (1) compare the time it takes to conduct an STM for inductive analysis (without any covariates) and directed content analysis (using manual deductive coding of PWS components as covariates), in identifying these contextual factors of ADRD caregivers influencing DHI engagement with CareVirtue (2) explore the usefulness of topics identified by STM in identifying contextual factors of ADRD caregivers that influence DHI engagement with CareVirtue through both inductive (without any covariates) and directed content analysis (using manual deductive coding of PWS components as covariates).

7.2 Hypothesis

Our central hypothesis is that STM can be effectively integrated with manual directed content analysis to identify contextual factors of ADRD caregivers influencing DHI engagement. This integration would involve performing the initial coding manually to identify the PWS components of ADRD caregivers influencing DHI engagement. STM would then be employed in the next coding stage to identify contextual factors or topics influenced by the prevalence of PWS components.

H1: Time efficiency

H1a: STM-supported inductive analysis without covariates will be faster than manual qualitative analysis.

H1b: STM-supported directed content analysis will take more time due to the inclusion of qualitative analysis but will be faster than manual qualitative analysis.

H2: Topic usefulness

H2a: Topics identified through STM-supported inductive analysis will identify distinct topics, but they will not be complementary to work system analysis of identifying contextual factors influencing CareVirtue engagement guided by the PWS framework.

H2b: Topics identified through STM-supported directed content analysis will identify distinct and complementary topics to work system analysis of identifying contextual factors influencing CareVirtue engagement guided by the PWS framework.

7.3 Methods

The study reported here is a secondary analysis that builds upon a previous study to assess how well a web-based digital health intervention called CareVirtue can support informal caregivers of those living with ADRD (R41AG069607) (Boutilier et al., 2022), and was done in parallel with a study aimed at understanding the contextual barriers and facilitators to engagement with CareVirtue (Chapter 6). The University of Wisconsin-Madison Institutional Review Board (IRB) approved this study.

7.3.1 CareVirtue

CareVirtue is a progressive web application developed in React to support and connect ADRD care networks that can be accessed via a web browser on any device with a data connection. CareVirtue was developed as a platform for caregivers to store and share information with members of their care network to address the unmet needs for tools to support coordination from caregivers in an online support group community. It aims to address the current gaps in existing caregiver-specific support technology for ADRD to support coordination, communication, and connection between care networks. At the time of the study, CareVirtue had the following features: 1) dashboard, 2) care journal, 3) care guide, 4) care team management, 5) shared calendar, and 6) geolocated resource list.

7.3.2 Parent study design and procedures

The research team conducted a feasibility study over eight weeks with 41 informal primary caregivers and other members of their care network. Participants were recruited between February and June 2021 through multiple community sites in Wisconsin and Southern California as well as through the Wisconsin Alzheimer's Disease Research Center by advertising in email, social media, and newsletters with the following eligibility criteria: self-identified primary caregiver of a person living with ADRD, at least 18 years of age, English speaking, has daily Internet access, and shares caregiving information/responsibility with other caregivers. Eligible participants underwent a virtual one-hour enrollment in which their informed consent was obtained. Participants also completed a pre-trial demographics survey and were provided with an orientation of CareVirtue's features. The research team helped the primary caregiver create their account and invited other members of their care network that the primary caregivers selected.

Participants were asked to use CareVirtue for 60 days following the enrollment visit. After 60 days, the research team conducted a post-trial interview virtually for an hour with the primary caregivers. The interview guide was developed through multiple iterations by the study team to broadly understand how CareVirtue was used and to understand caregivers' experiences with CareVirtue during the study period. The study team had expertise in engineering, caregiving, product development, technology commercialization, and qualitative research. Participants were asked specific questions about their experience with CareVirtue (e.g., "What features did you like the most and the least, and why?", "What changes did you make to your existing routine to use CareVirtue?") and about their broader context as a caregiver (e.g., "What does a good and bad day look like to you as a caregiver?", "What are the biggest challenges you've been experiencing as a caregiver?"). These interviews were audio recorded and transcribed verbatim by a professional transcription service and deidentified.

7.3.3 Current study analysis

To explore how STM can support content analysis of data collected from 41 semi-structured interviews, we performed two distinct analyses: STM-supported inductive analysis (without any covariates) and STM-supported directed content analysis (using manual deductive coding of PWS components as covariates),.

In the **STM-supported inductive analysis**, we first fit an STM to the interview data to uncover topics emerging directly from the text without any pre-defined frameworks or covariates. This allowed us to explore the data freely and identify potential topics based solely on what the participants expressed.

For the **STM-supported directed content analysis**, we employed a two-stage coding process to explore topics identified by STM within the pre-defined framework – the PWS model. In the first stage, we performed a deductive analysis manually using the components of the PWS framework. This stage of coding was part of the parallel study (Loganathar et al., *In progress*). This established a foundation of initial codes based on our existing knowledge about the factors influencing CareVirtue engagement. In the second stage, we then used STM to identify latent topics within the data and the initial codes as covariates, aiming to unveil complex relationships, such as how the presence of these topics varied with the PWS components.

Throughout the analysis, we documented the time taken for both approaches. We also analyzed the usefulness and relevance of the identified topics through team-based discussions.

7.3.3.1 Time-efficiency and usefulness of STM-supported inductive analysis

The STM analysis was performed in R using the *stm* package (Roberts et al., 2019). Figure 7-1 shows the steps involved in STM-supported inductive analysis.

To prepare the data for running the STM, we removed stop words using ISO 639 language code (Buchta & Hornik, 2024), the largest collection of stop words in English language. These are words such as ‘a’, ‘an’, ‘the’, ‘hmm’, etc.., that are prevalent across all documents and are non-discriminating. We also removed terms that were specific to this study such as ‘carevirtue’, ‘alzheimers’, ‘caregiving’, ‘dementia’, ‘interviewer’, and ‘respondent’. We then lemmatized and combined any words used in different tenses (e.g., use, using, uses). Each interview (document) and the associated words (terms) were tabulated in a document-term matrix. The document-term matrix from bag-of-words approach was then transformed using term frequency and inverse document frequency (tf-idf) to select important words (Manning et al., 2008).

We then fit STM models without any covariates and with a potential number of topics between 5 and 30. We assessed these models using a variety of measures to select the number of topics. The ideal number of topics was chosen based on quantitative measures such as held-out likelihood, semantic coherence, residuals, (Lee et al., 2019; Mimno et al., 2011) and team-based consensus with three researchers (PL, RP, AK) with expertise in Human Factors Engineering, qualitative methodology, and quantitative methodology. (See Appendix: Choosing the optimal number of topics in STM)

For each topic, we identified frequency and exclusivity (FREX) terms for each topic. The FREX terms identify words that are both frequent and exclusive to a topic identified and help label each topic (Bischof & Airoldi, 2012). FREX terms were calculated using the following equation:

$$FREX = \left(\left(\frac{w}{F}\right) + \frac{1-w}{E}\right)^{-1}$$

, where *F* is the frequency score of the term in the document or how frequently a term occurs within a document; *E* is exclusivity and is estimated as the conditional probability of observing a topic given the term, and *w* is the weight that determines the balance between frequency and exclusivity component – it ranges between 0 and 1 (0 represents full exclusivity and 1 represents full frequency).

We iteratively removed stop words and re-fit the model removed based on group discussions until words in the topics were coherent. We then visualized the prevalence of topics (per-document per-topic probability) for each topic and extracted example quotes from a document based on the FREX terms. We then named the topics appropriately through team-based discussions. We noted the distinctiveness, relevance, and clarity of topics. We also documented the time taken to complete the process.

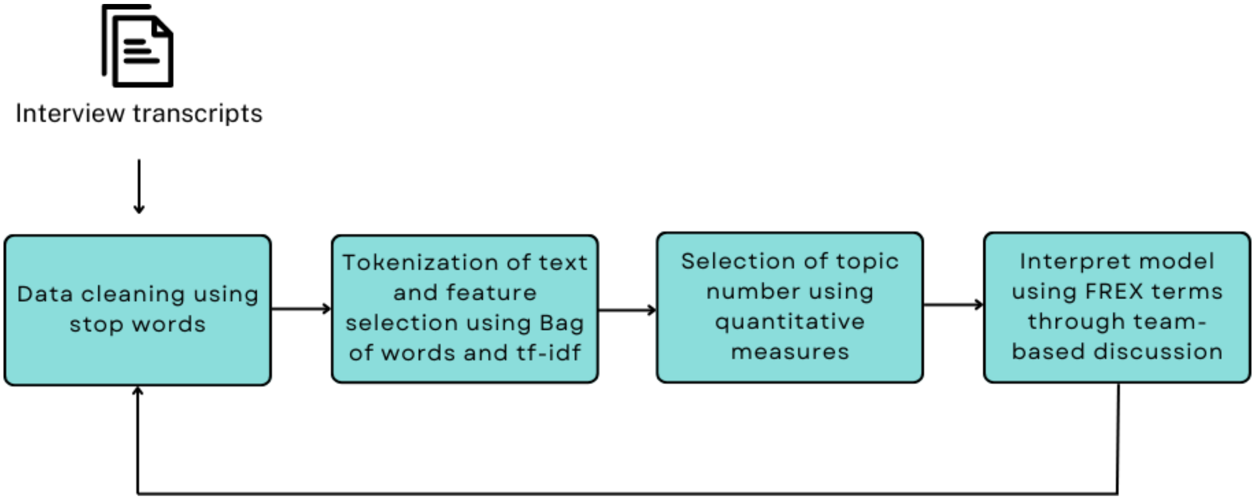

Figure 7-1 Steps involved in data analysis of interview data for STM-supported inductive analysis.

7.3.3.2 Time efficiency and topic usefulness of STM-supported directed content analysis

Conceptual framework

The Patient Work System (PWS) framework (Holden et al., 2015) was used to guide this analysis. PWS is a work system model that describes the work of non-professionals such as patients and informal caregivers doing work at non-professional settings like the home. This framework organizes the patient and caregiver context as a structured sociotechnical system of interacting components such as people, tools and technologies, tasks, organizational factors, socio-cultural factors, and physical-spatial factors (Holden et al., 2015).

For the purpose of this study, context does not include the process of engaging with CareVirtue. The PWS components were used to systematically code interview data by identifying relevant excerpts within the interview data that reflected the PWS components influencing CareVirtue engagement. These components were then used as a covariate and STM was run on the coded excerpts to identify any relationships within the data.

Manual deductive coding

I, the lead author (PL), first trained three other analysts (MO, KM, ZW) with experience in Human Factors Engineering on the definitions of the PWS components over a course of three one-hour meetings. Then, I, along with three members of the coding team (PL, MO, KM, ZW) performed the first cycle of coding by identifying passages with PWS components in each transcript using NVIVO 13. To establish reliability, two randomly selected transcripts were coded collaboratively by the four members during two dedicated two-hour meetings. Researchers then dually coded each transcript and met bi-weekly for an hour to discuss any discrepancies through consensus and ensure rigor over a course of five months (Barry et al., 1999). The resulting coded excerpts along with their corresponding PWS components were exported as a comma separated file (.csv). This document had the coded excerpt, participant identifier, and the corresponding PWS component in each row.

STM-analysis with PWS components as covariates

We performed a STM analysis of the coded passages with the PWS components as a covariate in R using the *stm* package. We first cleaned the data, tokenized the text, transformed the text using *tf-idf,* selected the topic number, interpreted the model and iterated the process until topics were distinct. The PWS components were chosen as covariates to assess how the PWS components might influence the prevalence of certain topics across the coded passages. Figure 7-2 outlines the steps involved in STM-supported directed content analysis.

Using team-based discussion, a qualitative analysis method to improve rigor (Barry et al., 1999), we identified new stop words and iterated on the process in Figure 7-2 twice. The resulting topics were named and interpreted through team-based consensus by a team of three researchers (PL, RP, AK). We documented the relevance of topics, their clarity, and distinctiveness through team-based discussions.

Using the *estimateEffect* function in *stm,* we then identified the influence of the work system components on the prevalence of the identified topics. This could reveal complex relationships within the data such as the influence of work system components on the prevalence of each topic. The *stm* package calculates the influence of the covariates using a simple regression (logistic-normal generalized linear) model based on a vector of document covariates $X_{d,}$ where d index the documents, for *K* topics:

$$\theta_d \,|\, X_{d\gamma}, \Sigma \sim LogisticNormal\left(\mu = X_{d\gamma}, \Sigma\right),$$

where, θ_d is the topic proportion, γ is a p-by-K – 1 matrix of coefficients, X_d is a 1-by- vector, Σ is K-1-by-K-1 covariance matrix.

We then documented the topics identified by the STM, the definitions of each topic that we came up with as a team, and the corresponding work system components that influenced the prevalence of each topic. To improve the rigor of this analysis, I, along with another member of the research team (PL, RP), critically reviewed 30 randomly selected coded excerpts for each topic, to ensure coded excerpts aligned with the STM-identified influence of the corresponding PWS components (Valdez et al., 2017). The total time taken to complete the process was documented throughout.

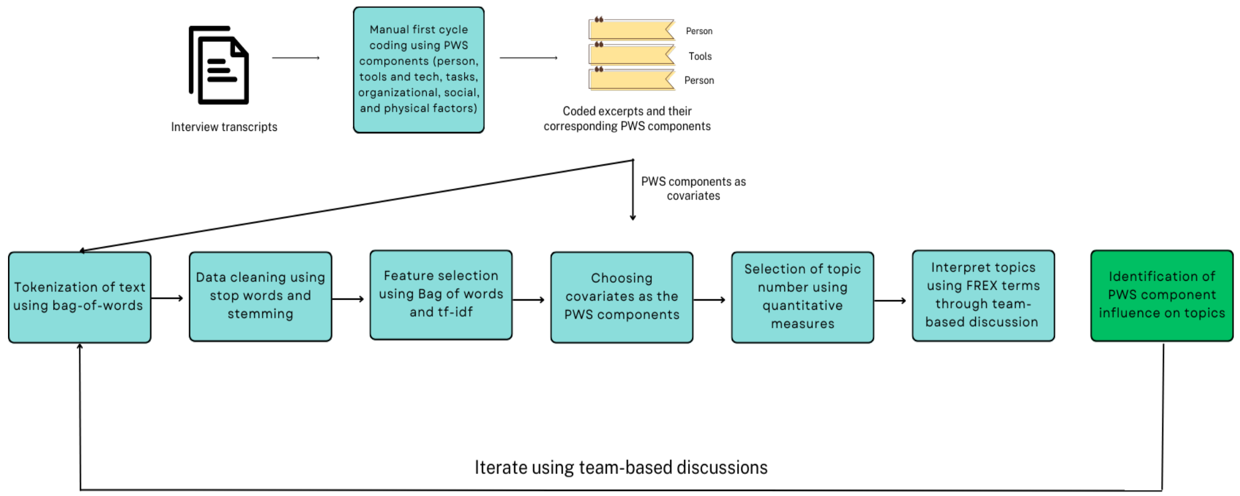

Figure 7-2 Steps involved in data analysis of interview data using STM-supported directed content analysis.

7.4 Results

We identified the following for the analyses: 1) time taken to identify topics; 2) usefulness of identified topics.

7.4.1 STM supported inductive analysis

The inductive analysis of interview transcripts using STM identified seven topics, out of which six topics were distinct and useful (Table 7-1). The number of topics (k = 7) were selected through team-based discussions and the model with the highest held-out likelihood and lowest residuals (See Appendix: Choosing the optimal number of topics in STM, Figure 13-1). The identified topics described adaptations, in-law relationships, hospice care, CareVirtue's journaling features, information management among informal care networks, and data logging.

7.4.1.1 Time taken to complete analysis

The STM model in R took less than a minute to converge and hence is trivial for this analysis. This was followed by 30 minutes of team-based discussion to refine stop words and rerun the model. An hour team-based discussion followed the second iteration. The total analysis took approximately 1.30 hours.

7.4.1.2 Topic usefulness

We identified seven distinct topics using STM (Table 7-1). We did not identify any coherent themes for one topic. While topics remained distinct, not all topics were directly relevant to engagement of ADRD caregivers with CareVirtue (e.g., exploring adaptations, in-law relationships). For instance, the topic, "exploring adaptations" encompassed discussions on participants' strategies to address challenges in their caregiving responsibilities, such as acquiring a tandem bike for a care-recipient who can no longer walk or experimenting with different toileting options (e.g., diapers vs. briefs) (P282). However, these adaptations were not directly relevant to engagement with CareVirtue. Furthermore, within the overarching topic of "exploring adaptations," we also identified the repeated use of the word, "depends", by one participant in reference to a brand of adult diapers (P282) and another participant (P292) frequently prefacing responses with "it depends on...".

Conversely, topics such as "hospice care," "journaling feature of CareVirtue," "data logging", and "information management among care networks" were identified as directly relevant to engagement with CareVirtue. Participants elucidated how these topics influenced their engagement with CareVirtue. For example, discussions around "hospice care" underscored the unique necessity of documenting care decisions made in a hospice setting when the caregiver resides separately from the care-recipient (P270). The topic "journaling feature of CareVirtue" included discussion of specific features like emoticons that resonated positively with participants.

Additionally, one topic identified in Table 7-1 lacked any discernible underlying theme related to engagement with CareVirtue. This ambiguous topic contained words from one participant that was providing care for their “aunt” from afar, the frequent mention of the word “day” (e.g., the other day, day care), and working “virtually” (P293).

Topic	FREX words	Definition	Illustrative example
Exploring adaptations (β = 0.167)	Depends, understanding, tough, bike, change, news, google, mother	Finding and adapting to new challenges in caregiving with the progression of disease.	“so we had been using like Depends, because things were just so unpredictable. [..] And so I got, a month ago, we got a tandem, a tri-tandem bike. So it's not a sit-by-sit, side-by-side bike, but it's literally a tandem bike with two wheels in the back. So I didn't want him to have to wear those Depends, right, because of all that squishy fabric. It's like wearing a pad on a bike. So I'm like, hey, let's just get you into regular underwear, you know. And so last weekend, we did that. And he got on the bike. And so it's like, okay, so shall we just kind of stay in these now and see how it goes? And, of course, he said, yeah, or okay, or no or nothing, whatever. I said, we're going to try it. And so we had a good weekend, last weekend. We had no accidents of any kind, no intentional of anything of any kind.” P282
In-law relationships (β = 0.166)	Law, shower, son, data, families, wife, missing, potential	In-law relationships among care networks and their involvement in caregiving (e.g., daughter-in-law being the primary caregiver) and associated challenges.	“As where some people, my brother-in-law, I swear would break his jaw, because he was just, he would stress so bad about it. And we were like . . . you’ve got to just, dad’s not doing this on purpose, you’ve just got to roll with it.” P212
Hospice care (β = 0.151)	Morphine, hospice, company, board, track, died, mouth	Issues pertaining to hospice care such as medication administration, tracking care decisions while primary caregivers do not live with the care-recipient, and end-of-life care.	“I was dealing with trying to find state regulations for a hospice company, so that when the investigators for these two different agencies, because there were two different complaints, that I basically could say, here's what I presented during the meeting.

Topic	FREX words	Definition	Illustrative example
			Here's why I was in the right." P270
CareVirtue's journaling features (β = 0.146)	Simple, smiley, toileting, print, journaling, forgot, fell, link	The features pertaining to the journal such as smileys, tags or categories such as toileting, and ability to print journal entries.	"I had to pick the category, whether it's about toileting or sleeping. […]. It was just, I guess it just seemed like all I was talking about was toileting." P262
-ambiguous topic 1- (β = 0.142)	Aunt, time, mom, feel, phone, virtual, day	Idiosyncratic theme that represents one participant's lexicon and specific caregiving arrangements	"I have some deadlines to do the tasks, and then sometimes I do virtual training. I don't really have time talking with my aunt." P293
Information management among informal care networks (β = 0.128)	Father, program, brothers, scheduling, terms, alerted, notified, familiar	Managing and communicating information about care-recipient within the care team.	"So it was somewhat useful in that, for me, my main goal was to get my brothers more involved and be able to communicate with them about what's going on with my father. And so that was kind of nice to have, you know, one place that I put information in, and then they can go to it. You know, they get alerted about it and can also go to it on their own and check. You know, so that part was really good. I don't know if you're going to be asking later, but like some of the things, it was hard for me to, scheduling, putting in his scheduling because it doesn't have recurring scheduling." P251
Data logging (β = 0.098)	Log, team, software, features, technical, blood, documenting, entry, diagnosis	Logging medical data such as vitals	"if she had a blood pressure concern, and I was taking daily blood pressure readings, or, you know, temperature readings or whatever, you know, that I could log in and just, maybe more often than daily, I don't know, but

Topic	**FREX words**	**Definition**	**Illustrative example**
			probably daily, log in and say, you know." P220

Table 7-1 Topics with their topic proportions across documents (β), FREX words, the definition of the topics, and illustrative examples from STM-supported inductive analysis

7.4.2 STM-supported directed content analysis

We identified 13 topics using STM-supported directed content analysis out of which 12 topics were clear and distinct. We could not identify any meaningful themes for one topic (Table 7-2). The number of topics (k = 13) were selected through team-based discussions and the model with the highest held-out likelihood and lowest residuals (See Appendix: Choosing the optimal number of topics in STM, Figure 13-2).

7.4.2.1 Time taken to complete analysis

The initial stage of coding using manual deductive coding required 99 hours, along with six 1-hour group meetings to reconcile any disparities. This stage, typically not a part of the STM-analysis, was the manual analysis process of STM-supported directed content analysis. Running the STM took less than two minutes and hence, was trivial for the purpose of this study. The STM model was then iterated twice. After each iteration, a 1-hour team-based discussion was held to discuss the topics and their interpretability. Any words that seemed to be repeated throughout all topics and additional stop words were removed or lemmatized (e.g., "like"). The entire process took a total duration of 102 hours.

7.4.2.2 Topic usefulness

We identified 12 interpretable, distinct, and useful topics using STM-supported directed content analysis (Table 7-2). All 12 topics included aspects of CareVirtue engagement were directly relevant to contextual factors of ADRD caregivers influencing their CareVirtue engagement. The addition of covariate increased the number of useful topics from the number of topics identified in inductive-STM.

The topic, "routines of primary caregivers," elucidated how participants seamlessly incorporated CareVirtue into their daily routines. Examples included one participant documenting weekly occurrences, while others bookmarked the platform for use during leisure activities on their laptops (P242). The topic, "informal care team," describes the characteristics of team members, their technological proficiency, and the dynamics influencing engagement with CareVirtue. A participant shared that a neighbor, a crucial team member, resisted technology and declined inclusion in CareVirtue (P262). The topic, "likable and dislikable Features of CareVirtue," contained participants' preferences and grievances regarding CareVirtue. Furthermore, one topic lacked discernible underlying themes related to CareVirtue engagement and appeared as a fusion of various other topics.

We then identified how each work system component influenced the topic prevalence of the 12 clear and distinct topics (Figure 7-3 and Figure 7-4). The prevalence of each topic identified by STM was influenced positively or negatively by the work system components. The prevalence of topics for "usability of CareVirtue" and "medication reminders and tracking" was solely influenced by the work system components, "tools-CareVirtue" ($p = 0.009$) and "tasks" ($p \approx 0.000$), respectively. The prevalence of the topic "informal care team" was positively associated with the person component ($p = 0.006$), organizational factors ($p = 0.031$), and tools-CareVirtue ($p = 0.036$). The topic prevalence of "likeable and dislikable features" was influenced by positively the work system component "tools-CareVirtue" and negatively by other work system components except socio-cultural factors, suggesting this topic was predominantly related to features pertaining to CareVirtue but not any other components. The prevalence of topic "routines" was influenced positively by the physical-spatial factors ($p \approx 0.000$) and tools-CareVirtue ($p \approx 0.000$), contrary to how the PWS placed routines as part of the organizational factors.

Some topics appeared to be influenced by the prevalence of work system components that contradicted the guiding definitions of context of DHI engagement and the framework used to guide this analysis. The prevalence of the topic "information management", that would be considered an outcome from interacting with CareVirtue according to the guiding definition of context of DHI engagement for this study (Chapter 2.5), was influenced positively by the work system components, organizational factors ($p = 0.001$) and tools-CareVirtue ($p = 0.028$) but was not associated with work system outcomes. Similarly, the prevalence of outcome-related topics "interpersonal influence" and "emotional catharsis" was positively associated with work system outcomes and organizational factors.

Topic	FREX words	Definition	Illustrative example
Routines of primary caregiver (β = 0.095)	Easy, day, routine, remind, sit, remember, bookmark	Integration of CareVirtue into existing routines	"I guess I didn't do much of it during the week. It would be kind of you know, at the end of the week, kind of compile some stuff. I suppose it probably would be better to try and get into it every day or every other day or something, so that you remember all the things that you wanted to put in there. And there again, time constraints. My not getting home until 8:00 or 9:00 at night kind of puts a damper on that." P242
Informal care team (β = 0.094)	Software, log, partner, wife, team, degree, lunch	Traits of informal care team such as technology literacy, roles of the informal care team members in care work and their degree of involvement	"She basically hates computers. She's one of my key care partners because she lives in the building, but I'm never going to get her on the platform unless maybe it's like through some sort of abbreviated text messaging or something like that" P262
Cross-platform compatibility (β = 0.090)	Difficult, quick, support, meet, phone, people, set	Using CareVirtue across many devices	"I like to sit down at my computer when I'm grading or if I'm doing a schedule or something like that, but as far as other stuff, I'm on my phone, and it's got to be an app that works well" P241
Likable or dislikeable features (β = 0.088)	Resource, user, help, edit, tool, summary, mind	Features that were liked or disliked by participants	"I added to it because I did research on the type of dementia that the person has and made it available to other caregivers to look at the resource page. So that was helpful." P252
Organizational tools (β = 0.085)	Calendar, list, appointments, google, ical, cross	Other organizational tools that were used to organize ADRD caregiving.	"I do to-do lists, but I do to-do lists on notes. So, yeah, I did some. But now again, because, yeah, I don't know, I have to really think about doing more over there because that kind of to-do list will be trickled down to whoever is . . . but they could look too. But it's not the way we use it, so I didn't actually care to put over there." P210

Topic	**FREX words**	**Definition**	**Illustrative example**
Journaling (β = 0.081)	Post, cut, categories, navigate, tag, hard, interface	Specific use-cases for journaling encompassing how it was used, difficulties associated with sorting categories.	"Well, I guess just because, you know, when I would make my short, little entry in the journal, instead of entering that grandma's grass was cut today, or grandma got her haircut today or whatever, instead of me having to do the journaling and then also send out the mass texts, or, you know, however I'm going to communicate to everybody else that that's done, it was only one step instead of doing two things. And, you know, had everybody looked at it, I wouldn't have had to do the journal, made the entry in the journal and also do the group text or whatever." P242
Information management (β = 0.080)	Weight, invite, online, picture, food, individual, daughter	Sharing, communicating, and deciding who has access to information such as weight, food habits, pictures of day-day activities of care-recipient to others in care team.	"I wasn't comfortable sharing that with them for them to enter things. It would be nice to have a functionality where it's more non-regular caregivers to be able to enter things without them being able to see the whole history or whatever or continue on it afterwards." P250
Emotional catharsis (β = 0.078)	Emoji, explore, month, life, survey, sad, smiley	Benefits to using CareVirtue, specifically emotional catharsis from writing about their lived experience.	"I stepped into it during an extremely stressful time with lots of different things going on. And it felt quite good to write about that and then use the emojis, you know, the red mad or the sad face, to just like hit it and then kind of use it as an emotional release with just a sentence or two." P211
-ambiguous theme 1- (β = 0.074)	Contact, comment, talk, emergency, free, share, reason	Idiosyncratic theme consisting of many other identified themes.	NA
Long term care planning (β = 0.064)	Mom, report, surprise, brother, document, ical, dad	Participant's need for preparing for	"And I found myself wanting to track things for my other parent than the one that I was actually doing for this event, because he's

Topic	FREX words	Definition	Illustrative example
		the progression of dementia.	kind of, he's mild cognitive impairment right now, not diagnosed dementia, so he's got a whole bunch of stuff we're tracking to see how he's progressing into." P282
Medication reminders and tracking (β = 0.061)	Schedule, doctor, medicine, forget, chore, whiteboard, blood	Medication reminders and tracking for self and the person living with ADRD	"I think that's something that would be valuable to me, you know, to actually have something that said, okay, I took my medicine today and put an X on my square. And that way, she get, she took her medicine and I took mine." P292
Interpersonal influence (β = 0.059)	Daily, basic, duties, experience, happen, write, utility	Advantages of observing and engaging with others' caregiving experiences, including the ability to assess and offer emotional support to fellow members of the care team.	"[seeing others' perspective] made me question, oh, how am I seeing things as, am I seeing things the right way, or, you know, just making me question how I'm seeing things, how I'm doing things." P213
Usability of CareVirtue (β = 0.045)	Technical, sister, issues, sign, email, law, frustration	Usability of the interface	"I would just tap on it without having to sign in with the password. But multiple times, myself and my other caregiver had this issue where we had to, all of a sudden, log in all over again." P241

Table 7-2 Topics with their topic proportions across documents (β), FREX words, definitions, and illustrative examples from STM-supported directed content analysis

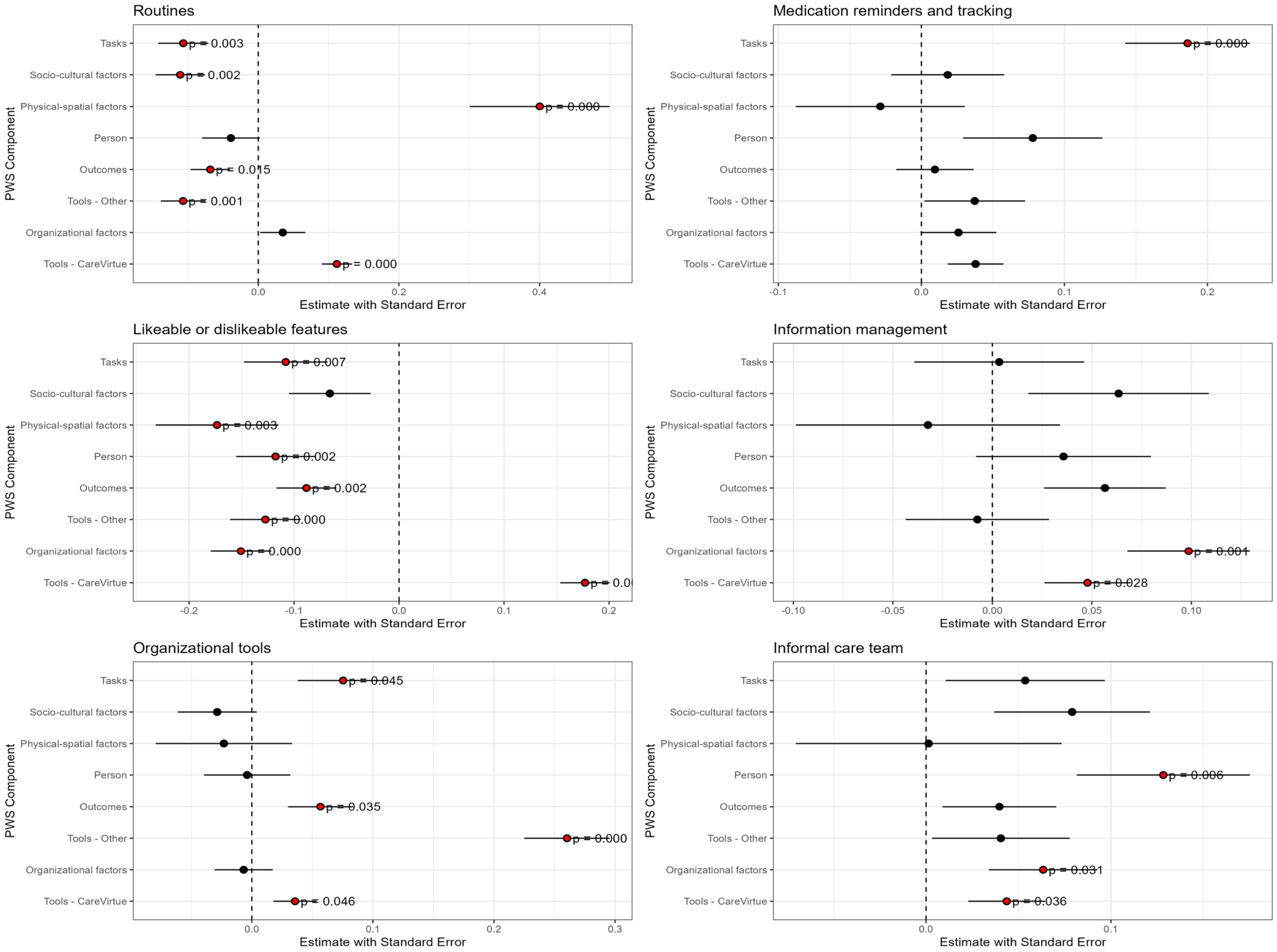

Figure 7-3 Regression coefficients for each topic with their standard errors. The red points indicate significant association with p-values (< 0.05). Each STM-identified topic is influenced by a combination of work system components positively (coefficients occurring right of the dotted vertical line) or negatively (coefficient occurring left of the dotted vertical line).

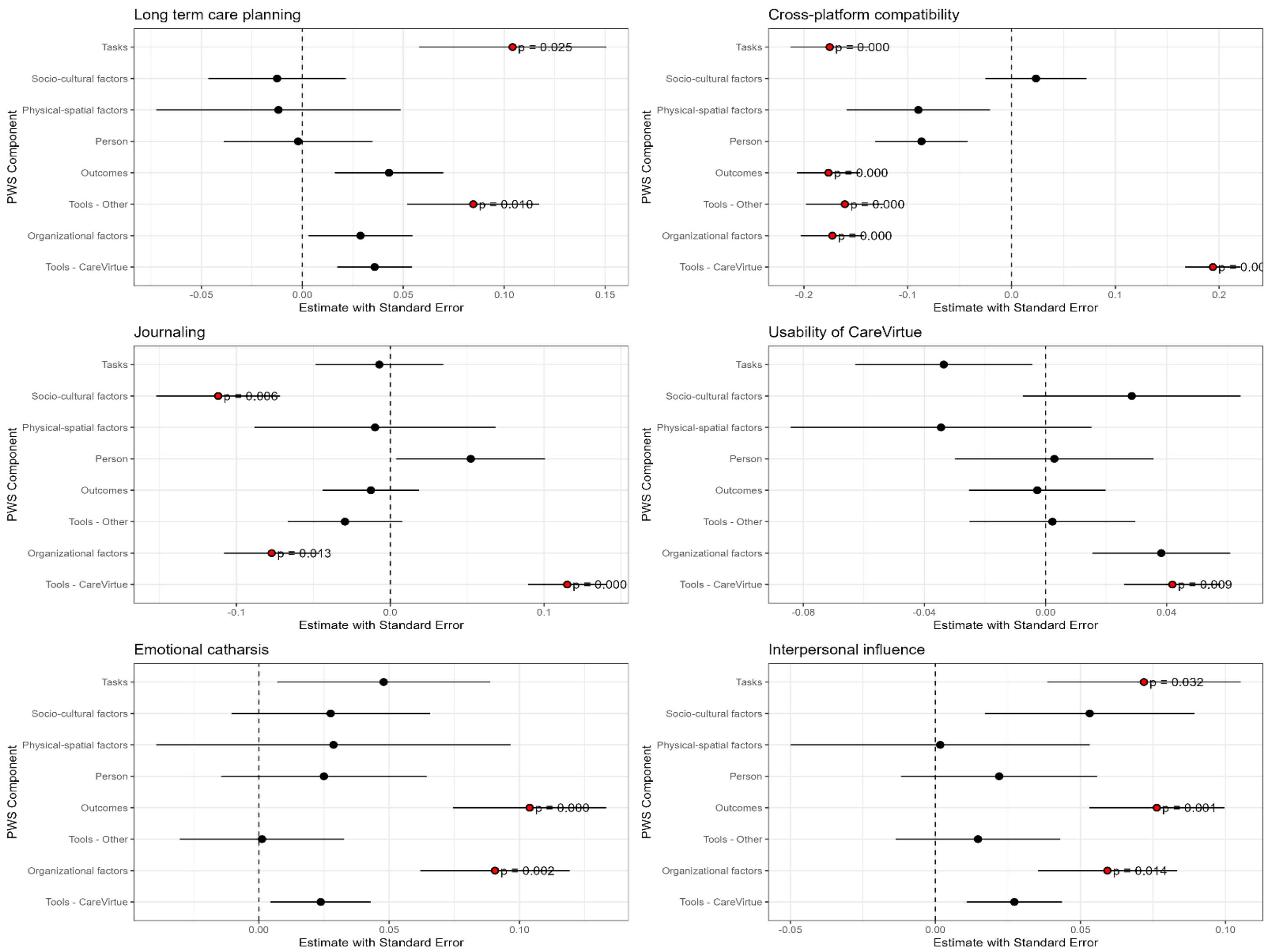

Figure 7-4 Regression coefficients for each topic with their standard errors. The red points indicate significant association with p-values (< 0.05). Each STM-identified topic is influenced by a combination of work system components positively (coefficients occurring right of the dotted vertical line) or negatively (coefficient occurring left of the dotted vertical line).

7.5 Discussion

The objective of this study was to explore how STM can support content analysis, both inductive and directed content analysis, for identifying contextual factors of ADRD caregivers that influence their engagement with CareVirtue – a web-based digital health intervention for ADRD caregivers. We utilized an inductive approach to STM and a directed content analysis approach to STM to analyze 41 semi-structured interviews with ADRD caregivers that participated in a feasibility study of CareVirtue (Boutilier et al., 2022). Our findings consisted of six interpretable topics and their FREX terms arising from the inductive STM analysis, out of which four topics were directly relevant to contextual factors influencing CareVirtue engagement, and two topics provided complementary insights into ADRD caregiving. We also identified 12 interpretable and directly relevant topics, their FREX terms, and the work system component influencing the prevalence of each topic from the STM-supported directed content analysis. The topics identified by STM-supported directed content analysis provided complementary ways to approach work system analysis and has implications for qualitative analysis for redesigning DHIs, work systems theory, and qualitative research.

Many prior studies have used STM in the field of Human Factors Engineering to supplement qualitative analysis (Alambeigi et al., 2020; Lee & Kolodge, 2020; Loganathar et al., 2023; Rutkowski et al., 2022). However, we utilized an innovative approach that combines manual qualitative approaches (e.g., team-based discussions, incorporating manual coding for one stage of coding, triangulation of investigators and approaches) with semi-automated, probabilistic STM to analyze interview data. This combined approach leveraging a mixed-method design to analyze in-depth interviews demonstrates a strong potential to balance the limitations of both qualitative analysis and quantitative topic-modeling based analyses. This approach can improve time-efficiency of qualitative analysis while also demonstrating an ability to lower misrepresentation of qualitative data by STM, especially in smaller sample sizes, using team-based discussions and manual coding.

7.5.1 Trade-off between time-efficiency and topic usefulness for rapid redesign of DHIs

The STM-supported directed content analysis can help improve time and resource efficiency in manual qualitative analysis, specifically for redesign of DHIs in applied healthcare settings such as commercial DHI businesses. This aligns with previous research documenting the time-efficiency of STM, particularly in large datasets (Aranda et al., 2021; Roberts et al., 2014; Rutkowski et al., 2022). For instance, STM-based inductive analysis took only 1.5 hours to identify factors that may influencing CareVirtue engagement, while manual qualitative analysis in a parallel study took over 200 hours to identify contextual factors influencing CareVirtue engagement (Loganathar et al., *In progress*). The combined approach in our study (STM-supported directed content analysis) took over 100 hours, lying somewhere in the middle between these two approaches in terms of time-efficiency (Table 7-3). Our research also provides a datapoint to showcase the time-efficiency of topic modeling approach in analyzing 41 transcripts. These findings suggest that while the combined approach may be the most time-efficient for a sample of similar size, analysis of interviews with lower sample sizes (e.g., case studies with 1-10 participants), may benefit from performing the manual qualitative alone as learning the topic modeling, analysis of stop-words and team-based discussions may take more time. On the other hand, our combined approach may not be valuable for very large sample sets (e.g., 300 in-depth interviews), as the initial stage of manual analysis may still be time-consuming but there may still be value in minimizing time demands from subsequent stages of coding. Future research could identify the ideal technique for analysis based on sample sizes.

Secondly, the combined STM and manual analysis approach in this study generated more topics for identifying contextual factors influencing CareVirtue engagement among ADRD caregivers that may be relevant to redesign compared to using STM alone as an inductive analysis. However, fewer number of topics compared to manual qualitative analysis alone from the parallel study were produced by the combined approach (Loganathar et al., *In progress*). This finding is in line with existing research that suggests that the number of topics identified by topic-models decreases with the size of the text (Deerwester et al., 1990; Rosario, 2000; Sbalchiero & Eder, 2020). The combined approach in our study chunked 10-15 pages of single-spaced interview transcripts into 467 coded excerpts of ~75-100 words through a reliable method that leveraged manual coding and qualitative rigor techniques and can be a useful technique for future researchers employing topic models to study large size qualitative data.

Thirdly, the quality and usefulness of the topics varied between the three approaches. This was evident in the identification of only four pertinent topics by inductive-STM. While the topics "exploring adaptations" and "in-law relationships" may be useful in supplementing theory-building by validating existing research regarding how caregivers constantly adopt various strategies and adapt to manage new challenges (Barton et al., 2021; Pinquart & Sörensen, 2011; Weiler, Lingg, Wilkins, et al., 2022), inductive-STM does not identify how these topics may directly support redesign of DHI. In contrast, STM-supported directed content analysis yielded twelve pertinent topics that offered valuable insights into the contextual factors influencing CareVirtue engagement, potentially informing the (re)design of the DHI. Many topics identified here such as informal care network, routines, information management, interpersonal influence, usability of CareVirtue, cross-platform compatibility, and organizational tools were also identified as contextual factors influencing engagement in a similar study (Loganathar et al., *In progress*). However, some topics like "likeable or dislikeable features", lacked specific detail. While this topic identified various features that are liked and disliked by participants but does not provide a coherent underlying theme for why these features are liked or disliked. This could be because the model grouped the answers to the question "what features did you like and why?" and "what features did you dislike and why?" as many participants used similar language to answer the question (e.g., "I really liked…" or "I did not like…"). This topic could be a desirable outcome if the goal of the inquiry was to identify sentiments associated with the various features, however, in our inquiry to understand what made these features likeable or unlikable, we could not identify any discernible contextual factors that drove the likability of a feature. This could be because participants just liked or disliked a feature without eliciting a response or it could indicate further needs to clean the data using stop words or removing interviewer's probe questions. However, removing interviewer questions in the data may remove important context for interviewee responses that may be required for accurate identification of topics.

Hence, there is a trade-off between time-efficiency and usefulness of topics in using STM-based approaches to qualitative analysis of interview data. While STM-supported directed content analysis reduced the time of manual directed content analysis by approximately 50% (Loganathar et al., *In progress*), the topics identified varied in usefulness across the two STM-based approaches. However, in applied health research settings such as in design of commercial digital health interventions, where stakeholders often want rapid results to constantly improve technologies and keep users engaged, STM-supported directed content analysis creates faster results while also maintaining qualitative rigor through triangulation of multiple investigators, consensus-building, and looking for disconfirming cases (Devers, 1999; Valdez et al., 2017).

7.5.2 STM-supported directed content analysis for complementing work system analysis

The findings from this study show potential in supporting the study of work system analysis in two ways. First, we identified that STM-supported directed content analysis shows a potential in studying work system interactions. Work system interactions (not to be interpreted as statistical interactions) involve one work system component that either influences, reinforces, or exists in the presence of, another or multiple other components (Holden et al., 2015; Wilson, 2000). Healthcare HFE often deals with complex work system interactions with a proliferation of technologies that are used across multiple settings by multiple people such as healthcare professionals, patients, and caregivers, demonstrating a need to study these interactions for (re)design of workflows and technologies (Carayon, 2006; Gorman et al., 2018; Holden et al., 2020; Valdez et al., 2015). However, studying these system interactions is typically complex with multiple data collection and analysis methods such as statistical techniques and conceptual qualitative analysis. Given this complexity, very few methods exist to study work system interactions (Holden & Carayon, 2021; Karsh et al., 2014; Rutkowski, 2022; Waterson, 2020; Weiler, Lingg, Eagan, et al., 2022).

By using the patient work system components as covariates to the STM-supported directed content analysis, we have demonstrated that the topics identified by STM can be represented as a regression equation with the work system components as the independent variables. Each topic identified by STM can therefore be considered an interaction of the statistically significant work system components that influence the DHI engagement process. For example, the prevalence of the topic "informal care team" as seen from Figure 7-3 is positively influenced by the work system components "person", "organizational factors", and "tools-CareVirtue". This suggests that DHI engagement may be influenced by an interaction between person characteristics such as technology literacy of primary and secondary ADRD caregivers and the organizational factors consisting of how roles are distributed within the informal care team. Additionally, this approach also suggests a potential inverse relationship between topic prevalence and the influence of these work system components. For example, if the prevalence of the topic "routines" increases, it may imply a reduced likelihood of certain work system components being present or influential in shaping that routine-related topic. This negative influence on the topic prevalence could mean that the higher the topic prevalence, lower the likelihood of the work system component influencing the certain topic. Future studies should explore STM as a potential method to study work system interactions.

Secondly, STM-supported directed content analysis can offer valuable insights for work system analysis of understanding DHI engagement. Like other mixed methods approaches, it can strengthen findings through corroboration (confirming existing knowledge) and elaboration (providing additional details) (Creswell, 1999). For example, STM identified topics like "usability of CareVirtue" that align with the work system model's conceptualization of tools and technologies (Loganathar et al., *In progress;* (Holden et al., 2015; Werner, Malkana, et al., 2017). On the other hand, STM-supported directed content analysis can also reveal complementary perspectives to work system approaches, providing additional details to build HFE theory. For example, as shown in Figure 7-3, the topic "routines" is positively influenced by both "physical-spatial factors" (workspace location) and "tools-CareVirtue" (CareVirtue's versatile use across multiple devices). This suggests that integrating CareVirtue into a caregiver's routine may depend on physical environment factors, like workspace location, and tool features, such as usability across multiple devices. While routines may be an organizational factor like the PWS suggests (Holden et al., 2015, 2017), how routines influencing DHI engagement are formed could be an interaction of multiple PWS components. Similarly, the prevalence of the topic “interpersonal influence” is positively influenced by outcomes and other PWS components like organizational factors. This could indicate that outcomes experienced by primary ADRD caregivers from using CareVirtue could also be influenced by the organizational factors such as the roles and relationships between the members of the care network. These findings further emphasize the importance of understanding DHI engagement as a holistic behavioral, cognitive, and affective process (Kelders et al., 2020; Milne-Ives et al., 2024; Perski et al., 2017), where complementary theories to work systems approach such as distributed cognition may provide additional knowledge in how cognitive aspects of DHI engagement may be distributed to the PWS components and how the various PWS components influence the different aspects of DHI engagement (Hutchins, 2006; Hutchins & Klausen, 1996; Werner et al., 2018).

	Inductive STM analysis	**STM-supported inductive and deductive analysis**	**Manual inductive and deductive analysis**
Time taken			
Team training on PWS framework	0	6 hours	6 hours
Data preparation	1 hour	2 hours	1 hour
First cycle coding	2 min (STM run)	78 hours	78 hours
Meeting to build consensus and resolve discrepancies for first cycle coding	1 hour	14 hours	10 hours
Second cycle coding	0	2 min (STM run)	92 hours
Meeting to build consensus and resolve discrepancies for second cycle coding	0	2 hours	16 hours
Total time	~ 2 hours	~ 102 hours	~ 203 hours
Number of useful and pertinent topics identified	4	12	30
Percentage of topics relevant to guiding research question	57%	92%	100%
Percentage of topics that were unclear or no underlying theme	8%	14%	0%

Table 7-3 Comparison of time-efficiency and topic characteristics

7.5.3 Integrating qualitative techniques shows potential for improving rigor of topic models

While our study aimed at exploring how STM can support qualitative analysis of in-depth interviews, we also identified that qualitative analysis could strengthen STM by improving the validity and reliability of topic modeling process, a common concern while using topic-models (Laureate et al., 2023; Ulstein, 2024). For example, incorporating team-based discussions to improve rigor is a popular technique to establish rigor in qualitative analysis (Devers, 1999; Guba & Lincoln, 2001; Valdez et al., 2017). By incorporating team-based discussions to determine stop-words and interpreting themes, we provided additional context that could address the biggest limitation of the bag-of-words approach that STM- the lack of consideration of context. Bag-of-word approach fails to consider the sequence of words and only considers the high level of context of the word (i.e., the document within which the word occurs). We also searched for disconfirming cases by viewing the passages for each topic and documenting how each passage aligned with the topic. Additionally, STM makes it easier to triangulate data sources, another popular way of establishing rigor in qualitative research by its ability to include covariates. The covariates could be varying data sources and the effects on topic prevalence could be observed.

Furthermore, incorporation of qualitative techniques such as those used in this study could also strengthen qualitative analysis using Large Language Models (LLMs) that are increasingly being used in research (Morgan, 2023; Schiavone et al., 2023; van Manen, 2023). Team-based discussions, a cornerstone of qualitative research, can be adapted to guide LLM analysis. Researchers can leverage these discussions to curate high-quality training data, refine prompts, and evaluate the coherence and interpretability of LLM outputs. Additionally, qualitative techniques like coding and thematic analysis can be used to assess the validity of LLM-generated insights by comparing them to human interpretations of the data.

7.5.4 Limitations

Our study should be considered in the light of several limitations: 1) we still observe some topics that are ambiguous and incoherent. This could potentially be because of the small sample size of 41 participants and the varying lengths of interviews and the coded passages that may misrepresent the topics identified. As words like “like” are used frequently by one participant and sparingly in others, this can create an overlap between topics, making them less distinctive and harder to interpret. Future studies should explore STM-supported directed content analysis in larger samples. Future studies could also use contextual word embeddings as an input to STM that can potentially mitigating the impact of “like” in different contexts. 2) this analysis was a secondary analysis, meaning the data collected was based on a different inquiry and could have biased the model. Future studies should plan for data collection and structuring of interview-guide more rigorously if STM is to be used. 3) As this method combined qualitative manual approach and used the codes as a covariate to a probabilistic topic model, the influence of the covariates on the topic prevalence relies on the accuracy of the initial manual qualitative analysis. In a traditional qualitative analysis, researchers may change the codes from the initial stages of analysis in the subsequent stages of coding as they develop a more nuanced understanding of the data (Saldana, 2015). This could have potentially skewed the model and lead to the identification of erroneous topics and/or topics that are influenced by the presence of wrong work system components. However, this could also be a useful tool in rapid qualitative analysis for researchers to quickly check if their understanding of the data, as depicted by the topic prevalence and influence of covariates, is right or if any coded passages need to be revisited. 4) Team-based discussions for iteratively removing stop words, while could be a useful approach to improving rigor, the decisions made could also bias the model. While care was taken to remove relevant stop words and retain the sanctity of the data, introduction of stop words could affect the reproducibility of the research.

7.6 Conclusion

This study investigated how STM-supported directed content analysis can enhance qualitative research in DHI (re)design. The findings demonstrate its value in achieving a balance between time efficiency and qualitative rigor. This makes it particularly suitable for the rapid development of DHIs where user engagement is critical. Additionally, this approach complements work system analysis by revealing work system interactions and offering fresh perspectives on how these interactions influence DHI engagement. By integrating qualitative techniques with topic modeling, this study paves the way for future research to capitalize on the strengths of both approaches for a more comprehensive understanding of complex phenomena. Beyond the immediate findings, the study highlights the significant contributions of STM to both practical and theoretical aspects of qualitative research. On the practical side, STM-supported directed content analysis offers substantial time savings compared to manual analysis alone. This is particularly valuable in applied healthcare settings where rapid results are essential for DHI development and user engagement. Furthermore, this approach generates topics directly relevant to DHI redesign, providing actionable insights for researchers and developers. The theoretical contributions of STM lie in its ability to offer a complementary inductive perspective on qualitative data. Through the identification of inductive topics that are built bottom-up from words in conjunction with the covariate influences, STM-supported directed content analysis offers a complementary perspective to existing theories that can be further used to refine and build HFE theories.

8 Discussion

In this chapter, I will summarize the results of this dissertation, describe the contributions of this work to literature, discuss research limitations, and outline potential avenues for future research.

The purpose of this dissertation was to identify how contextual barriers and facilitators of ADRD caregivers are associated with varying patterns of engagement with an ADRD caregiving digital health intervention—CareVirtue, and to explore how Structural Topic Modeling can support identifying contextual factors relative to advanced qualitative analysis techniques such as directed content analysis.

8.1 Problem Summary

ADRD are neurogenerative diseases affecting over 6.2 million adults in the US and majority of the care for those living with ADRD are provided by ADRD caregivers like friends and family (Alzheimer's Disease Facts and Figures, 2024). While caring for those living with ADRD can produce positive outcomes, ADRD caregiving can also produce several negative outcomes such as stress, decreased quality of life, depression, and increased susceptibility to other diseases (Harris et al., 2021; Wilks et al., 2011; Wilson, 1989). While several DHIs have been developed and designed to address the growing need for support for ADRD caregivers, negative outcomes continue to persist. Barring factors such as access to efficacious DHIs, adequate engagement with these DHIs is one of the crucial factors in ensuring ADRD caregivers are able to get positive outcomes such as improved quality of life and lowered stress and depression (Deeken et al., 2003; Faieta et al., 2021; Godwin et al., 2013). However, current research suggests that there are various patterns of engagement with DHIs in real-world setting among ADRD caregivers, such as low usage, selective usage of features in multi-component DHIs, or abandonment of DHIs altogether (Eysenbach, 2005; Zhang et al., 2019).

Context in which the DHI engagement takes place is known to play a crucial role in influencing DHI engagement patterns (Centi et al., 2019; Christie et al., 2018a; Guisado-Fernández et al., 2019b; Hardiker & Grant, 2011; Lalloo et al., 2022; Xu et al., 2023). However, the context of DHI engagement of ADRD caregivers, specifically those associated with the various engagement patterns with DHI is underexplored (Christie et al., 2018b; Gitlin et al., 2015). Context of DHI engagement has been defined as "any information that can be used to characterize the situation of an entity, where an entity is a person, place, or object that is considered relevant to the interaction between a user and an application, including the user and application themselves" (Dey & Abowd, 1999). Studying complex constructs such as context of DHI engagement requires in-depth qualitative analyses of observational data that is time-intensive and laborious (Creswell et al., 2007; Dennison et al., 2013).

Therefore, the objective of this dissertation was to identify contextual barriers and facilitators that are associated with various engagement patterns with a DHI designed to support ADRD caregivers—CareVirtue—and to explore the use of semi-automated text analysis technique, Structural Topic Modeling, for identifying contextual factors using existing theoretical frameworks for improved time-efficiency through these primary questions: (1) How are contextual barriers and facilitators influencing DHI engagement, defined by the patient work system model, of ADRD caregivers associated with various engagement patterns in CareVirtue? (2) How does structural topic modeling support content analysis for identifying contextual factors of ADRD caregivers that influence engagement in CareVirtue?

To address these questions, I conceptualized the context of DHI engagement of ADRD caregivers with DHI as a work system. I did not consider the process of DHI engagement, or the outcomes reported as a result of DHI engagement as context in this analysis. I then aimed to discover the contextual barriers and facilitators that influenced engagement with a DHI designed to support ADRD caregivers—CareVirtue. To address the first question, I used a mixed-methods approach to analysis, where I first confirmed the presence of multiple engagement patterns with CareVirtue through a clustering technique. Then, I performed directed content analysis of interview transcripts to identify the contextual barriers and facilitators of ADRD caregivers that influenced CareVirtue engagement using the patient work system model for conceptualizing context. Finally, I integrated the quantitative and qualitative results to identify how contextual barriers and facilitators of ADRD caregivers were associated with various engagement patterns CareVirtue (Chapter 6). To address the second research question, I evaluated how STM-supported directed content analysis compared to manual qualitative analysis and an inductive STM analysis in terms of time efficiency and topic usefulness (Chapter 7). The following results support the objectives of this dissertation.

8.2 Summary of objective 1: exploring how context influences DHI engagement

Chapter 6 addressed the objective of exploring contextual barriers and facilitators influencing CareVirtue engagement of ADRD caregivers that are associated with the various engagement patterns through a novel sequential mixed methods analysis in three phases: clustering to identify CareVirtue engagement patterns, directed content analysis to identify contextual barriers and facilitators influencing CareVirtue engagement, and integration of engagement patterns with corresponding contextual barriers and facilitators. I first showed that there were three distinct engagement patterns of ADRD caregivers with CareVirtue— low and declining usage, moderate and consistent usage, and high and increasing journal usage. Then, I used directed content analysis to identify contextual barriers and facilitators influencing engagement guided by a codebook developed from the Patient Work System model, an HFE-based work system model from a patient work perspective. The codebook contained 22 contextual factors — five person factors, six tool factors, three socio-cultural factors, five organizational factors, one physical-spatial factor, and two task factors — and eight outcomes related to engagement with CareVirtue.

From the integration of these quantitative clusters and the qualitatively identified contextual barriers, contextual facilitators, and outcomes, I identified contextual barriers, contextual facilitators, and outcomes that were associated with each engagement pattern. The "low and declining usage" engagement pattern is composed of ADRD caregivers with an average age of 57.62 years (SD = 11.57), of which 53% provided care for a parent or parent-in-law. Additionally, 70% of these ADRD caregivers were employed. This engagement pattern was associated with higher presence of contextual barriers, specifically associated with organizational factors like workload, distribution of care work settings across multiple spaces such as hospice and home, and informal care network characteristics such as strained relationships among family members that cause disagreement in care decisions.

The "moderate and consistent usage" engagement pattern was composed of ADRD caregivers with an average age of 61 years (SD = 9.31), of which 63% provided care for a parent or parent-in-law. This group consisted of both working and non-working ADRD caregivers. This engagement pattern was associated with a presence of both contextual barriers and facilitators, like task characteristics such as the need to manage one's own self-care tasks like medication management.

The "high and increasing usage" engagement pattern was composed of ADRD caregivers with an average of 65.8 years (SD = 4.09). 80% of ADRD caregivers belonging to this group were retired and 20% worked part-time. 80% of these caregivers also provided care for their spouses. This engagement pattern was associated with a presence of more contextual facilitators than contextual barriers. The contextual factors that are associated with this type of engagement is the personal values of ADRD caregivers such as the need to be respectful to the boundaries of the person living with ADRD along with the social stigma associated with ADRD created a need for these caregivers to safely vent. This need was satisfied by CareVirtue, and hence resulted in a high surge of use in the care journal.

This dissertation identified that using work systems approach to study DHI engagement as a cognitive and behavioral process, can be useful in evaluating and redesigning DHIs. This dissertation also identified specific contextual barriers and facilitators of ADRD caregivers that, if addressed, have the potential to improve engagement with DHIs and proposed various design recommendations for each engagement pattern. Future research should expand on these findings by delving deeper into the context of the various subgroups of ADRD caregivers identified in this work to develop a complete understanding of their unmet needs for design of effective DHIs. Additionally, research should also focus on exploring if the proposed design recommendations influence engagement patterns in real-world settings.

8.3 Summary of objective 2: exploring mixed-methods STM for studying context

Chapter 7 of this dissertation focused on exploring how STM can support qualitative analysis, specifically in supporting directed content analysis of interview transcripts using the Patient Work System model. I evaluated how STM-supported directed content analysis compared to STM-supported inductive analysis and manual directed content analysis in terms of time-efficiency and topic usefulness in identifying contextual factors of ADRD caregivers influencing CareVirtue engagement. For this objective, I used the same 41 semi-structured interviews with ADRD caregivers and the codes from the first cycle manual coding as covariates for the STM-supported directed content analysis.

In this analysis, I ran two different STM models—the first STM was run on the interview transcripts without any covariates; the second STM model was run on the coded passages from the first stage manual coding from Chapter 6 using the PWS components as the covariates. The first model, named as the STM-supported inductive analysis, identified six clear and distinct topics, out of which four were pertinent to contextual factors. While some of the identified topics such as 'journaling features of CareVirtue', and 'medical data logging' could considered a part of the context that influenced engagement with CareVirtue, there is insufficient interpretive evidence to conclude that these topics discussed were contextual factors influencing DHI engagement. The second STM model, or the mixed-methods STM-supported directed content analysis, identified twelve clear and distinct topics, all of which could be considered relevant to contextual factors of ADRD caregivers that influenced DHI engagement such as 'CareVirtue usability', 'interpersonal influence', and 'medication reminders and tracking'.

The work system components also influenced the prevalence of each topic identified by the STM-supported directed content analysis, identified by the in-built regression analysis of *stm* package in R. The tools component positively influenced the prevalence of the topics 'routine integration', 'cross-platform compatibility', 'likable and dislikable features', 'journaling', 'usability of CareVirtue', and 'organizational tools'. The person component positively influenced the prevalence of the contextual factors 'informal care team'; the tasks component positively influenced the prevalence of the topics 'medication reminders and tracking', 'long term care planning', and 'organizational tools'; organizational factors consisted of 'emotional catharsis', 'information management', 'interpersonal influence', and 'informal care team'; and physical-environmental factors consisted of 'routine integration.' The socio-cultural factors did not influence the prevalence of any topics. This mixed methods STM also reduced analysis time from over 200 hours in manual qualitative analysis (Chapter 6) to a little over 100 hours, where over 95 hours is attributed to the manual coding for the STM.

These findings show a high potential in using STM not only for inductive analyses but also for directed content analysis, specifically using frameworks such as work system models. STM-supported directed content analysis has the potential to reduce time for manual qualitative analysis and produce meaningful and clear insights. Additionally, STM-supported directed analysis also shows a potential in aiding theory building by providing insights into how the prevalence of each topic may be influenced by the presence of work system components. This approach can strengthen existing work systems theory through corroboration of existing knowledge such as the identification of various factors influencing DHI engagement from a systems-perspective (e.g., usability of DHI, information management, informal care network characteristics, etc.) and elaboration of work system interactions (e.g., work system interactions behind routines influencing DHI engagement). Future research should explore further validating the topics identified by STM-supported directed content analysis and exploring it as a tool to study work system interactions. This could prove to be highly beneficial in healthcare HFE research, specifically in studying complex work system interactions.

8.4 Comparison of objective 1 and objective 2 results

To assess how the topics identified by STM-supported directed content analysis (Chapter 7) may be useful, I have reviewed the objective 2 findings (Chapter 6) in terms of objective 1 findings. Specifically, I am comparing the topics identified by STM-supported directed content analysis to the contextual factors influencing CareVirtue engagement identified by the manual qualitative analysis of Chapter 6 (Appendix: Contextual barriers and facilitators of ADRD caregivers influencing DHI engagement).

While the topics 'cross-platform compatibility', 'emotional catharsis', 'interpersonal influence', and the 'usability of CareVirtue' were similar to the contextual factors identified in objective 2, other topics identified by STM-supported directed content analysis varied. A description of how each topic varied is presented in Table 8-1. These findings have several implications for theory-building and design of DHIs.

First, the comparison provided in Table 8-1suggests that STM-supported directed content analysis could be a useful tool, specifically in healthcare and industry contexts where rapid design insights to a prototype may be needed. While five topics did not have the same level of granularity as identified by the manual qualitative analysis, the five topics still provide valuable insights into how features such as the care journal were used, and the characteristics of the informal care team (such as technology literacy and role of informal caregivers) influenced engagement with CareVirtue. These findings underscore the significance of considering informal care team attributes in the redesign process. Moreover, the extensive granularity identified in manual qualitative analysis may not always be necessary, especially when the aim is to identify common needs among participants swiftly to iterate on designs. In this regard, STM-supported directed content analysis still identifies topics across most work system components, offering a more comprehensive perspective than inductive STM alone. Thus, this approach remains beneficial compared to some existing methods that are technology-centric and overlook the complexity of engagement context in DHI redesign.

Second, while STM-supported directed content analysis may not generate theory, it may aid in generating HFE theories by providing complementary perspectives to existing frameworks, such as the PWS. It may also have potential in being used as a tool for studying work system interactions. Some topics identified, like routine integration, highlight the interaction between multiple work system components. Future studies could explore STM-supported directed content analysis as a tool for exploring work system interactions.

Topics identified from STM-supported directed content analysis	**Differences in representation of topics from themes identified in manual qualitative analysis**
Routine integration for primary caregiver	STM-supported directed content analysis identified routine as an interaction between tools, physical-spatial factors, and organizational factors
Informal care team	STM-supported directed content analysis did not identify psychological well-being needs of primary and secondary caregivers
Cross-platform compatibility	No difference
Likable or dislikeable features	While STM-supported directed content analysis identified several features that were liked or disliked, specific reasons that may have influenced the liking or disliking were not identified.
Organizational tools	STM-supported directed content analysis identified organizational tools as an interaction between organization and tools but did not describe many other organizational factors such as workload, distribution of care work spaces, and differences between formal care takers, family members, and healthcare professionals identified under “organization” component of manual analysis
Journaling	STM-supported directed content analysis identified journaling as a feature that was discussed by describing specific use-cases but did not describe various social factors that impeded or facilitated journaling.
Information management	STM-supported directed content analysis did not describe the granularity of what information was managed with who.

Topics identified from STM-supported directed content analysis	**Differences in representation of topics from themes identified in manual qualitative analysis**
Emotional catharsis	No difference
Long term care planning	STM-supported directed content analysis emphasized the need for long term planning of care through monitoring whereas manual qualitative analysis only identified the need for tracking the behaviors of the person living with ADRD
Medication reminders and tracking	STM-supported directed content analysis identified task-complexity and conflict with medication management while manual qualitative analysis identified task-complexity and task-conflicts for multiple tasks
Interpersonal influence	No difference
Usability of CareVirtue	No difference

Table 8-1 Differences between the how each topic identified by STM-supported directed content analysis is represented relative to the closest counterpart themes identified by manual qualitative analysis. Green indicates topics that are similar, yellow indicates topics that are captured by STM-supported directed content analysis but not to the same granularity as manual analysis; blue indicates topics existing as interactions between multiple work system components, and purple indicates a topic that offers additional insights than just manual analysis.

8.5 Theoretical contributions

8.5.1 Towards an expanded understanding of the context of DHI engagement among ADRD caregivers

A major contribution of my dissertation is that it lays the groundwork for expanding our conceptualization of the context of DHI engagement for ADRD caregivers for the purpose of design of DHIs.

While several models exist in the field of HFE and HCI to conceptualize context of DHI engagement, the notion of context is still ill-defined and there is a lack of conceptual models and tools available to study context (Winograd, 2001). Two existing conceptualizations of contexts for DHI engagement arise from two epistemologies: 1) positivist, where context is a “form of information, delineable, stable, and separable from activity” and 2) phenomenological, where context is “particular to each occasion or activity, the scope of context is defined dynamically, context may or may not be relevant to some particular activity, and it arises from activity, being actively produced, maintained, and enacted” (Dourish, 2004). While the earlier conceptualization is useful in operationalizing context for the purpose of design, the latter conceptualization is necessary to understand the conceptual relationship between various factors that influence DHI engagement, which is also essential for design of DHI (Alegre et al., 2016). Hence, there is a need to abstract the phenomenological conceptualization to higher levels to communicate the dynamic and complex context of ADRD caregivers for the purpose of design of DHI that supports ADRD caregiving work.

My dissertation addresses this need by using the work systems model to conceptualize the complex context of DHI engagement of ADRD caregivers. This approach provides both context categories that are useful for operationalizing context for the purpose of (re)designing DHIs and provides a model to understand the complex relationships between these context categories to develop a conceptual understanding. With this conceptualization, the process of engaging with a DHI was not considered context. The outcomes (positive or negative) experienced from engaging with the DHI was also not considered context. However, as work system models are typically represented at one point in time, these outcomes may further influence the context and shape the context differently for subsequent points in time (Carayon, Hundt, et al., 2006; Holden et al., 2013), which is not captured in this dissertation.

Using the work systems approach to conceptualize context enables the extension of work systems theory and principles into studying context of DHI engagement and evaluating DHIs. First, is the concept of caregiver journey. The work systems approach suggests that caregiving occurs along a journey that is "longitudinal, boundary-spanning, and dynamic health work done by caregivers, spanning the period between when one begins and ends their caregiving", and that design of DHIs should take into account the several settings, people, and the continuously changing caregivers goals and tasks (Werner, Rutkowski, et al., 2022). My dissertation validates this finding by identifying DHI engagement is influenced by the several settings caregiving takes place in such as home, hospice, house of the person living with ADRD, places of professional work, and healthcare systems, as identified by the contextual factors 'distribution of care work' and 'workspaces' in Chapter 6. We also found that several people influenced the DHI engagement of primary caregivers such as secondary caregivers and formal caretakers. This finding suggests that context of DHI engagement for ADRD caregivers could potentially be defined as *the parts of the caregiving journey that influence DHI engagement, including the ADRD caregiver and the DHI.* While there remains a larger caregiving context, this definition excludes those parts of the caregiving journey that do not influence DHI engagement. This conceptualization of context of DHIs could be particularly useful in evaluating DHIs within a caregiver journey for redesign.

Secondly, the work system models allow the exploration of 'work system configuration' for understanding the context of DHI engagement (Holden et al., 2013; Werner et al., 2020). Configurations suggest while there may be several parts of the caregiver journey that could influence DHI engagement, the extent to which each work system element influences DHI engagement may vary. This is demonstrated by the finding that all three work systems depicted by the engagement patterns experienced almost all the positive outcomes identified, while the 'low and declining' and 'moderate and consistent' patterns experienced two barriers in outcomes. This suggests that engagement patterns may be influenced by the varying intensities of the elements. While this dissertation did not quantify the strength of these influences, the concept of configurations may be valuable in identifying the most relevant context of DHI engagement (parts of the caregiving journey that influence DHI engagement).

Finally, my dissertation highlights the heterogeneity of ADRD caregivers, suggesting that the context of DHI engagement varies across ADRD caregivers. For example, some contextual factors influencing DHI engagement existed across all engagement patterns, whereas some contextual factors were unique to some patterns. This finding aligns with existing evidence of caregiver heterogeneity and suggests that different caregiver groups may engage with DHIs based on their individual needs and goals (Koehly et al., 2015; Werner, Rutkowski, et al., 2022; Young et al., 2020). Engagement patterns served as a tool to understand this heterogeneity, potentially representing distinct work systems with different needs. Consequently, the context of DHI engagement varies based on the caregiver, their location in the caregiving journey, and the people involved in the care.

In conclusion, my dissertation expands the conceptualization of context of DHI engagement for ADRD caregivers as the parts of the caregiving journey that influence DHI engagement. These influential parts can be prioritized through the concept of work system configuration, recognizing that the influential parts may vary across ADRD subgroups. This expanded understanding can guide future DHI (re)design to better support ADRD caregivers throughout their caregiving journey.

8.5.2 Towards an expanded understanding of DHI engagement

My dissertation also delves into the concept of DHI engagement for the context of supporting ADRD caregivers through DHIs. Similar to the debate surrounding context, DHI engagement is a multifaceted concept with various definitions in the literature. Perski et al. (2017) proposed a two-part definition: "the extent of usage and a subjective experience characterized by attention, interest, and affect." O'Brian et al. (2008) view engagement as a dynamic process with an entry point, sustained engagement, potential disengagement (due to user satisfaction or frustration), and possibly re-engagement.

My research identified distinct patterns of DHI engagement among ADRD caregivers: low and declining usage (caregivers using the DHI infrequently despite reporting positive outcomes like improved information management), consistent and moderate usage (almost constant use throughout the study), and high and increasing usage (caregivers reporting positive outcomes like caregiving appraisal and a surge in journaling in the latter half of the study). These findings suggest that while engagement can be measured by usage and subjective experience, there's merit in exploring process-based conceptualizations.

While O'Brian's model suggest that user disengagement is due to the attributes that were created from the interaction between the user and the DHI, my dissertation suggests that all three user groups report experiencing positive outcomes and high System Usability Scale ratings. However, the context of use for the three engagement groups identified are widely different based on the findings in Chapter 6. This indicates that conceptualization of engagement should also include the context in which it is used.

Drawing a parallel to the structure-process-outcome model within existing work system models (Carayon, Schoofs Hundt, et al., 2006; Holden et al., 2013, 2015), user engagement appears to be a process influenced by the structure (context) leading to various outcomes. These outcomes then dynamically influence the engagement process (e.g., increased journaling after positive feedback). Therefore, user engagement could be a process shaped by the context of DHI use, leading to both positive and negative outcomes that further influence the engagement process itself. Future studies should focus on developing a combined model for understanding context of DHI engagement and the process of engagement.

8.5.3 Analysis approaches for studying context of DHI engagement

This dissertation used two mixed methods approaches to study DHI engagement. In Chapter 6, it was demonstrated that studying DHI engagement patterns using a work systems approach could help identify varying contexts of ADRD caregivers. In Chapter 7, it was demonstrated that quantitative approaches such as STM could improve methodological rigor of manual qualitative analysis, improve time-efficiency, and aid in theory generation for understanding context of DHI engagement. Together with the two approaches, this dissertation proposes mixed methods approaches for studying complex constructs such as DHI engagement.

In Chapter 7, it was demonstrated that STM has the potential to address some of the methodological limitations associated with qualitative analysis techniques such as content analysis that is required for studying concepts like context of DHI engagement. One limitation with the existing qualitative analysis techniques is that it time and resource intensive with some studies citing that manual analysis of one 60-minute transcript could take anywhere between 200-400 minutes (Neal et al., 2015). The use of STM-supported directed content analysis halved the total time taken for analysis of interviews. This suggests that STM-supported directed content analysis could be useful in healthcare and industry settings for generating quick design insights for prototypes.

Additionally, while several rapid approaches to manual qualitative content analysis have been used in the literature, the ability of rapid approaches to complement exploratory studies such as studying context of DHI engagement in ADRD caregivers, is limited (Taylor et al., 2018; Vindrola-Padros & Johnson, 2020). STM when used along with manual qualitative analysis has the potential to produce meaningful topics that can aid in understanding of the context of DHI engagement and can help in (re)design of DHIs. STM-supported directed content analysis produced eight topics that were similar to those identified by the manual qualitative analysis (routines, emotional catharsis, interpersonal influence, usability of CareVirtue, cross-platform compatibility, informal care team, information management, and medication reminders). These similarities suggest that STM-supported directed content analysis has the potential to identify similar themes as manual qualitative analysis. STM-supported directed content analysis also identified four topics that were not identified by the manual qualitative analysis (journaling, likable and dislikable features, organizational tools, long-term care planning) and provided varying perspectives from manual qualitative analysis (e.g., routines), suggesting quantitative methods have the potential to provide alternative perspectives through inductive identification of topics that might otherwise be overlooked by manual qualitative research methods and biases that arise from using existing frameworks to guide coding and theory building. By providing a combination of varying perspectives, this method also establishes its potential in enhancing qualitative research through methodological triangulation (the use of multiple analysis methods on the same data to improve rigor of findings), when used in conjunction with manual qualitative data analysis.

However, STM-supported directed content analysis did not identify topics related to macro-level factors such as socio-cultural factors and organizational factors (e.g., personal values, distribution of care work, etc.) that influenced CareVirtue engagement as identified by the manual qualitative analysis in Chapter 6. These factors are expressed differently across participants, which STM as an inductive approach may have missed. Additionally, STM-supported directed content analysis also did not identify topics that were prevalent in one or two participants (e.g., access to internet, physical well-being). These findings suggest that STM being an inductive method may overlook important features that need to be taken into consideration for the design of DHIs such as populations ranging from various socio-economic groups, highlighting the importance of manual qualitative approaches that may be necessary to complement quantitative approaches.

Furthermore, this approach offers a more comprehensive perspective than some existing semi-automated methods by identifying topics across the work system components. Hence, it may be a useful tool for studying work system interactions that future studies should explore. STM-supported directed content analysis can be used with a variety of qualitative and quantitative data, which can be important to improve the rigor of mixed methods studies in healthcare HFE. Although this study serves as an example of using STM as a data analysis technique within HFE, additional research is needed to identify and determine if STM is suitable for analyzing more complex work system studies involving interactions. Finally, this approach may also serve as a process-control tool for complementing qualitative analysis through identification of any inconsistencies in first stage coding.

In Chapter 6, it was demonstrated that studying DHI engagement patterns could reveal varying contexts of ADRD caregivers in which engagement takes place, that could further be used for gaining design insights for DHIs. The three engagement patterns were associated with varying presence of 22 contextual barriers and facilitators. However, it is difficult to discern if these varying contexts of ADRD caregivers were different caregiver groups on their respective caregiving journeys or if they belonged to a similar group of ADRD caregivers on different parts of a caregiving journey through a manual qualitative analysis of each engagement pattern alone. While Table 6-3 suggests that there could be group differences (e.g., spousal caregivers as a predominant composition of 'high and increasing' engagement pattern), there is also an overlap between the presence of group characteristics between the 'low and declining' and 'moderate and consistent' patterns, such as the relationship with the person living with ADRD and employment status. Elucidating this ambiguity calls for complementing qualitative analysis with quantitative approaches such as STM, epistemic network analysis, and other statistical techniques to identify group level differences and variations in the caregiving journey.

8.6 Practical contributions

8.6.1 A method for evaluating DHIs

I was able to demonstrate through Chapter 6 that studying DHI engagement patterns using a work systems approach could serve as a useful tool to evaluate the fit of a DHI within various ADRD caregiver work systems. By conceptualizing DHI engagement as a social, behavioral, and cognitive process (Perski et al., 2017; Yardley et al., 2016), and by studying the context of DHI engagement of the engagement patterns, I identified distinct imbalances in each engagement pattern (i.e., contextual barriers influencing DHI engagement that are not mitigated by the contextual facilitators influencing DHI engagement) (Carayon, 2009). The imbalances could serve as a focus point for redesign efforts of DHIs for optimizing DHI engagement. An alternative approach to redesign could also be prioritizing the commonly occurring barriers and facilitators across the engagement patterns for optimizing engagement across all patterns. Additionally, this method also provides insights into understanding the contextual barriers and facilitators that may have led to selective usage of certain features such as the journal by a certain group of ADRD caregivers. Understanding these contextual factors and outcomes behind high usage of certain features could help DHIs identify ADRD caregiver subgroups that the DHI could be marketable to.

Several design implications for DHIs that support care work of ADRD caregivers are presented in Chapter 6. For example, the context of ADRD caregivers that were low users revealed that there was a higher need for documentation of communication and care decisions that happen at hospice where the person living with ADRD lives. I propose several design features that address can address the unmet needs of different subgroups of ADRD caregivers (Table 6-5).

8.6.2 Implications for automated qualitative analysis

In Chapter 7, I explored how qualitative and computational methods can be mutually beneficial. While my primary focus was investigating how STM could support qualitative analysis of semi-structured interviews, specifically using directed content analysis, the research also revealed the potential for qualitative techniques to strengthen STM analysis itself.

One of the biggest limitations of the bag-of-words approach used in STM is its neglect of lexical context, i.e., location of a word relative to another in a sentence or paragraph that might change its meaning. To address this, I incorporated team-based discussions to identify stop-word identification and interpret the topics. Team-based discussions, often involving multiple researchers with interdisciplinary expertise, are used in qualitative health research to improve reflexivity and add rigor to the analysis (Barry et al., 1999; Rankl et al., 2021). Particularly, working in teams offers an opportunity for assumptions to be challenged and research accounts to be strengthened through collective interpretation of the data (Barry et al., 1999). The team-based discussions added valuable insights to the analysis, potentially overcoming a major limitation of the STM analysis. Furthermore, by utilizing disconfirming cases, I was able to refine the model's results and stimulate even more productive team discussions.

My research also suggests that these qualitative techniques can be valuable for improving qualitative analysis with Large Language Models (LLMs), which are becoming increasingly popular in qualitative research. While Large Language Models (LLMs) like ChatGPT are gaining traction for qualitative coding, their ability to capture nuanced themes remains limited. Existing studies suggest they excel at identifying broad patterns but struggle with deeper interpretations (Morgan, 2023; Schiavone et al., 2023). This is where team discussions, a cornerstone of qualitative research, and other qualitative rigor techniques (Valdez et al., 2017) can be instrumental. By collaboratively selecting relevant data, refining prompts, and critically evaluating LLM outputs, researchers can leverage the strengths of these models (speed, broad theme identification) while mitigating their weaknesses. Team discussions can ensure the LLM is trained on appropriate information, receives clear and focused prompts, and that the generated themes are critically analyzed for coherence, interpretability, and potential biases. This collaborative approach can ultimately improve the quality and trustworthiness of LLM-generated themes, leading to more robust qualitative research.

Overall, my dissertation highlights the synergy between qualitative and computational methods. By demonstrating their potential for collaboration, this research paves the way for more robust and nuanced approaches in both STM analysis and LLM-based qualitative research.

8.7 Strengths

This dissertation should be considered considering several strengths both int terms of how the study was conducted and the outputs of the study. With respect to how the study was conducted, I tools several steps to address the following pillars of trustworthiness: credibility, transferability, dependability, and confirmability (Devers, 1999; Guba & Lincoln, 2001).

To establish credibility, I used methodological and data triangulation, conducted memoing, and searched for negative cases. Data triangulation involved using more than one type of data (DHI platform metrics, interviews, and demographic survey data were used in this study). Methodological triangulation involves the use of qualitative and quantitative approaches. My research used a mixed-methods approach for data analysis and integrated qualitative and quantitative data and analysis procedure. Further, I also present quotations from multiple participants. Additionally, I looked for disconfirming evidence in addressing both my research questions and refined my description of contextual factors influencing DHI engagement for each engagement pattern in the first research question. In the second research question involving STM, I looked for disconfirming passages for each topic identified by the STM for each iteration. This helped to remove stop words and build consensus on topics identified by the STM. Memoing involves the intentional documentation of ideas, views, and intuitions across all stages of the data analysis process. I memoed all stages of my work.

To establish transferability, I provided a detailed overview of the context in which the study occurred and provided a thick description of the data and data analysis.

To ensure dependability, all data analysis was conducted in a pair or group setting, with disciplines such as human factors, biomedical engineering, and industrial engineering represented. I documented all research activities to develop an audit trail and provided a thick description of the methods.

To establish confirmability, several data analysis meetings were conducted in group settings that challenged decisions about the methods, meanings, and interpretations of the data. This process provided an external check on the research.

8.8 Limitations

My dissertation research has several limitations that are important to consider. Chapter 6, which explored user engagement patterns, was limited by the diversity of the participant pool, with a majority being white and being in urban locations within the US. Future research should aim for a more representative sample to ensure the generalizability of findings for caregiver support tools. Additionally, the use of secondary data analysis in this study may have introduced bias due to the original interview questions focusing on user preferences. Future studies would benefit from conducting primary research with carefully designed, unbiased interview questions. Finally, an important limitation of this data is that it is qualitative and thus cannot be generalized, nor interpreted purely by its quantitative aspects. While some of the data is quantified, it is not necessarily the case that the number of identified contextual factors behind each engagement pattern would represent the most prevalent or significant contextual factor driving each engagement pattern.

Chapter 7, which investigated the use of STM for qualitative analysis, also has limitations. The analysis revealed some ambiguity and incoherence in the identified topics, potentially caused by uneven use of certain words across participants. Future research could explore using contextual word embeddings to mitigate this issue. Furthermore, the single-level structure of STM may have limited the clarity of topic relationships. Future studies might benefit from employing multi-level topic models. Finally, the secondary nature of the data used in the second study could have introduced bias. In addition, there may have been an inevitable bias in naming STM topics as the STM was conducted after the manual qualitative analysis. Future research planning to utilize STM should prioritize the design of data collection and interview guides specifically tailored to optimize the model's effectiveness.

Additionally, both Chapter 6 and 7 used the patient work system (PWS) model to guide the research. While the PWS model is a descriptive model, it was not directly informed by the work done by ADRD caregivers and may miss factors that impact the work system from a caregiver's perspective. Additionally, while the PWS model was developed to study the context of patient work, my research used the model to guide the study of user engagement as a process. This changed the original intent of the model and may not be as simple as applied as it was in this study. There may be theoretical disagreement as to whether the context of patient work consists of similar factors as that of context of use for DHI designed to support care work.

This dissertation offers valuable design insights based on the identified contextual factors influencing caregiver engagement with CareVirtue. However, a key limitation of using the work system model lies in establishing the direction of influence: do contextual factors impact DHI engagement, or vice versa? Several measures were taken to address this, such as avoiding transcripts suggesting post-use work system changes, team discussions focused on directionality, and coding CareVirtue benefits as outcomes rather than contextual factors. Despite these efforts, some findings may still reflect contexts influenced by the DHI itself.

Future studies can address this limitation by collecting longitudinal data from multiple sources. Entry and exit interviews could be used to capture the work system's state before and after DHI use, providing a clearer picture of directional influence. Finally, these findings are based on the evaluation of a single DHI, CareVirtue. Future research should aim to validate the mixed-methods analysis used in this study by applying it to a wider range of DHIs, strengthening the generalizability of the results.

These limitations highlight areas for further exploration and refinement in future research on DHI engagement for ADRD caregivers. By addressing these limitations, future studies can contribute even more robust and generalizable insights to this important field.

8.9 Future research

There are a multitude of ways to extend this work. One way to extend this work further would be to explore the relationship between context and DHI engagement. This research identified distinct contextual factors associated with engagement patterns. Future work could delve deeper into this relationship through longitudinal studies that would allow researchers to track how contextual factors evolve over time and how these influence engagement patterns with DHIs. While this research identified associations, future studies could explore causal relationships between specific contextual factors and DHI engagement.

This research also laid the foundation for conceptualizing context and the process of DHI engagement. Future research should focus on further elucidating the levels of context identified in this research and provide a combined approach to model context in which DHI engagement occurs.

Furthermore, the use of STM in qualitative research could be further explored in studying more complex concepts such as work system interactions. Future work could leverage STM to examine the complex interactions between these factors, providing a more holistic understanding of the work system and its influence on DHI engagement. The current study utilized a single-level topic model, STM. Future work could explore the use of multi-level topic models, such as hierarchical topic models, to capture the hierarchical nature of many HFE frameworks.

8.10 Conclusion

This dissertation explored how contextual factors are associated with varying engagement patterns with digital health interventions (DHIs) for caregivers of people with Alzheimer's Disease and Related Dementias

(ADRD), and investigated the potential of Structural Topic Modeling (STM) to aid qualitative analysis in healthcare Human Factors and Ergonomics (HFE) research.

The research identified three distinct DHI engagement patterns among ADRD caregivers: low usage, consistent usage, and high surge in journal usage. Each pattern was associated with specific contextual factors, highlighting the complex relationship between context and engagement. Additionally, the study suggests that STM, combined with manual techniques like directed content analysis, can be a valuable tool for qualitative analysis. This approach can reduce analysis time, produce clear topics, and aid in creating taxonomies for identifying contextual factors. This work contributes to our understanding of DHI engagement for ADRD caregivers by proposing a three-level conceptualization for understanding context and suggesting a process-based view of engagement. Furthermore, it demonstrates the potential of STM to address limitations in traditional qualitative analysis methods such as the time and resource constraints involved in manually analyzing complex concepts such as context. The findings also inform the design of DHIs for ADRD caregivers by identifying unmet needs associated with different user groups and engagement patterns. This research paves the way for future studies to build upon these findings and contribute even more robust and generalizable insights to improving DHI development for ADRD caregivers.

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10 Appendix: Interview guide for post-trial interviews

1. Thinking about your experience using CareVirtue over the last few months, how was it useful to you in your daily caregiving?
- What features did you like the most?
- What features made it less useful to you, that you liked the least?

2. What was your experience like with fitting CareVirtue into your day-to-day life?
- What parts of CareVirtue did you use on a daily basis? What made you return to use CareVirtue?
- What made you feel confident in using CareVirtue in your day-to-day life? What made you feel less confident?
- What changes did you make to your daily routines to use CareVirtue? [probe about nature of changes and whether they were positive or negative]
- What additional functionality would make CareVirtue more impactful for you and other caregivers?
- How did CareVirtue fit with the tools and resources you & your care team were already using?
- What parts did you want to use but did not use as often? Why?

3. Care team/secondary caregivers?
- What functions of CareVirtue were most useful in interacting with your care team?
- How could CareVirtue have been more useful to your care team interactions?
- How has using CareVirtue influenced the involvement of the other care team members?
- What kind of feedback have you received from your care team on the CareVirtue app?

4. How would you describe CareVirtue to friends, family, and other people in your life?

11 Appendix: Clustering results

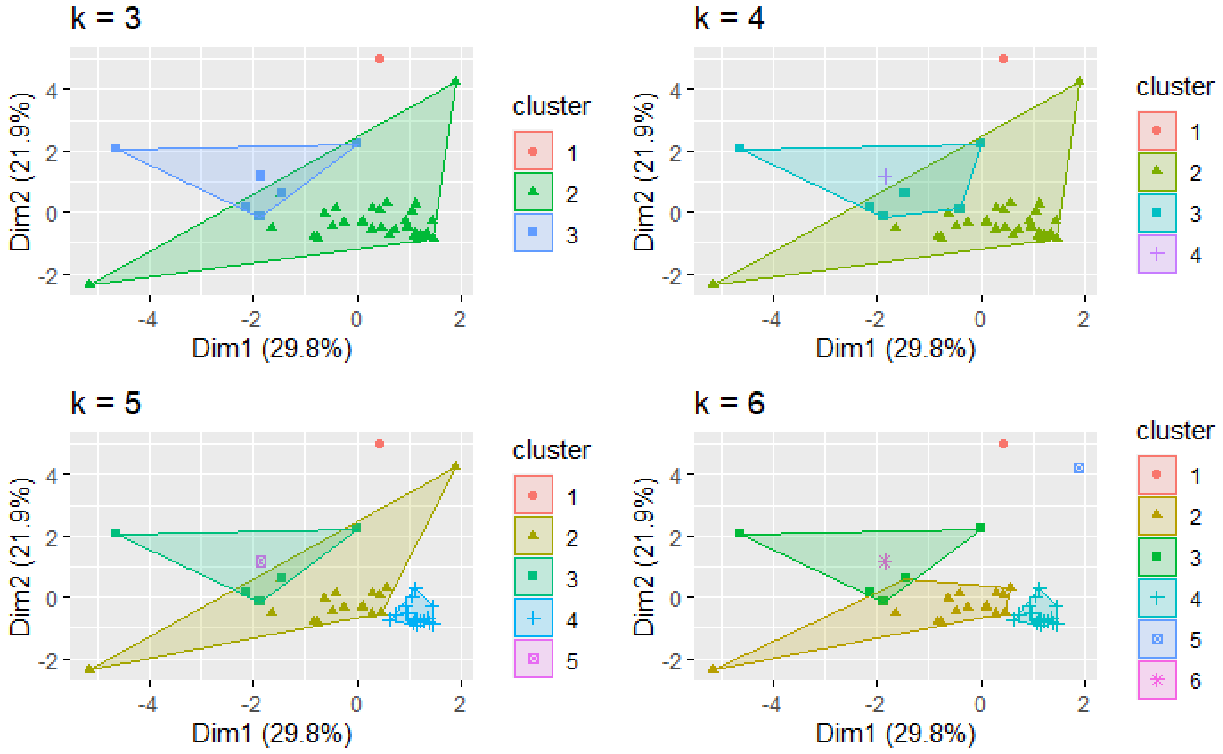

Figure 11-1 Visual exploration of clusters using k-medoid technique. This figure shows the results of applying the K-Medoids clustering algorithm with varying numbers of clusters (k) - 3, 4, 5, and 6. When k is set to 6, the K-Medoids algorithm appears to separate the three potential outliers from the main body of data. Compared to other k values (3, 4, and 5), k=6 results in a more balanced distribution of data points across the three main clusters. Lower k values (3, 4, and 5) lead to a higher degree of overlap between clusters, suggesting less distinct groupings.

	Score	Method	Clusters
Internal validation			
Connectivity	9.55	k-means	3
Dunn	0.54	k-means	3
Silhouette	0.69	k-means	3
Stability validation			
AD	0.08	k-medoid	6
ADM	0.02	k-means	6
FOM	0.05	k-means	6

Table 11-1 Internal and stability validation measures for the optimal clustering method and number of clusters. Internal validation measures depict how distinct the clusters are whereas stability measures depict how reliable the clusters are. Internal validation suggests that k-means with k = 3 clusters provide the best clusters whereas stability validation suggests mixed optimal method and optimal number of k = 6 clusters. In conjunction with visual exploration of clusters (Figure 5) and the fact that k-medoids is less sensitive to the influence of outliers relative to k-means, we chose the k-medoids technique with k = 6, resulting in 3 clusters and 3 outliers (*Figure 11-1*, k= 6).

12 Appendix: Contextual barriers and facilitators of ADRD caregivers influencing DHI engagement

PWS Component	**Contextual factors occurring as a barrier, facilitator, or both.**	**Description**
Person	Technology literacy and attitude of primary caregiver	The primary caregiver's knowledge, attitude, and experience with technology.
	Technology literacy and attitude of secondary caregivers	The secondary caregiver's knowledge, attitude, and experience with technology.
	Psychological well-being of primary caregiver	Psychological and emotional well-being needs of primary caregivers.
	Psychological well-being of secondary caregiver	Psychological and emotional well-being needs of secondary caregivers.
	Physical well-being of primary caregiver	The primary caregiver's physical well-being.
Tools	CareVirtue's Versatility	CareVirtue's ability to be used on multiple devices
	CareVirtue's access and usability	CareVirtue's ease of use and aid with navigating the interface
	CareVirtue's privacy	Appraisal of CareVirtue's trustworthiness and privacy
	Integration of existing tools with CareVirtue	CareVirtue's ability to integrate with tools currently used by the primary caregiver
	Satisfaction with using other existing tools	A primary caregiver's satisfaction and perception of usefulness of other tools
	Access to internet	Access to internet in the place where caregivers reside
Tasks	Complexity of caregiving tasks	The primary caregiver's perception of the complexity of the caregiving tasks such as the need for meticulous execution of tasks
	Conflicts with self-care tasks	Perceived conflicts associated with self-care tasks of primary caregiver and their caregiving tasks.
Socio-cultural factors	Social support	How a primary caregiver appraises the social support they receive from their care network and the community.
	COVID	The influence of the COVID-19 pandemic in the lives of caregivers, their support network, and the person living with ADRD
	Personal values	Existing values and beliefs about social and emotional support.
Organizational factors	Formal care network characteristics	The size, composition, geographic distribution, and the role of formal care network members or agencies in the network such as healthcare professionals, specialists, hired caretakers.

PWS Component	Contextual factors occurring as a barrier, facilitator, or both.	Description
	Informal care network characteristics	The size, composition, geographic distribution, and the role of informal care network members such as family members, friends, and other informal caregivers.
	Workload	Demand placed on care network's cognitive resources to carry out tasks or activities within a specified amount of time.
	Routines	Existing and scheduled processes that occur as a part of a caregiver's everyday activities inclusive of both caregiving related activities and non-caregiving activities such as working on a computer all day, going for a walk in the mornings, etc.
	Distribution of care work settings	Where care work happens and how it is distributed between different settings based on the location of the person living with ADRD
Physical-spatial factors	Workspaces	The primary caregiver's location of professional work.
Outcomes	Emotional catharsis	Processing and release of negative emotions relating to a caregiver's lived experience through journaling.
	Caregiving appraisal	Evaluation of the experience of caregiving, including the challenges and rewards.
	Caregiving reappraisal	The change of one's perspective on caregiving, often in a more positive way.
	Interpersonal influence	Ability to see the perspective of others in the care network in regards to caregiving
	Information management among informal care network	Ability to enable visibility and awareness of daily activities, care appointments, and disease progression of the person living with ADRD among their informal care networks.
	Information management with healthcare professionals and associated empowerment	Ability to manage and communicate information regarding the progression of the person living with ADRD with healthcare professionals to aid decision making regarding care.
	Care coordination and planning	Ability to coordinate care transitions with members of the care network and logistics around caregiving responsibilities.
	Monitoring care recipient	Observing and understanding trends in symptoms of the person living with ADRD.

Table 12-1 Definitions of contextual factors

Contextual factors	Illustrative example for contextual factor as a facilitator to DHI engagement	Illustrative examples for contextual factor as a barrier to DHI engagement
Person		
Technology literacy and attitude of primary caregiver	"I thought it was really simple to use. But I've been working with computers for too many years. Used to do programming, I was a graphic designer. So I thought it was very easy to use." (P252)	"I'm not as computer literate as young people are because you guys grew up with this, and I don't." (P273)
Technology literacy and attitude of secondary caregivers	X	"So people in my age range, which is not [technology literate] ... my brothers were resorting to a paper calendar [..] I find that irritating because I'm very much a techie person." (P212)
Psychological well-being of primary caregiver	"I think [the emoticons were] the most valuable for me, because I think we need to identify how we're feeling. And sometimes we don't even know because there's so much going on." (P292)	"And then my only other suggestion was maybe like something like the caregiver could blog or rate themselves each week or how they took care of themselves, or how did they, you know, what did they do for themselves that week, or how are they feeling kind of a thing, because I mainly just talked about his behaviors and that kind of thing. But sometimes caregivers need a safe place to vent too." (P272)
Psychological well-being of secondary caregiver	X	"my daughter, I think she will do it. I mean, it's just a matter of [..] she wants to figure out the whole thing. And I understand why because she's very close to my wife, and she deteriorated a lot..the decline is so fast, that's really, it's a tough thing to take." (P211)
Physical well-being of primary caregiver	X	"It's difficult for me to do it, yeah [..] I have some health issues with my back that doesn't require me, it's hard for me to function and do it." (P233)
Tools		
CareVirtue's versatility	"I don't like doing things on the phone, and my phones are not very good. So it was on my computer." (P260)	"for people like me that aren't real technologically savvy, if I can just get the icon app on my phone, that's easier to me than, you know, actually going to a website and then logging in and whatever" (P264)
CareVirtue's access and usability	"So in the beginning, it was a little awkward, but with just repeated usage, it got really easy, and I was able to instruct multiple caregivers on how to use it" (P202)	"You can only add things at the end [in care guide]. And so you have to redo your whole schedule if you want to add something between." (P271)
CareVirtue's privacy and trustworthiness	"Social media and I don't mix [..] But knowing that it was something I could write out, and knowing it wasn't going to be shared to everybody in the world by accident, privacy was a big thing." (P232)	"It was a problem that the other caregivers, besides myself being the primary administrator, had each other's email and phone information, because I had a caregiver

Contextual factors	**Illustrative example for contextual factor as a facilitator to DHI engagement**	**Illustrative examples for contextual factor as a barrier to DHI engagement**
		that I had to let go, because she was very negative" (P202)
Integration of existing tools with CareVirtue	"I think it worked really well with, I would go, I mean, I can have a couple of windows open, and I would have her, MyUnityPoint up, and then I would just, basically, you know, copy over any PT, any doctor's appointments, you know, when she needed a blood test." (P243)	"we had already posted them on our texting, and, therefore, entered them in our contacts. And, again, whether there's a way to somehow, I just, it's a pet peeve of mine, one-time data entry." (P220)
Satisfaction with using other existing tools	"sometimes we use Messenger, not just for my, for her care, you know, but for anything family. [..] which is not necessarily a secure, you know, thing, and this one is. So, yeah, it has just created something that was specifically and exclusively for her care" (P234)	"I utilized my phone more. Also, again, because of the reminder feature, right? My phone pops up, oh, you know, Dad has PT this afternoon at 2:30.." (P251)
Access to internet	X	"while I have my laptop on most of the time, [care recipient] barely does because she's up there in the middle of nowhere Wisconsin, and so Internet for her is even a challenge." (P222)
Tasks		
Complexity of caregiving tasks	"I just would make an entry like grandma's grass was cut today. So then, you know, instead of trying to remember, [..] now when did the grass have to be cut? When do I need to redo the medications? I could just kind of keep that, you know, keep that logged." (P274)	"The caregiving that I'm doing with a person with somewhat mild dementia doesn't need all the kind of coordinating through different providers that this software seems to kind of focus on" (P215)
Conflicts with self-care tasks	X	"to actually have something that said, okay, I took my medicine today and put an X on my square. And that way, she took her medicine and I took mine. We get so focused on her stuff, that we forget about other stuff."(P211)
Socio-cultural factors		
Social support	"[With CareVirtue, my sister] will call me and say, oh, you had a rough couple days, huh?" (P260)	"I didn't really need a lot as far as emotional support. I was in, I was principal at a Lutheran school for 21 years, so as far as even spiritual, that type of support, I'm already equipped to do that." (P212)

Contextual factors	**Illustrative example for contextual factor as a facilitator to DHI engagement**	**Illustrative examples for contextual factor as a barrier to DHI engagement**
COVID	X	"I was never able to get anyone else connected on my team. Like I say, with the COVID and the quarantines and all that stuff, it just didn't work out" (P252)
Personal and social values	"I don't want to embarrass [care recipient]. I don't want, I don't know what he can hear, what he can't hear. I know he can't hear most times, but sometimes when you're talking to people, people don't always understand how much he can or can't. Or I just didn't want anything to come between our relationship. And its key, and [CareVirtue] is a silent partner" (P264)	"And [receiving social support] by setting up a, setting this thing up with an online platform always felt a little too impersonal" (P290)
Organizational factors		
Formal care network characteristics	"We have an agency that comes in to assist them in the morning. And we were able to give [CareVirtue] to them as well as they will be going for a respite care visit in the next three weeks, [..] They'll be able to see exactly, this is what she wants for breakfast. This is the TV shows.. "(P232)	"[My aide] only comes two hours a week, and I didn't think she was qualified to handle [CareVirtue]." (P210)
Informal care network characteristics	"My one brother who does not live in San Diego with me, he was the one to comment more often." (P251)	"[My family is] totally, they're really, really disconnected. And so I did not invite them, yeah. It just would've caused more chaos, more phone calls, more, it wouldn't have been helpful." (P273)
Workload	"it'll be a good way to update my sister, because she can look at it on her time, and I can fill it out on my time. And we don't have to interrupt each other per se to get it done, because she's still working and everything." (P260)	"I think I hesitated many times [sharing CareVirtue] just because they have their own lives, and, you know, one of them has young children, and, I mean, they're both are very busy people and taking care of a lot of other people." (P203)
Routines	"I really didn't necessarily make a change [to my routine]. Because like I've said before, it was easy to integrate some time on this application while I'm doing other stuff on my laptop first thing in the morning and, you know, getting the day going." (P271)	"But after you've already formed your habits and adjusted and dealing with it, it wasn't very, it was just, essentially it was just an extra job for me to do on top of what I was already doing." (P280)
Distribution of care work settings	X	"I think because I was using it on such a limited scope, you know, kind of looking at everything, and because he was in a nursing home, a lot of the daily cares, all that stuff, I didn't have to worry about." (P212)
Physical-spatial factors		
Workspaces	"It's fairly easy to fit in, I mean, but I'm on a computer or my phone a lot because of	"There are days where I'm just never home or . . . night and I don't think about jumping on

Contextual factors	**Illustrative example for contextual factor as a facilitator to DHI engagement**	**Illustrative examples for contextual factor as a barrier to DHI engagement**
	work, so it was easy to just pop in there and write in what I needed to do or write in what I needed to because I was on a phone or something anyway." (P204)	the computer at that time. So if I would have thought to put it through on my phone, I would have used it more. (P232)
Outcomes		
Emotional catharsis	"you're kind of forced to in a way, and so, in a good way, and so that's when I think you start processing more your feelings . . . processing about it." (P292)	X
Caregiving appraisal	"So it, it also gave me a record that I could go back and look at. Because, you know, I know in years to come, you know, when I am grieving, I will be able to say, hey, you know, this or that." (P264)	X
Caregiving reappraisal	"But the print, putting your thoughts in print is to me the real strength and where the value came into play. And then looking at it [..] it kind of helped me get a sense of, okay, this, I'm going down a bad path here. Maybe I need to change my thinking a bit. (P292)	X
Interpersonal influence	"Seeing some of [secondary caregiver's] perceptions that were different than mine was very interesting. It made me question, oh, how am I seeing things." (P231)	"It's very personal. Even though they are family members, it's kind of like do I really want them to read about my inner thoughts about this, you know, because it could frighten them." (P292)
Information management among informal care network and hired helpers	"The biggest thing was it allowed me to bring my brother and sister, both of whom live a thousand or more miles away, closer into the loop." (P220)	"You run across an article that you might want to share with everybody else. You throw that out there in a notes sort of thing, and/or, you know, a list of things to follow up on that, you know, you could share with people." (P271)
Information management with healthcare professionals and associated empowerment	"Well, I tend to think the doctor doesn't take me seriously sometimes.[..]. So, I think the fact that I can say, I wrote it down… this day, a sure thing." (P210)	"I think it would be a cool, you know, tool if you could work with your physicians on this kind of thing. Because, you know, it would be easy to send them updates that way that occasionally, you know, we got a new prescription for my wife and it would have been nice to, you know, communicate via this tool" (P271)
Care coordination and planning	"There is suggested task list like cleaning, but that was pretty much it. So being able to put her specific preferences next to that, it just bumped the next person's care level up for her. (P232)	X

Contextual factors	Illustrative example for contextual factor as a facilitator to DHI engagement	Illustrative examples for contextual factor as a barrier to DHI engagement
Monitoring care recipient	“I found it really useful because it made me think back to the day and actually even longer than that, kind of when taking care of my mom, as far as if she's progressing, or if she's been doing anything different.” (P243)	X

Table 12-2 Contextual factors and illustrative examples for each contextual factor occurring as a barrier or facilitator to DHI engagement for ADRD caregivers

13 Appendix: Choosing the optimal number of topics in STM

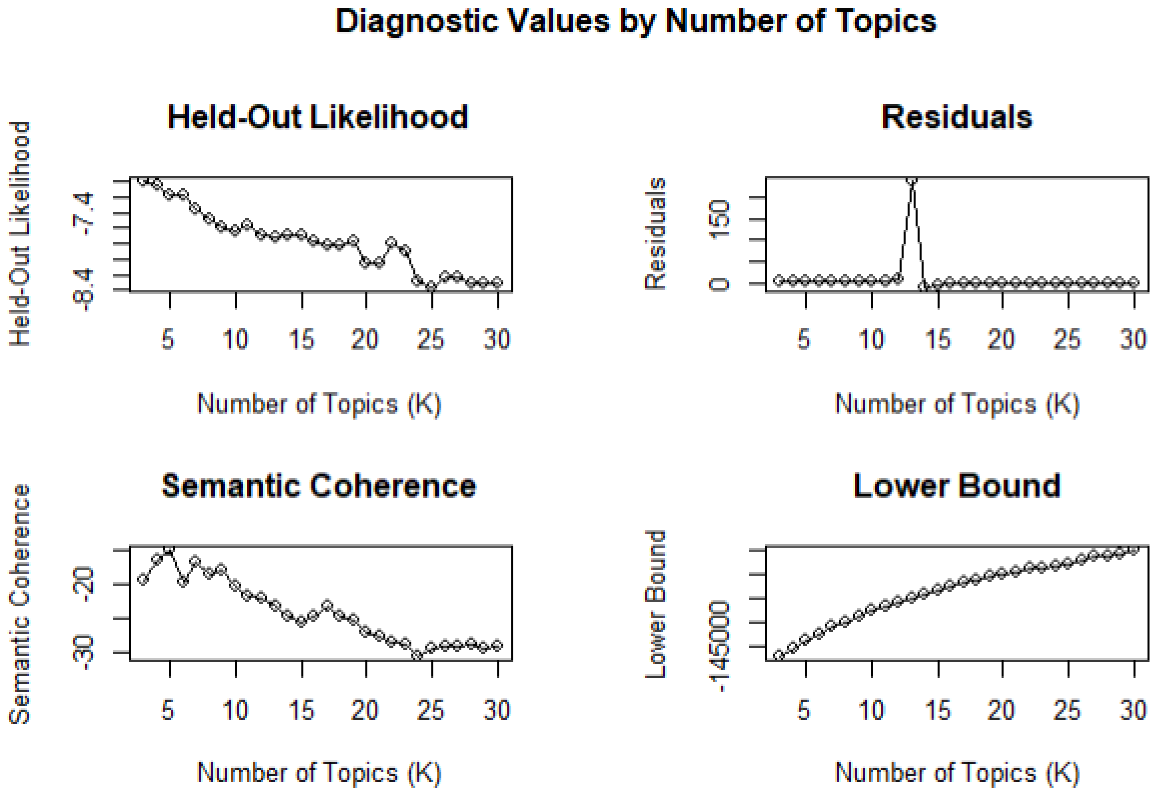

Figure 13-1 Validation metrics to select the number of topics for inductive STM

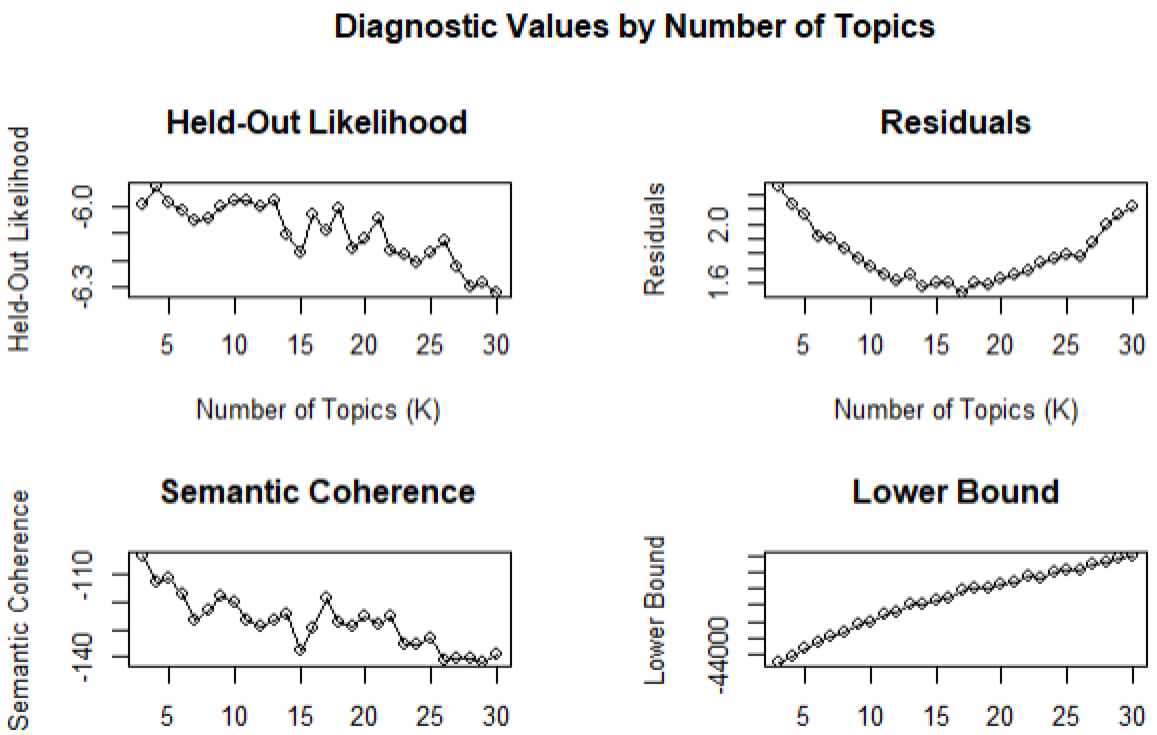

Figure 13-2 Validation metrics to select the number of topics for STM-supported directed content analysis