Goodbye UTI (GUTI): Prototyping A Digital Intervention to Support Dementia Family Caregivers with Urinary Tract Infection Prevention and Management

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Abstract

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Urinary tract infections (UTIs) are a leading cause of potentially preventable hospitalizations for persons living with dementia (PLWD), significantly increasing caregiver burden and healthcare costs. This dissertation proposes the development of Goodbye UTI (GUTI), a digital intervention designed to assist family caregivers (FCGs) in preventing, managing, and tracking UTIs in PLWD. Given the unique challenges of dementia care, where PLWD often cannot express urinary discomfort, caregivers face difficulties in recognizing early symptoms and ensuring timely treatment. The goal of GUTI is to bridge this gap through an accessible digital tool that empowers caregivers by providing clinical guidance, symptom tracking, and educational content aligned with UTI prevention guidelines. The paper followed the three-paper dissertation format and was structured into three phases, following a human-centered design (HCD) approach. In the

first phase, a comprehensive conceptual framework for UTI prevention and management was created, informed by a scoping review of the literature and the Centers for Disease Control and Prevention's (CDC) four-tiered Social Ecological Model. The second phase examined the current digital interventions for UTI prevention and management in PLWD and their FCG through a comprehensive scoping review. By analyzing various study designs, intervention types, frameworks, and operation methods, we aimed to inform the development of a more effective, tailored prototype that better serves the needs of PLWD and their caregivers. The final phase involved identifying the context of use, user needs and preferences through interviews and surveys with main stakeholders, especially FCGs. These insights will inform our future study regarding the design of the GUTI prototype, tailored to the specific requirements of caregivers managing PLWD with moderate to late-stage dementia. The GUTI digital intervention aims to alleviate caregiver burden by equipping FCGs with tools to manage urinary health for their loved ones more effectively. This digital support could potentially reduce UTI-related emergency department visits and hospitalizations among PLWD. As a scalable, home-based solution, GUTI has the potential to enhance the well-being and quality of life for both caregivers and PLWD. If successful in reducing caregiver burden, improving urinary health management, and lowering emergency visits and hospitalizations, GUTI could serve as a model for developing similar digital health solutions to address other challenges in dementia care.

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DEDICATION

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Chapter 1. Introduction

Introduction

There are more than 55 million people living with dementia worldwide, and an estimated 6.2 million Americans age 65 and older are living with Alzheimer Disease and related dementias (ADRD), and 72% are age 75 or older.[1] Dementia mainly affects older people and Alzheimer's disease is the most common form of dementia which contributes to 60-70% of cases.[1,2] Persons living with dementia (PLWD) are at heightened risk of being admitted for hospitalizations or emergency department visits than individuals without dementia.[3,4] Mortality after discharge is also increased, especially for ADRD patients with advanced dementia.[5] Urinary tract infections (UTI) are among the leading reasons for potentially preventable hospitalizations (PPH), defined as hospital admissions deemed avoidable with proactive ambulatory care.[4] Hospitalizations of PLWD often create substantial financial, emotional and physical burden in FCGs.

Technological solutions such as telehealth and digital tools have helped reduce risks of hospitalizations by strengthening connection with primary care clinicians, thereby reducing caregiver burden, depression, stress and improving quality of life for both the patient with dementia and the caregiver. [6–8] Previous work also showed that it is feasible to manage and prevent UTI by utilizing digital applications[9] in diverse clinical populations such as healthy adults, pregnant women, and males with suspected UTI. However, this work is yet to be extended to a dementia context. People living with dementia, especially in moderate to late-stage dementia, may experience challenges recognizing urinary symptoms and expressing their needs.[1,10] Therefore, it is a challenge for dementia FCGs to identify PLWD's needs since they may not be familiar with the symptoms of UTIs and may not seek reliable medical information required to ensure the PLWD receives the appropriate treatment. [11,12] The study intends to address this gap by developing prototypes of a digital intervention to help dementia FCGs

manage urinary health in people with moderate and late-stage dementia. The methods and procedures for the prototype development will be informed by the principles of the human center design (HCD).

Specific Aims

This dissertation describes a step-based approach to develop a digital intervention, "Goodbye UTI (GUTI)" with three specific aims:

Aim 1: To propose a conceptual framework for UTI prevention and management in PLWD and their FCGs. The author conducted a literature review on building the knowledge in nursing science to 1) identify factors and outcomes of UTIs in community-dwelling older PLWD; 2) generate a conceptual framework informed by the Centers for Disease Control and Prevention's (CDC) four-tiered Social Ecological Model[13]; and 3) integrate preventive measures in the framework.

Aim 2: To explore the current state of science in digital interventions for urinary tract infections prevention and management in PLWD. To enhance the development of a more effective prototype tailored to the needs of PLWD and their caregivers, the author aimed to gain deeper insights into existing digital interventions focusing on UTI prevention and management in PLWD. To accomplish this objective, the author conducted a comprehensive scoping review within the realm of nursing science, examining current digital interventions for UTI management and prevention in PLWD. This review encompassed reporting the study design, the current types of digital interventions, underlying structures or frameworks, dosage, intensity of the intervention, and how the intervention was operated, all within the scope of UTI prevention and management for PLWD and their caregivers.

Aim 3 To establish a list of design considerations regarding user needs and requirements for FCGs of PLWD. Utilizing the first two phases in the iterative process model of HCD defined in DIN EN ISO 9241-210, which includes four main activity phases: 1) understand user needs and context; 2) specify user requirements; 3) produce design solutions; and 4) evaluate design against requirements (figure 1.1.), the author employed a qualitative descriptive approach, and conducted semi-structured interviews with dementia caregivers online via Zoom. These interviews captured detailed insights from participants. Additionally, the author compiled a comprehensive list of thematic design considerations, encompassing the selection of digital tools, content, features, and functionalities, which were be summarized for analysis.

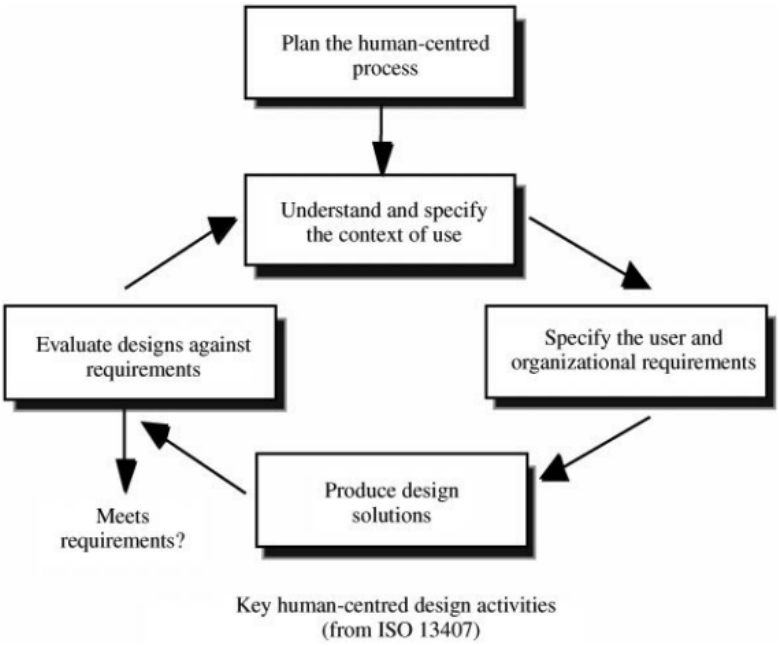

FIGURE 1. The human-centred design cycle.

Figure 1.1. Human-centered design (HCD) has four main activity phases pictured by Maguire et al. (2010): (1) Specify the user and the context of use; (2) Specify the user requirements; (3) Produce design solutions; and (4) Evaluate designs against requirements.

Significance

This study holds significant value in advancing dementia research in three aspects: 1) to raise awareness of the negative impacts of UTIs in PLWD and their FCGs; 2) to present the critical need for a comprehensive framework focused on UTI prevention and management for community-dwelling PLWD and their caregivers; and 3) to highlight the importance of a human-centered design (HCD) approach that involves dementia caregivers in developing digital interventions for UTI management.

First, UTI is a major health concern in PLWD. PLWD who were 65 and older had higher hospitalization rates and more severe complications, such as delirium, cognitive decline, and mortality, compared to older adults without dementia. Hospitalizations not only worsen dementia symptoms but also impose a substantial emotional, physical, and financial burden on caregivers. These challenges highlight the urgency of a preventive approach to reduce UTI-related complications in PLWD and lessen caregiver strain. Second, there is a lack of a comprehensive UTI prevention framework explicitly tailored for community-dwelling PLWD and their caregivers. Current practices in existing frameworks like the Prevention of Lower Urinary Tract Symptoms (PLUS) model and diagnostic leaflets for UTIs primarily target women or the general older adult population, omitting the unique risks and needs of PLWD. Developing a specialized framework is essential to fill this gap and provide dementia caregivers with more relevant, accessible UTI prevention and management resources. Finally, involving FCGs in the design process is critical to developing user-friendly tools that directly address their practical challenges in managing UTIs in PLWD. The HCD approach offers the best approach to include stakeholders such as FCG to participate in the design and evaluation of the intervention, directly addressing their needs and ultimately improving the quality of life for both PLWD and their caregivers by reducing preventable hospitalizations and associated burdens.

Innovation

This study is innovative in three ways. First, to our knowledge, this will be the first digital application designed specifically to track and potentially prevent UTI occurrence among PLWD. Second, this study will be the first UTI digital-based intervention to integrate latest UTI clinical guidelines along with behavior change techniques to promote urinary health in PLWD. And third, if successful the resulting intervention will likely benefit both PLWD by decreasing risks of their negative health outcomes in PLWD and FCGs by empowering them to provide better care and reducing their caregiving burden. It is our hope that the intervention will ultimately reduce UTI occurrences and UTI readmission rates in PLWD. We envision that the proposed digital intervention will be disseminated as home-based care interventions or prescribed by clinics that serve patients with dementia as one of prescriptions for prevention of UTI in people with dementia.

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Chapter 2. A Conceptual Framework for UTI Risk Factors in Community-Dwelling Older People Living with Dementia

Abstract

Background and Aims: UTIs greatly impact hospitalization rates for people living with dementia (PLWD). This study aims to craft a framework through a scoping review, assessing UTI symptoms, risk factors, and non-pharmacological prevention strategies in community-dwelling older PLWD.

Research Design and Methods: Our scoping review followed PRISMA-ScR guidelines, exploring databases for topics like geriatric care, urinary tract issues published from January 1977 to April 2023. Two reviewers assessed data, organizing it using the Social-Ecological Model to construct the UTI Prevention (UTIP) framework.

Results: The literature review scrutinized 1394 articles, selecting 14 through rigorous evaluation. Detailed demographic characteristics, synthesized UTI symptoms, 14 risk factors, and seven outcomes for older community-dwelling PLWD were included. Moreover, the review rersults outlined ten preventive domains and proposed a comprehensive UTIP framework spanning individual, relational, community, and societal levels. This framework aims to structure prevention of UTIs among older PLWD in community settings, integrating risk factors and outcomes to bolster effective prevention strategies for this population.

Discussion and Implications: The review introduced a UTIP framework, and non-pharmacological preventive measures tailored for elderly PLWD in community settings. However, some factors in the framework require further validation to strengthen their associations with outcomes. Preventive measures from studies had limitations like small sample sizes, bias risks, and inconsistent findings. Future research should prioritize robust randomized trials with strong statistical power, strict criteria, and consistent individual-level interventions to

boost outcome reliability and validity. Such efforts may enhance the credibility of findings and contribute significantly to refining preventive strategies for this vulnerable population.

Introduction

Urinary Tract Infection (UTI) hospitalization constitute 10% of preventable admissions in people without dementia but this proportion increases to 25% for people living with dementia.[1] Notably, people with dementia have a 3.4-fold higher likelihood of hospitalization due to UTIs.[2] These hospital admissions are concerning, given their association with further health complications such as heightened delirium risk, cognitive deterioration, and elevated mortality rates among PLWD.[3–6] Delirium, in particular, can be triggered by UTIs in PLWD, often leading to symptoms of increased confusion, agitation, or withdrawal.[3,7] PLWD also frequently display symptoms such as dysuria, fever, suprapubic pain, gross hematuria, and new or heightened urgency or incontinence.[5,7] As UTIs progress, they can accelerate dementia progression and intensify hospitalization needs. Given that people with moderate and late-stage dementia may struggle to articulate their symptoms, there is a heightened risk of severe UTI complications, including renal failure or septic shock. These ramifications not only adversely affect the individual but also impose substantial societal, caregiving, and financial burdens.[1,2,8–11] Recognizing UTI risk factors in PLWD is crucial for reducing unnecessary hospital stays and fostering overall wellbeing.

Towards a UTI Prevention Framework for People Living with Dementia

Risk factors are individual characteristics that elevate the probability of disease onset.[12] Understanding what lead to disease and how disease can be prevented can greatly reduce the occurrence of the disease, help promote and preserve individual's health status. Identifying modifiable factors, outcomes, and creating a coherent framework are the keys to tailoring the appropriate prevention interventions.[13] For UTI, these factors encompass genetic, behavioral, and comorbid determinants.[14,15] Moreover, individuals with specific demographics face particular

risks such as women who are post-menopausal,[16,17] men with benign prostatic hyperplasia (BPH),[14] and residents residing in long-term care.[18]

While guidelines exist detailing UTI management for different populations like women,[15-17] children,[21] people living with catheters,[20] older adults,[4,14, 18] and residents in long-term care facilities,[17-18] limited research targets community-dwelling seniors with cognitive challenges, especially PLWD who may experience challenges recognizing urinary symptoms and expressing their needs.[10,22] Indeed, there appears to be a knowledge gap regarding UTI risk factors in a high-risk population with dementia.

To bridge this gap, the Centers for Disease Control and Prevention's (CDC) four-tiered Social Ecological Model offers a strategic approach.[23] This model elucidates the complex interplay between personal, relational, community, and societal determinants and provides an inclusive framework for understanding health behaviors. By integrating this model, we can discern various factors predisposing PLWD to UTIs and understand the subsequent symptoms and health complications, notably delirium-induced cognitive changes, increased infection rates, falls, and mortality.[3,18,24]

Study Aims

This research aimed to construct a conceptual framework for UTI prevention and management specifically tailored to community-dwelling PLWD. Given its holistic portrayal of interconnected determinants across multiple levels, it is timely to conduct a scoping review to explore and analyze the emerging literature. A scoping review provides a comprehensive approach that encompasses primary studies, reviews, and grey literature, aligning with the diverse nature of the topic.[25-27] This inclusive methodology allows for the identification of key concepts, gaps, and emerging themes within the existing body of literature. Through this scoping

review, the goal was to construct a robust conceptual model that informs future research endeavors aimed at developing targeted preventive strategies, enhancing surveillance measures, and optimizing intervention efficiency for UTI prevention and management in community-dwelling PLWD.

Using findings from the literature, the primary goal is to discern key factors and UTI symptoms that might shape health behaviors and outcomes in this population using the adapted social-ecological model. Specifically, the study aims were:

Aim 1: To review professional literature for symptoms, risk factors, outcomes, and prevention measures for UTI that could influence health behaviors and outcomes in PLWD.

Aim 2: To illustrate a UTI prevention (UTIP) conceptual framework for community-residing PLWD, grounded in the CDC's Social Ecological Health Model.

Methods

Overview

We conducted a scoping review adhered to the guidelines from the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews).[25] The PRISMA-ScR guideline was built upon prior scoping review frameworks of the Joanna Briggs Institute[26] and Arksey and O'Malley.[27] We adhered to the PRISMA-ScR framework six steps: (1) indicate whether a protocol and registration exist, (2) identify eligibility criteria, (3) locate information sources and search, (4) selection of sources of evidence, (5) chart data from the selected studies, and (6) synthesize results.[25]

Step 1: Protocol and Registration

This paper was modeled after our previous scoping review regarding behavior change factors and retention in in web-based interventions for informal caregivers of PLWD.[28] We drafted our protocol following the PRISMA-ScR framework.[25] The final protocol was registered prospectively with the Open Science Framework on April 23rd, 2023 (registered from the website[29]; registration DOI: https://doi.org/10.17605/OSF.IO/F9HQC).

Step 2: Eligibility Criteria

Inclusion Criteria

Studies meeting the following criteria were included: (1) studies referred to the risk factors and preventive measures of urinary tract infections; (2) studies that include the community setting and population of people with dementia or referred to the disease "dementia"; (3) observational study (e.g., cohort studies, case-control studies, and cross-sectional studies), experimental design including quasi-experimental studies (e.g., nonequivalent control with pretest-posttest design, nonequivalent control with posttest only, one group pre-post, and time series designs) and randomized controlled trials, and feasibility study; (4) published from January 1977 (the earliest related literature identified by the databases) to April 2023 in a peer-reviewed journal, and (5) published in English.

Exclusion Criteria

Studies meeting the following criteria were excluded: (1) the UTI risk factors of the reported population did not include the PLWD; (2) basic science articles (e.g., animal studies, neuroanatomy, neuroimaging, anatomy, physiology, bacteriology, pathology, or biochemistry) fundamental to the study of medicine; (3) primarily focused on delirium, or developmental

disorders, or other; (4) letters to the editor, editorials, essays, or other op-ed pieces; (5) gray literature or conference papers; (6) other (case study, proposed study, or study protocol).

Step 3: Information Sources and Search

A literature search was conducted in four databases to identify all relevant literature: PubMed, CINAHL, Embase, Web of Science. Keywords and Medical Subject Headings (MeSH) terms were used regarding the concepts of geriatric care, home care residents, home residents, long term care facility, urinary pathogens, urinary tract – abnormalities, and antecedence. The following were specific keywords used in the searching strategies: ("Urinary Tract Infections"[Mesh] OR Urinary tract infection OR UTI OR bacteriuria) AND ("Patient Outcome Assessment"[Mesh] OR "Outcome Assessment, Health Care"[Mesh] OR "Treatment Outcome"[Mesh] OR "Patient Reported Outcome Measures"[Mesh] OR "Risk Factors"[Mesh] OR risk factors OR outcomes) AND ("Dementia"[Mesh] OR dementia OR Alzheimer's OR senile OR senility). Detailed search strategies are provided in *Multimedia Appendix 1*. We also conducted a reference check to include potentially relevant studies. Based on the PubMed, the research period was from January 1977 to April 2023.

Step 4: Selection of Sources of Evidence

We uploaded all citations to Rayyan,[30] a web-based research tool that helps researchers to collaborate in reviews and other knowledge synthesis projects. After duplicates were removed, 2 reviewers (KCW and YS) subsequently screened all the articles by title, abstract, and full text. The reviewers engaged in a process of cross reviewing their findings to mitigate any potential screening bias. In cases of disagreement, they engaged in discussions pertaining to the suitability of articles in relation to the research objectives and the predefined inclusion and exclusion criteria, with the aim of reaching a consensus. Moreover, a third reviewer (OZ) was included to

act as an arbitrator in cases where discrepancies between the two reviewers arose. The workflow is illustrated in *Figure 2.1. Prisma-ScR guideline*.

Step 5: Charting the Data After Reviewing All Eligible Studies

Two reviewers (KCW and YS) generated a data-charting table to guide the data abstraction process. The data-reporting table displays a summary of these study features: author, publication year and location, study design, composition of the target population, study period, risk factors of UTI, major symptoms of UTI in PLWD, study sample of the study, and prevention strategies brought up in the article.

Step 6: Synthesis of Results

We reported results in the following order: (1) sample; (2) sample characteristics; (3) study period; (4) major symptoms; (5) risk factors; (6) outcomes; (7) study sample; and (8) prevention strategies proposed by the study *(Table 2.1., Table 2.2.)*. Sample and sample characteristics included study design, location, numbers of participants included in the study, participants' compositions (gender, mean age, proportion of people with dementia). By the definition of National Institute of Health (NIH), symptoms are the subjective physical or mental problems reported by PLWD or their caregivers that may indicate a UTI or its condition.[31] Risk factors are characteristics that precede and are associated with a higher likelihood of UTI's negative outcomes in PLWD.[23] The outcome in this study refers to any possible effects (health outcomes, clinical responses, patient reported data) in PLWDand their caregivers caused by the UTI identified in the study. The author categorized the reported risk factors and outcomes according to the CDC's Social Ecological Health Model.[23]

Results

Study Selection and Characteristics

The literature review yielded 1394 articles in total with 195 articles from the PubMed, 149 articles from CINAHL, 824 articles from EMBASE, and 226 articles from Web of Science. After 362 duplicates were removed and 998 irrelevant articles were excluded based on the review, 34 articles were retrieved for full article review. In total, only 14 studies were included in the final list after full article eligibility criteria were applied (see *Figure 2.1.* for the PRISMA-ScR flow diagram).

Studies meeting our criteria were published between 1993 to 2022. Among the fourteen studies, 64% (n=9) were conducted in the USA, other countries include Spain (n=1), Switzerland (n=1), India (n=1), France (n=1), and Scotland (n=1). Half of the included studies (n=7) were narrative reviews, 21% (n=3) were retrospective studies, 14% (n=2) were prospective observational studies, with one case-control study and one randomized controlled trial. Studies that reported the composition of PLWDin their samples range from 23% to 53%. Mean age of study participants reported in the studies ranged from 72 to 85 years old.

Definition and Symptoms

To date, there is no concise definition for UTIs and associated symptoms despite several consensus guidelines proposed by various groups.[14] For the purpose of this article, UTIs were broadly defined as a collective term for infections that localized in any part of the urinary tract.[14,32,33]

Only 50% (n=7) of the included studies reported major symptoms of UTI in community-dwelling older adults and people with dementia. The most commonly reported symptoms of UTI were **delirium, confusion, and/or altered mental status**[7,14,34–37] and **fever or blunted fever response.**[7,14,35–38] Some other symptoms included **frequency,**[7,14,34,35,37] **dysuria,**[7,14,35,37] newly onset or worsening **incontinence and urgency,**[7,14,34,35] **lethargy,**[14,36,37] and **suprapubic flank pain.**[7,14,35] The least discussed symptoms were **anorexia**,[36,37] **gross hematuria**,[7] **urine retention,**[35] **change in baseline function,**[14] **nausea and vomiting,**[35] and **pyelonephritis.**[38] Interestingly, MacRae et al.[35] specifically identified that the altered mental status, new onset incontinence, urinary retention, nausea and vomiting as the typical symptoms in older PLWD. See *Table 2.1.* for sample characteristics and major symptoms of included studies.

Risk Factors and Outcomes

This paper systematically reviewed risk factors and outcomes of UTIs in older individuals, including those with dementia, across various contexts such as older females/males, veterans, individuals with indwelling catheters, community-dwelling elderly, hospitalized patients, and skilled nursing facility residents. We provided a comprehensive overview of our study alongside delineating 14 risk factors and 7 associated outcomes within the older people affected by dementia residing within community settings (as depicted in *Table 2.2.*). The identified 14 risk factors include genetic and epigenetic influences, medical history, comorbid conditions, impairments, cognitive aspects, lifestyle behaviors, caregiver roles, healthcare provider home visits, institutionalized care settings, community living conditions, exposure to pathogens, social support networks, and adherence to protocols/policies. Additionally, the 7 outcomes encompassed negative health outcomes, financial strains, caregiver burden, hospital or

emergency room visits, hospitalization episodes, societal impact, and burden on healthcare systems.

Development of A Conceptual Framework for UTIs Prevention (UTIP) in Community-Dwelling Older People Living with Dementia

The UTIP framework was adapted from the CDC's four-level Social Ecological Model [23] which considered the complex interplay between individual, relationship, community, and societal levels. The unit of analysis in this study referred to older PLWD. The concept environment in this study resided in community household settings where PLWDand their caregivers resided and where the UTIs took place. Collating all the factors and outcomes, we proposed the four-level UTIP framework to help with UTI prevention and management in community-dwelling older PLWD (*Figure 2.2.* for the UTIP Framework).

Individual

Individual was defined as the first level that identified biological and personal behavioral factors that increased the possibility of PLWD getting a UTI. This study subcategorized the individual-level risk factors into those that were biological (biology/body) and those that were modifiable (mind/behavior). The rationale of dividing the individual level was attributable to the impact of personal beliefs, thoughts, knowledge, behaviors, and habits on individuals' minds and behaviors, all of which have the potential for modification. Consequently, addressing and modifying these factors would emerge as a pivotal aspect for future interventional studies to prioritize and address effectively.

Body/Biology. Genetic and epigenetics, medical history/comorbidities, functional/physical were three main body/biology factors attributed to UTI. In genetic and epigenetic factors, age,[6,7,14,35,39,40] gender as female,[7,14] race and ethnicity[6,39] were identified as the most common risk factors. Older adults with dementia age 75 or above had a higher incidence of UTI.[35,39] A study mentioned race as white had a higher incidence of UTI[39] while another study found that both Hispanics and African Americans had an elevated risk of hospitalization compared to whites not of Hispanic origin.[6] In medical history/comorbidities factor, a history of UTI,[5,14,37] long-term indwelling urinary catheter,[5–7,14,35,37,38,41] chronic illness such as diabetes, dementia, cardiovascular conditions, metastatic disease, cancer, liver disease, immunosuppressed patients, systemic disease, kidney failure, Parkinson's disease, stroke, benign prostatic hyperplasia among males, cystocele among females[5–7,14,34,36,37,39,40,42] all contributed to higher UTI occurrence. For functional/physical aspect, two of the major risk factors in elderly people with cognitive impairment were reduced functional capability[6,34,35,37,40] and urine incontinence.[7,14,34,35,37,38] In fact, a retrospective study which analyzed the data from the Centers for Medicare and Medicaid Services in 2003-2004 has discovered that the ability to walk was associated with a 69% lower rate of hospitalization for UTI.[6] Other factors related to UTI include urinary retention,[5,7] age-related change in genitourinary abnormalities that impaired voiding such as reduction in bladder capacity, uninhibited contractions, decreased urinary flow rate, and post-void residual urine, etc..[7,36–38,43]

Mind/Behavior (Modifiable Factors). Cognition, perception, and lifestyle behavior were three prominent factors frequently discussed in our included literature pertaining to the occurrence, mortality, and hospitalization rates of urinary tract infections (UTIs) among older adults residing in community settings, particularly PLWD. Cognition referred to the dementia-

related changes in cognitive function, verbal disability, or the increased challenge for PLWD to maintain their continence.[35] Perception involved the part where PLWD feel deprived of their dignity, or frustration and stress in toileting.[35] Lifestyle behavior usually indicated the daily event or activities in life. Dehydration and poor personal hygiene[35] were two main factors affecting the UTI in PLWD. Dementia affected cognitive function, memory, and decision-making abilities, which impacted an individual's ability to recognize and respond to their body's thirst signals or remember to drink an adequate amount of fluid and even take care of themselves. Individuals with dementia might struggle with communication difficulties, which made it challenging for them to express their needs in fluid, their hygiene needs, or even understand instructions from caregivers.[10] Additionally, PLWD might experience difficulties with swallowing or reduced mobility,[44] which could impede their ability to access fluids independently. These physical challenges made it challenging for PLWD to perform essential personal hygiene tasks, including brushing teeth, combing hair, or bathing without assistance.[10,44]

Relationship

The relationship level examined the close connections with PLWD that might mitigate their risks of UTI occurrence, urgent visit, or hospitalization. Two of the risk factors brought up by the literature were the role of caregivers[35] and home visits from the healthcare providers.[6] A review from Scotland pointed out that the caregiver's awareness and observation could be an important factor for UTI detection since it was essential to pay close attention to any subtle deviations from an individual's typical behavior, and gathering such information was most effectively achieved through individuals who possessed a deep understanding of them, such as family members, caregivers, or nurses.[35] Another retrospective cohort study conducted in 2003-2004 found that a visit from a healthcare professional at the time of admission to the skilled nursing facility

(Hazard Ratio 0.68) was one of the modifiable predictors that contributed to the lower rate of hospitalization for UTI.

Community

The community level of analysis investigated the environments in which social interactions took place and aimed to identify the specific attributes of these settings that were linked to the occurrence of UTIs.[45] Institutionalized care, living in community, living in acute/subacute care or rehabilitation units, and exposure to nosocomial pathogens were four contributing factors affecting the occurrence of urinary infections. Rodriguez-Mañas narrative review in 2020 reported that the exposure to nosocomial pathogens increased the likelihood of developing the UTIs.[37] The high incidence of asymptomatic bacteriuria, which meant that having bacteria presented in the bladder or urine but without an infection, was a remarkable aspect of institutionalized elderly people. Elderly adults living in supervised housing, or diseases that required institutionalized care (cerebrovascular disease, Parkinson disease and Alzheimer disease) were prone to have asymptomatic bacteriuria as well as a higher chance of developing UTI.[35,38] A retrospective analysis of three prospective cohorts in 2017 also mentioned that UTI was more frequent in acute/subacute care of rehabilitation units (RR 1.594).[5]

Societal

The societal level examined the overarching social factors that contributed to the environment in which urinary tract infections (UTIs) occur. There were two predictors of UTI under the societal level, social support and protocol/policy. Social support referred to the supports from family members, friends, health-care provider, or other social resources.[7,35] The presence of various protocol and policy-related challenges could lead to confusion in diagnosing urinary tract infections (UTIs) in community-dwelling elderly individuals living with dementia.

These challenges included poorly defined clinical criteria for UTI diagnosis, reliance on laboratory criteria rather than clinical symptoms for defining infection, limited guidance on diagnostic test utilization and interpretation, difficulties in selecting appropriate empiric antimicrobial therapy, distinguishing asymptomatic bacteriuria (ASB) from UTI, particularly in older adults with dementia, and an increased risk of adverse events and drug interactions associated with antibiotic use.[7] These issues collectively impacted the occurrence of UTIs, office/ER visits, and hospitalizations among community-dwelling PLWD.

Health Outcomes of UTIs in Community-Dwelling PLWD

The UTIP model oversaw the health outcomes of UTI following the four-level social ecological model framework. At individual level, PLWD were experiencing adverse health outcomes[7,34,35,40] on both their physical and mental well-being, along with substantial financial strains[35,37] as a result of the UTI. It was reported that UTI in elderly could cause negative health outcomes such as higher rates of infection, morbidity, sepsis, benign cystitis, pyelonephritis,[7,34,40] and result in rapid deterioration in an individual's general health and well-being, higher rates of hospital-acquired complications (e.g., pressure ulcers, falls, and delirium),[35] or even affect the PLWD's quality of life (QoL).[37] UTI occurrences also produced burdensome financial costs for PLWD and their families, as well as healthcare organizations.[35,37] At the relationship level, the specific outcome pertained to the caregiver burden since dementia caregivers faced increased levels of distress when PLWD was admitted with UTI.[35] Hospital/emergency room (ER) visits[7] and the hospitalization[6,7,14,35–38] were two main UTI outcomes in PLWD at the community level. It was found that UTI in elderly people with dementia had an 8-fold increase in length of hospital stays.[35] Lastly, the societal burden[14,37] and the healthcare burden[14,41] were two UTI outcomes in

PLWD that contributed to the societal level since UTI in PLWD usually created additional healthcare costs.[35,41]

Preventive Measures for UTIs in People Living with Dementia and Their Caregivers

The study had summarized preventive measures listed by each study within individual and interpersonal levels in the conceptual framework since these two levels contained the most modifiable factors that might directly impact the events of UTIs in our target population. This study proposed collective preventive strategies for UTIs prevention in older PLWD and their caregivers under the community setting (see table 2.2.). Ten themes of preventive measures emerged in the table: compounds, dietary, hormone, tools, settings, caregiver supports, personal hygiene, physical activity and mobility, medical treatment, lifestyle/behavior. However, three of the studies concluded that there is still a lack of evidence in some of the non-antibiotic approaches and suggested that more clinical research is needed in diagnostic procedures, treatments, prevention, and infection control.[36,37,43]

Discussion

This scoping review was the first to explore UTI symptoms, risk factors, outcomes, and prevention strategies that might influence health behaviors and health outcomes in community-dwelling PLWD. We presented a novel UTI prevention (UTIP) conceptual framework for community-dwelling PLWD built upon the CDC's Social Ecological Model of Health. The UTIP framework presented fourteen risk factors and their interactions within the ecosystem, and defined health behaviors and seven outcomes of UTIs in PLWD within individual, relationship, community, and societal levels. The supporting materials in the recommended prevention table provided preliminary perspectives in UTIs prevention and management for PLWD and their caregivers.

The prevention framework and recommendation table in this study were summarized from narrative reviews, retrospective and prospective, case-control and randomized controlled trial studies. Half of the included studies were narrative reviews about UTI in elderly adults, which suggested a low level, and a lack of evidence[46] in exploring UTI risk factors for people with dementia. Two reviews explored hospital admission in people with dementia also pointed out that there was a lack of evidence to explain why people with dementia were admitted to general hospitals, and future studies should utilize multiple national data sources and advanced methodologies to identify risk factors and clinical reasons for UTI hospital admissions.[47,48]

In this scoping review, the most frequently reported symptoms of UTIs in elderly PLWD were delirium, confusion or altered mental status, and fever or blunted fever response. This result concurred with a recent systematic review which concluded that an altered mental status such as delirium (28.9%) or confusion were the most commonly atypical presentations of UTI in the elderly and in demented patients.[49] A secondary analysis of atypical infection presentations in older adults also revealed that elderly patients with infections such as UTIs typically exhibit a subdued fever response, ranging from 37.8°C to 37.2°C.[50]

Our study also noted that a new onset of incontinence, urinary retention, nausea, and vomiting remained typical UTI symptoms in older PLWD. Numerous studies had also identified urinary incontinence and retention as conditions with a significantly high prevalence rate among individuals with dementia.[49,51,52]

This review followed the methodology of PRISMA-ScR and summarized the first UTI prevention (UTIP) conceptual framework for community-dwelling PLWD built upon the CDC's Social Ecological Model of Health. However, there were two published UTI prevention

frameworks.[13,53] The first framework was published by Brady et al.,[53] targeting UTIs prevention in girls and women. Brady's framework integrated a prevention science paradigm, Glass and McAtee's Society-Behavior-Biology Nexus, and the World Health Organization's conceptual framework for action on social determinants of health to create the Prevention of Lower Urinary Tract Symptoms (PLUS) conceptual framework. The PLUS framework encompassed different aspect of social ecology system (individual with mind and behavior, interpersonal, institutional, and societal/community), blending biology system (individual with biology and body, cellular, molecular, genomic) with social ecology, and placing an emphasis on adopting a prevention science paradigm through a life course (embodiment, childhood, adolescence, young adult, midlife adult, older adult) perspective. The second framework was a leaflet including a diagnostic chart proposed by Jones et al. in 2020 by applying an information leaflet and diagnostic flow chart to improve the management of UTI in older adults. The leaflet included a table of UTI intervention recommendations for older adults utilizing theoretical domains framework (TDF), behavior change wheel (BCW), and behavioral change techniques (BCTs).[13] Both frameworks stressed the importance of behavior change in the prevention of UTIs with different target populations, women and older adults, respectively. However, the PLUS framework failed to present on varieties of UTI outcomes in their target population. Also, the framework intentionally considered UTI risk factors and protective factors for women across their lifespan, which excluded some of the target populations in this study (e.g., male, elderly people with cognitive impairment). Meanwhile, the leaflet and diagnostic flow from Jones et al. only provided UTI recommendations for community-dwelling older adults without a rigorous framework and without considering a multitude of risk factors. Furthermore, neither PLUS framework nor the UTI leaflet included a UTI prevention framework specifically for community-

dwelling PLWD. Hence, there was a need for the development for our UTIP framework targeting the needs of PLWD and their caregivers.

This review summarizes 10 themes of preventive measures including compounds, dietary, hormone, tools, settings, caregiver supports, personal hygiene, physical activity and mobility, medical treatment, and lifestyle/behavior. The themes from this paper are similar to a narrative review published in 2018 which specifically discussed nonantibiotic prevention and management of recurrent urinary tract infection.[54] Sihra et al.s'[54] review provided twelve extensive themes covering behavioral, dietary, phytotherapy, NSAIDS, probiotics, methenamine hippurate, estrogens, intravesical glycosaminoglycans, immunostimulants, vaccines, and competitive inoculation. Also, the review from Sihra et al. [54] suggested broader strategies for general adults while our preventive measures were more tailored for people with memory loss.

Limitations

There are two limitations in this study. First, there are no available published guidelines regarding UTIs prevention and management in PLWD and their caregivers. The study has integrated and synthesized information from several studies for different types of UTIs and different target populations (mostly senior adults or women) in order to build the framework for UTIPs for our target population. Several modifiable factors in the UTIPs framework may require further validation or second-hand data-analysis to strengthen the relationship among risk factors and outcomes. Second, there are no best, effective non-pharmacological intervention for UTIs prevention. Most of the preventive measures summarized from the studies had small sample sizes with a high risk of bias, and inconsistent results. There was also a lack of well-powered randomized trials with strict inclusion criteria and consistent dosing in individual intervention.

Conclusion

Based on our review, we proposed a conceptual framework, UTIP, and ten themes of UTIs prevention recommendations that aligned with different stages of community dwelling older PLWD and their caregivers. The UTIP conceptual framework examined four levels of risk factors and outcomes with ecological lens from individual, relationship, community, and societal level. By exploring risk factors and outcomes at multiple levels of influences, healthcare professionals and policy makers will be able to locate effective preventive measures that ultimately affect the health behaviors and health outcomes in both individuals and population. The paper identifies ten themes of prevention recommendations for UTIs non-pharmacological prevention. We support the dissemination of these findings to impact health promotion programs, practices, and policies, and in turn, the health of a population across the life course.

Relevance to Clinical Practice

This scoping review underscores the significance of addressing UTIs among older PLWD within community settings, which holds profound relevance to nursing clinical practice across several dimensions. Firstly, it enhances nurses' comprehension of UTI symptoms and risk factors in clinical settings. By delineating UTI symptoms and risk factors specific to older community-dwelling individuals with dementia, the review equips clinicians with insights to refine their diagnostic acumen and expedite the identification of UTIs within this susceptible cohort. Furthermore, the UTIP framework, spanning individual, relational, community, and societal levels, offers a comprehensive strategy for UTI prevention. Clinicians can leverage this framework to craft tailored preventive plans tailored to each patient's unique needs and circumstances. Secondly, the review synthesizes non-pharmacological prevention strategies for optimizing UTI management in individuals with dementia. Clinicians can integrate these

evidence-based strategies into their practice, encompassing education on hygiene practices, fluid intake management, and environmental modifications, thereby mitigating UTI incidence among PLWD residing in community settings. Lastly, the review delineates research priorities and evidence-based practices, emphasizing the imperative for further validation of factors within the UTIP framework and the enhancement of evidence quality supporting preventive measures. Clinicians are urged to stay abreast of emerging research to continually refine their clinical practice and deliver optimal care to older adults with dementia. In clinical practice, healthcare professionals can operationalize insights gleaned from this review by implementing UTI screening protocols, deploying non-pharmacological preventive strategies, and advocating for continued research endeavors to bolster UTI prevention and management within this demographic.

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Tables

Table 2.1. Study Sample Characteristics and Major Symptoms of UTI in Community-Dwelling Older people living with dementia (N=14) Listed Chronologically from Most Recent.

Author & Year	Study Design, location	Sample	Sample Characteristics	Study Period	Major Symptoms
Bradley et al. (2022)	Case-control study, USA	169958 women aged ≥ 65 years in evaluation for UTI	0% men, mean age not listed	2011-2018	NR
MacRae et al. (2022)	Review, Scotland	Older people living with dementia	NR	NR	Symptoms in older people living with dementia: Altered mental status, new onset incontinence, nausea and vomiting, urinary retention. For people without dementia: Fever, dysuria, loin pain, frequency
DeRosa et al. (2021)	Retrospective cohort study, USA	262,515 veterans admitted with UTI	100% male (mean age 72.1; SD:12) 22.5% have dementia (mean age 80.7; SD:9.7)	2009-2018	NR
Rodriguez-Mañas (2020)	Narrative Review, Spain	Elderly adults	NR	NR	General symptoms: dysuria, frequency, urgency, incontinence. Specific in elderly patients: confusion, delirium, increased lethargy, blunted fever response, new-onset incontinence, anorexia.
Kakde et al. (2018)	Prospective, observational study, India	95 elderly patients aged ≥ 60 years with UTI symptoms and diagnose	55.78% male, 36.84% have dementia	1 year (year not specified)	Frequency of micturition, altered sensorium
Cortes-Penfield et al. (2017)	Review, USA	Elderly adults	NR	NR	General older adults: dysuria, or fever accompanied by frequency, suprapubic pain, gross hematuria, costovertebral angle tenderness, or new or worsening urgency or urinary incontinence. For patient with catheter: fever, rigors or delirium

Author & Year	Study Design, location	Sample	Sample Characteristics	Study Period	Major Symptoms
Girard et al. (2017)	Retrospective analysis of three prospective cohort, France	4669 geriatric patients (1510 in 2009, 1547 in 2012, 1612 in 2015)	32.3% male 52.5% dementia Mean age 85.4 yo; SD:7.2	2009-2015	NR
Detweiler, et al. (2015)	Review, USA	Elderly adults	NR	paper published after 1980	Fever (>38 C), chillness, dysuria, frequency, urgency, new-onset or worsening incontinence, and suprapubic or flank pain. Clinicians often include lethargy, confusion, or a change in baseline function (this can be hard to assess in complicated patients with baseline impaired cognition or extensive comorbidities)
Matthews et al. (2011)	Review, USA	Elderly adults	NR	1966-2011	Increased lethargy, delirium, blunted fever response, and anorexia.
Nicolle et al. (2009)	Review, USA	Elderly adults	NR	NR	Fever, acute pyelonephritis
Rogers et al. (2008)	Retrospective cohort, USA	408,192 residents of 4267 skilled nursing facilities in California, Florida, Michigan, New York, and Texas (2003–2004 data from the Centers for Medicare and Medicaid Services)	Male (34%), 80 years of age or older (62%).	2003-2004	NR
Saint et al. (2006)	Prospective, randomized, unblinded, controlled trial, USA	75 hospitalized men aged 40 and older who required a urinary collection device (41 indwelling catheter; 34 condom catheter)	100% men 37% dementia Mean age: 73.6	1997-2001 (3.5 year)	NR

Author & Year	Study Design, location	Sample	Sample Characteristics	Study Period	Major Symptoms
Gavazzi et al. (2002)	Reviews, Switzerland	Elderly adults	30% of dementia in the age over 85	NR	NR
Eberle et al. (1993)	Prospective, observational study, USA	195 residents of skilled nursing facilities	35% men, mean age: 85 +/- 8	1983-1985 (18 months)	NR

Note: UTI: Urinary Tract Infection; NR: not reported.

Table 2.2. Risk factors, Outcomes, Study Sample, and Prevention Strategies.

Author & Year	Study Sample	Risk Factors	Outcomes	Prevention Strategies
Bradley et al. (2022)	Incidence of UTI	**Genetic & Epigenetics**: age older than 75 years (aOR 1.26), race as white **Medical history/comorbidities:** (cardiovascular conditions (aOR 1.06), diabetes (aOR 1.14), dementia (OR 1.25), renal disease, and chronic obstructive pulmonary disease (all P's < 0.01) as compared with controls.)	NR	NR
MacRae et al. (2022)	UTI in elderly people with dementia	**Genetic & Epigenetics:** age of 80 years **Medical history/comorbidities:** urinary catheter. **Lifestyle Behavior:** dehydration, personal hygiene. **Physical/Functional:** urine continence, reduced functional ability and sensory issues. **Cognition:** dementia-related changes in cognition, verbal disability, the increased challenge of maintaining continence, confusion with environmental settings. **Perception:** deprivation of dignity, frustration and stress in toileting. **The role of caregivers:** caregiver awareness. **Social Supports:** relying on others. **Environmental/Community:** institutional care settings.	**Caregiver Burden:** increased levels of distress in caregivers and patients **Negative Health Outcomes:** rapid deterioration in an individual's general health and well-being, higher rates of hospital-acquired complications (e.g., pressure ulcers, falls, and delirium). **Hospitalization:** 8-fold increase in length of hospital stays **Financial Burden:** burdensome financial costs for healthcare organizations"	**Dietary:** • Adequate fluids intake: fresh water available at all times; hot/cold drinks routinely offered, encourage fluid consumption. Use brightly colored cups/glasses can make drinking more visible. • Encourage consumption of foods with a high liquid content such as soup, jelly, or yogurt. **Tools:** • Provide aids for drinking: double-handed cups. **Settings:** • Understand the use of facilities: design of bathrooms (use of color and contrast, layout, singe, and adaption) **Caregiver supports:** • Relief stress, frustration in toileting: proper eye contact, approach people from the dominant side, assist rather than do, hand-under-hand technique (allow patient to use their own dexterity to operate on tasks) **Personal Hygiene** Effective skin hygiene, particularly around genital area, wiping genital area from front to back after voiding, inspecting the skin for signs of redness or skin excoriation, and the use of proper barrier products to maintain skin integrity and prevent incontinence-associated dermatitis., monitor and record individual's toileting patterns, prompt the person to use the toilet regularly.

Author & Year	Study Sample	Risk Factors	Outcomes	Prevention Strategies
DeRosa et al. (2021)	Mortality and hospital readmission for patients with and without dementia at 30, 60, and 90 days from UTI diagnosis.	**Genetic & Epigenetics:** age. **Physical/Functional:** people with dementia limited functional capabilities, severe memory deficits, impaired verbal capabilities, and increased mortality risk. **Medical history/comorbidities:** medical comorbidities (heart failure, metastatic disease, MI, mild liver disease, tumor, and severe liver disease)"	**Negative Health Outcomes:** veterans with dementia admitted with UTI were associated with more mortality at 60-day, 90-day from UTI diagnosis, and readmitted more at 30- (15%), 60-,90- day intervals.	NR
Rodriguez-Mañas (2020)	Cystitis, pyelonephritis, recurrent UTI, cather-associated UTI, urosepsis in community & institutionalized elderly adults	**Physical/Functional:** age-related changes in immune function, cognitive deficits, functional disability, bowel/bladder incontinence, **Medical history/comorbidities:** history of UTIs, presence of a urinary catheter, medical comorbidities (dementia, cancer) **Community/Environmental:** exposure to nosocomial pathogens"	**Negative Health Outcomes:** affect patient's quality of life (QoL). **Hospitalization:** hospitalization **Societal Burden:** severe social burden **Financial Burden:** economic burden	**Compounds** • Early evidence suggests that using xyloglucan-based medical devices (Utipro Plus) to increase microbial resistance may protect against symptomatic recurrence. *****Lack of strong evidence** in non-antibiotic approaches (cranberry products, OM-89 vaccine, estrogen therapy, phytodrug, probiotics, non-steroidal anti-inflammatory drugs, D-mannose, estrogens, vitamins (C & D), and immunotherapy) for elderly adults.*
Kakde et al. (2018)	Risk of mortality in elderly UTI patients	**Medical history/comorbidities:** diabetes mellitus (46.31%), benign prostatic hyperplasia (41.50%) among males, cystocele (30.95%) among females. **Physical/Functional:** Impaired morbidity & urinary incontinence (especially for people with dementia)"	**Negative Health Outcomes:** morbidity, sepsis, benign cystitis, pyelonephritis	NR
Girard et al. (2017)	Nosocomial UTI	**Medical history/comorbidities:** history of urinary tract infection in the previous six months, with a catheter (Z-test, $P < 0.001$), with intermittent, indwelling, or suprapubic catheters, immunosuppressed patients **Genetic & Epigenetics:** gender (being female) **Physical/Functional:** acute retention, post-void residual, dependency. **Community/Environmental:** in acute/ subacute care or rehabilitation units.	**Negative Health Outcomes:** renal insufficiency	NR

Author & Year	Study Sample	Risk Factors	Outcomes	Prevention Strategies
Cortes-Penfield, et al. (2017)	UTI and CAUTI (catheter-associated UTI)	**Genetic & Epigenetics:** age, gender. **history/comorbidities:** uncontrolled diabetes mellitus, treatment with the sodium-glucose co-transporter 2 inhibitors (e.g., canagliflozin and dapagliflozin), urine catheter, a higher incidence of baseline cognitive impairments (i.e., dementia). **Physical/Functional:** Anatomic abnormalities of the urinary tract, particularly those which produce incontinence or urinary retention, (e.g., prostatic hyperplasia), vaginal atrophy in postmenopausal women. **Lifestyle Behavior:** sexual intercourse. **Social Supports:** supports from family members, friends, health-care provider, or other social resources such as, a home visit from health-care provider. **Protocol/Policy:** poorly defined clinical criteria to diagnose UTIs, reliance on laboratory criteria rather than clinical symptoms to define infection, limited guidance regarding the use and interpretation of diagnostic tests, challenges for selecting empiric antimicrobial therapy, difficulty distinguishing ASB from UTI, particularly in older adults with dementia, increased risk of adverse events and drug interactions related to antibiotic use.	**Negative Health Outcomes:** 5% more infections, increased morbidity, and mortality. **Hospital/ER Visits:** increased office visits, ER visits. **Hospitalization:** hospitalizations.	**Medical Treatment** • Correct anatomic abnormalities of the urinary tract, particularly those which produce incontinence or urinary retention, (e.g., prostatic hyperplasia). • Controlled diabetes mellitus, treatment with the sodium-glucose co-transporter 2 inhibitors (e.g., canagliflozin and dapagliflozin), vaginal atrophy in postmenopausal women. **Lifestyle/Behavior** Identify and address to the UTI caused by sexual intercourse, urinary catheterization.
Detweiler et al. (2015)	Prevalence of UTI and bacteremia	**Genetic & Epigenetics:** gender, age, genetic variations. **Medical history/comorbidities:** benign prostatic hypertrophy in men, uropathogenic virulence, history of UTI, comorbid conditions (e.g., diabetes, dementia, incontinence, and iron deficiency anemia), urine catheter **Lifestyle behavior:** sexual activity.	**Healthcare Burden:** healthcare burden, **Hospitalization:** increased hospitalization	**Dietary** • Hydration as a prevention and a treatment. (Increase fluid intake but do not take excessive fluid) • Cranberry supplements (no statistical significance), • d-mannose (found in pineapple), prophylactic therapy, **Hormone** Oral estrogen therapy.

Author & Year	Study Sample	Risk Factors	Outcomes	Prevention Strategies
Matthews et al. (2011)	Asymptomatic bacteriuria, acute uncomplicated cystitis, acute uncomplicated pyelonephritis, antibiotic resistance, catheter-associated (CA) bacteriuria/symptomatic UTIs, and antibiotic prophylaxis for recurrent infections.	**Physical/Functional:** urolithiasis, prostatic hypertrophy and prostatitis (men), obstruction (ie, ureteral, urethral strictures or pelvicalyceal), neurogenic bladder, cystocele, vesicoureteral reflux. **Medical history/comorbidities:** systemic disease, kidney failure, polycystic kidneys, immunosuppressed (e.g., kidney transplant), immunocompromised (systemic steroids, HIV infection), malignancy (genitourinary tumors), urinary tract instrumentation, urinary catheter (indwelling urethral, suprapubic, percutaneous nephrostomy, intermittent) urologic procedures, ureteral stent, nephrostomy tube, dementia, or stroke. **Community/Environmental:** Living in the community.	**Negative Health Outcomes:** benign cystitis, severe sepsis, death, morbidity **Hospitalization:** increased hospital admissions"	**Dietary:** • The use of cranberry, either as juice or concentrated extract capsules, has been the most promising agent at reducing recurrence rates of UTIs in the elderly population. ******Lack of strong evidence** for using methenamine salts and estrogen-containing products; intravaginal estrogen is the preferred route of administration in preventing recurrent UTI in postmenopausal women to oral-estrogen*.
Nicolle, L. E. (2009)	Bacteremia and UTI in elderly	**Medical history/comorbidities:** chronic indwelling catheter. **Physical/Functional:** genitourinary abnormalities that impair voiding, such as obstruction of the urethra or ureters, cystoceles in women, or bladder, diverticula, voiding abnormalities accompanying chronic neurologic diseases. MEN-Prostate hypertrophy, prostate disease, history of stroke. WOMEN- reduced mobility, urinary incontinence, receiving estrogen treatment. **Community/Environmental:** living in supervised housing, diseases that require institutionalized care (cerebrovascular disease, Parkinson disease and Alzheimer disease).	**Hospitalization:** increased hospitalization	**Compounds** • Long-term low dose prophylactic antimicrobial therapy. **Dietary** • Cranberry products. **Hormone:** • Topical vaginal estrogen. **Medical Treatment** Correction of underlying genitourinary abnormality
Rogers et al. (2008)	Hospitalization for UTI	**Genetic & Epigenetics:** advancing age, race& ethnicity (both Hispanics and African-Americans had an elevated risk of hospitalization compared to whites not of Hispanic origin) **Medical history/comorbidities:** medical comorbidities (Parkinson's disease, diabetes mellitus, dementia, renal failure, and stroke, transient ischemic attack (TIA) or hemiplegia), urine catheter use (2.78 times greater than patient without foely) **Physical/Functional:** walking ability **Healthcare Provider:** a physician visit at the time of admission to the skilled nursing facility. **Protocol/Policy:** physician order ""do not hospitalize."" "	**Hospitalization:** increased hospitalization	**Physical Activity and Mobility:** • The ability to walk was associated with a 69% lower rate of hospitalization for UTI.

Author & Year	Study Sample	Risk Factors	Outcomes	Prevention Strategies
Saint et al. (2006)	Incidence of developing bacteriuria patient's satisfaction of the urinary device"	**Medical history/comorbidities:** condom catheter reduce adverse outcome (P=0.04)	**Negative Health Outcomes:** morbidity. **Healthcare Burden:** additional healthcare costs.	NR
Gavazzi et al. (2002)	Bacterial colonization and infection	**Physical/Functional:** mechanical changes (reduction in bladder capacity, uninhibited contractions, decreased urinary flow rate, and post-void residual urine), urothelial change (enhanced bacterial adherence), prostatic hypertrophy in men, and hormonal changes (lack of estrogen in postmenopausal women).	**Negative Health Outcomes:** higher rates of morbidity and mortality.	More clinical research is needed in diagnostic procedures, treatments, prevention, and infection control.
Eberle et al. (1993)	Frequency of antibiotic treatment, infections, hospitalization, discharge home or death	**Physical/Functional:** WOMEN- incontinent of bowel (OR 5.3) and bladder (OR 6.3), functionality disabled (OR 3.2), **Medical history/comorbidities:** WOMEN- medical comorbidities (carry a diagnose of dementia (OR 2.4)) MEN- medical comorbidities (cancer (OR 6.5))	NR	NR

Note: aOR: adjusted odds ratio; NR: not reported; UTI: urinary tract infection.

Figures

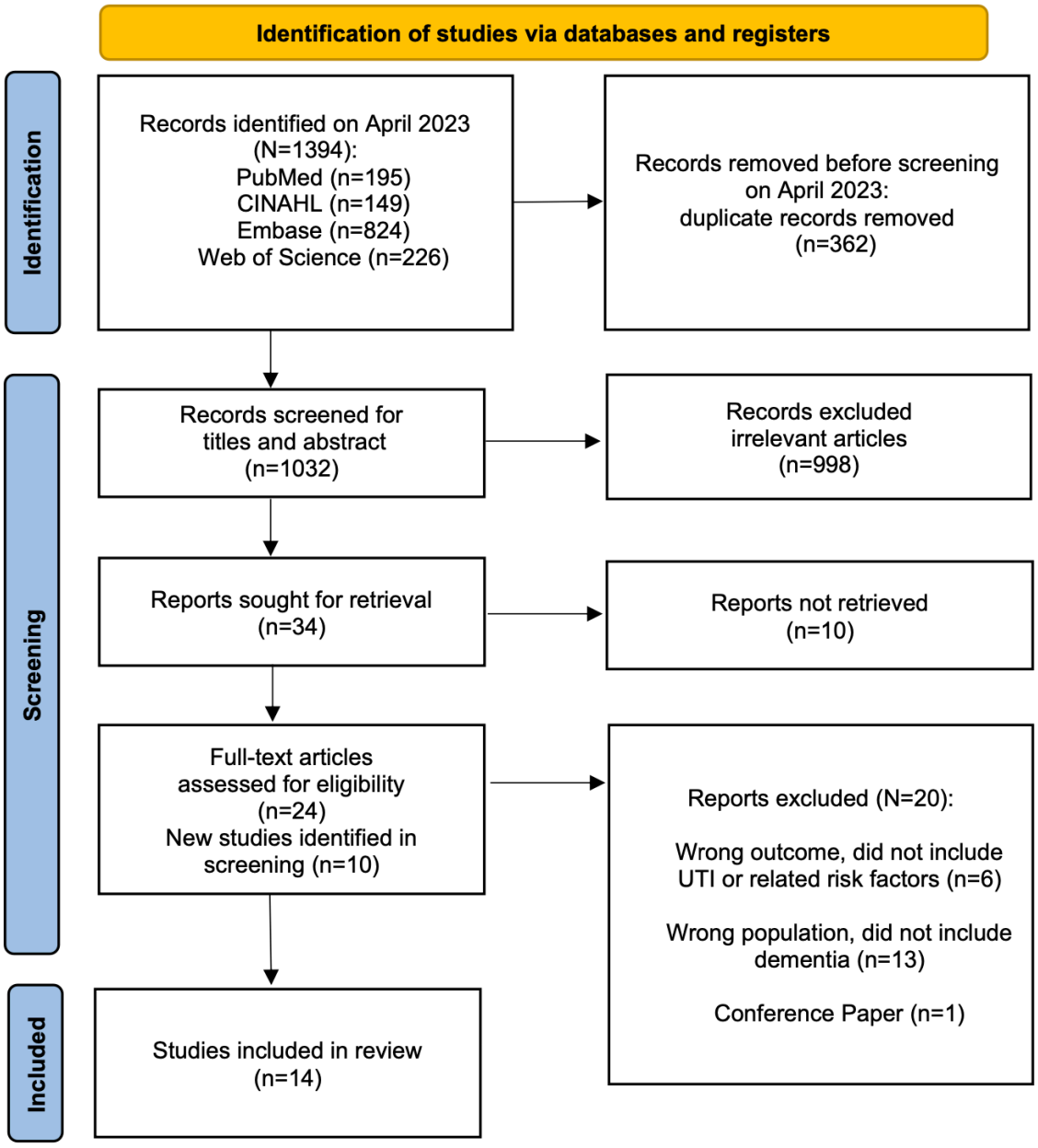

Figure 2.1. Prisma-ScR guideline

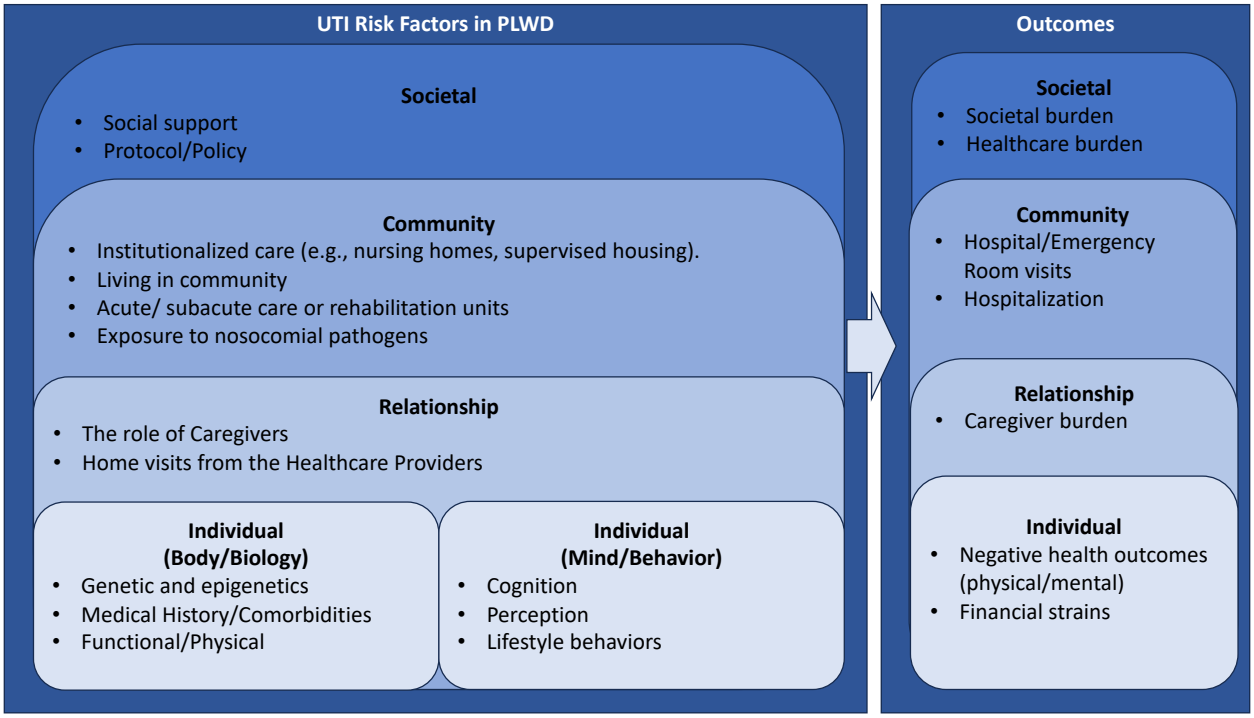

Figure 2.2. UTI Prevention Framework for Community-Dwelling People Living with Dementia

Chapter 3. Current Digital Interventions for Urinary Tract Infection Prevention and Management in Persons Living with Dementia

Abstract

Background and Objectives:

Digital interventions, such as smartphone apps, wearable devices, and telehealth, hold promise for improving UTI detection, monitoring, and prevention. However, their effectiveness for people with dementia and their caregivers remains unclear. This review aimed to identify the types of digital devices and applications, outcome variables and key findings in these interventions.

Research Design and Methods:

A scoping review was conducted using the PRISMA-ScR framework and searched for studies from 1998 to 2024. The review included quantitative, qualitative, and mixed-method studies that described digital interventions for UTI management in persons with dementia. Studies were excluded if they lacked detailed intervention descriptions or outcome reporting. Data were charted and summarized to address the study aims.

Results:

Seven studies were included from 1800 screened. Three digital interventions were evaluated: Technology Integrated Health Management (TIHM), a real-time locating system (RTLS), and a smart diaper system (SDS). The TIHM and RTLS showed high effectiveness in UTI detection, with sensitivities up to detect UTI incident up to 91%, while the SDS had lower sensitivity.

Discussion and Implications:

The review highlights the potential of sensor-based technology and AI in early UTI detection. However, most interventions lack theoretical foundations and preventive strategies, suggesting a need for more comprehensive approaches involving caregivers and clinical guidelines.

Introduction

Urinary tract infections (UTIs) refer to infections localized in any part of the urinary tract and can occur in individuals throughout their lifetime. Older adults living with dementia were 3.4 times more likely to be admitted to hospital or visit the emery room (ER) for UTIs and experience worse health complications (e.g., increased risk of delirium, cognitive decline, and higher mortality rates) compared to patients without dementia.[1–5] UTIs also impose high societal costs on the healthcare system and add significant caregiving burdens for persons with dementia and their family caregivers (FCGs).[6] Therefore, effective UTI prevention and management are crucial for avoiding unnecessary hospitalizations, preventing future admissions, and enhancing the well-being and longevity of PLWD and their FCGs.[7]

Current approaches for UTI prevention and management in persons living with dementia typically include antimicrobial therapy, hydration, and hygiene practices.[7–9] However, these traditional methods face significant challenges. Recognizing UTI symptoms can be difficult due to communication barriers and atypical symptom presentation in this population.[7,9,10] Caregivers often rely on non-verbal cues and observation to detect potential infections.[7,11] Additionally, memory issues and difficulties adhering to medication schedules in persons with dementia complicate the management of treatment regimens, including antibiotic therapy.[12,13] Communication barriers further hinder effective interactions between healthcare providers, caregivers, and persons with dementia.[11,14] A collaborative approach, involving healthcare professionals and caregivers, is essential to developing tailored care plans that prioritize UTI prevention and management while addressing these challenges.[7]

Digital health interventions have shown promise in disease management, risk factor prevention, reducing caregiver burdens, and promoting healthy behaviors in persons living with

dementia and their caregivers.[9,15–17] Digital devices, such as smartphone applications, wearable devices, and telehealth platforms,[18,19] have the potential to revolutionize UTI detection, monitoring, and adherence to preventive measures and treatment regimens.[20,21] These technologies can facilitate remote monitoring of hydration levels, provide reminders for medication adherence, and offer educational resources for caregivers.[20,22] Moreover, telehealth platforms enable virtual consultations, improving access to timely healthcare services for persons with dementia, especially in remote or underserved areas.[23,24]

While some studies have integrated UTI trainings, guidelines, or UTI symptom diaries into mobile and online interventions for healthcare workers or adult patients,[25–27] there remains a significant research gap regarding the role of digital interventions in UTI prevention and management for persons living with dementia and their caregivers, as well as the outcomes these interventions can achieve. Understanding the types of digital interventions described and tested in the current scientific literature for this population, along with their effectiveness in reducing the incidence of UTIs, is crucial. Digital interventions present promising opportunities to enhance UTI detection, monitoring, and adherence to preventive measures and treatment regimens. Embracing these interventions can significantly improve the quality of life and well-being of persons living with dementia and their caregivers.

To address this research gap, we conducted a scoping review to provide an overview of existing research on digital interventions designed for UTI prevention and management in community-dwelling persons living with dementia and their caregivers. Our research questions were: 1) What types of digital interventions and devices are described and tested in the current scientific literature for persons living with dementia and their caregivers to manage or prevent UTIs occurrences? and 2) What outcome variables are included and what are the key findings in

current digital interventions for urinary tract infection (UTI) prevention and management in persons living with dementia and their caregivers?

Methods

This study utilized a scoping review as our methodological approach considering the broad nature of our research question, the heterogeneity of the studies we retrieved, the diversity in different stages (mild to severe stage) of the dementia population and their caregivers, and a lack of relevant comprehensive reviews in prior literature.[28,29] We adhered to the steps of PRISMA-ScR framework protocol: (1) indicate whether a protocol and registration exist, (2) identify eligibility criteria, (3) locate information sources and search, (4) selection of sources of evidence, (5) chart data from the selected studies, and (6) synthesize results and reported our data following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.[29] The study was registered prospectively with the Open Science Framework on April 26th, 2024 (see registration DOI: https://doi.org/10.17605/OSF.IO/G2SZW)

Eligibility Criteria

We included publications of quantitative, qualitative, or mixed methods that met the following criteria: 1) provided a description of interventions aimed at managing or preventing UTIs in persons living with dementia and their caregivers; 2) involved digital technological devices (such as sensors, computers, tablets, or mobile phones) delivered via the internet; 3) employed research designs including experimental, quasi-experimental (such as nonequivalent control and pre-post, nonequivalent control and post only, one group pre-post, and time-series designs), randomized controlled trials (RCTs), cohort studies, and feasibility studies with

findings; 4) were published in English; and 5) were published from January 1998 to January 2024, taking into account the introduction of the first PubMed Mesh Term in 1999.

We excluded publications that met any of the following criteria: 1) focused solely on formative development of technology systems; 2) were not published in peer-reviewed journals; or 3) were case studies. Additionally, studies on technologies exclusively used by health professionals were excluded, as well as those reporting only on technical aspects or parts of a technology (e.g., interfaces or prototypes), systematic reviews, and study protocols.

Information Sources and Search

A comprehensive literature search was conducted in collaboration with a University of Washington Health Science Librarian within the five databases to identify all relevant literature: PubMed, CINAHL, Embase, IEEE Xplore, and Web of Science. Keywords and Medical Subject Headings (MeSH) terms were used regarding the concepts of digital intervention, dementia, urinary pathogens, and urinary tract infections. The following were specific keywords used in the PubMed searching strategies: ("Mobile Applications"[Mesh] OR "Computers, Handheld"[Mesh] OR "Internet"[Mesh] OR "Telemedicine"[Mesh] OR "Internet-Based Intervention"[MeSH] OR "Self-Help Groups"[Mesh] OR "Social Media"[Mesh] OR social media OR smartphone OR telehealth OR telemedicine OR health app OR mHealth OR eHealth OR eMedicine OR internet-based intervention OR web-based intervention OR online intervention OR computer OR internet OR "app based" OR “self help group” OR “support group”) AND (UTI OR urinary tract infection OR bacteriuria OR "Urinary Tract Infections"[Mesh]) AND ("Aged"[Mesh] OR "older adults" OR "elderly" OR "geriatric" OR "aging") ("Brain Diseases"[Mesh] OR "Neurocognitive Disorders"[Mesh] OR dementia OR cognitive impairment OR Alzheimer's OR brain disease OR cognitive disorder OR cognition disorder). Detailed search terms are provided in *Multimedia*

Appendix 3.1. We also conducted a reference check of the included studies to include potentially relevant studies.

Selection of Sources of Evidence

All citations were uploaded to Rayyan,[30] a web-based research tool that helps researchers to collaborate in reviews and other knowledge synthesis projects. After duplicates were removed, 2 reviewers subsequently screened all the articles by title, abstract, and full text. The reviewers engaged in a process of cross reviewing their findings to mitigate any potential screening bias. In cases of disagreement, they engaged in discussions pertaining to the suitability of articles in relation to the research objectives and the predefined inclusion and exclusion criteria, with the aim of reaching a consensus. A third reviewer was included to solve any conflicts that arose during the title and abstract screening phase, and the full-text review phase.

Data Charting and Critical Appraisal

A data-charting table was generated to address the research questions and to guide the data abstraction process. The data-reporting table displays a summary of these study features: authors, study characteristics (year of publication, study design, country), sample characteristics (sample size, mean age, and gender ratio), study aims, intervention descriptions as well as intervention length, settings, dosages, type of technology involved, and main findings. We did not conduct a standardized critical appraisal of the included studies since our primary goals were to provide an overview and map out the topics.

Synthesis of the results

We presented the results through a structured and narrative synthesis, visually, and in tabular form. To answer our research questions, we grouped the aim, intervention & methodology, and key findings into *Table 3.1.*. Additionally, we compared each study

characteristics (year, author, country, research design), participant demographics (sample size, mean age, users), and the intervention settings and length from each included studies as presented in *Figure 3.2.* Finally, we grouped the technologies thematically in each study and reported in *Table 3.2.* to provide details regarding intervention name, description, data collected, dosage, and technological devices involved in the intervention.

Results

Study Selection

The literature research produced a total of 1800 articles from five databases and other sources (citation search and Google Scholar). The databases search from the PubMed, CINAHL, Embase, IEEE Xplore, and Web of Science yielded 1797 results, 1 from the citation search and 2 from Google Scholar. Removing duplicates left 1708 articles. After abstract and title screening, 1697 irrelevant articles were removed, and 11 studies were retrieved for the full article review. In total, 7 articles were included in the final list after full article eligibility criteria were applied. The workflow is illustrated in *Figure 3.1.* Prisma-ScR flow chart.[31]

Characteristics of the included studies, participants, and interventions

Figure 3.2. summarized the characteristics of the included studies, participants' features, and interventions in this scoping review.

Study Characteristics

Of the seven included studies, the articles were published from 2020 to 2024, with a surge in 2021-2022 (2 studies each year). Geographically, the United Kingdom accounts for 72% of the research (n=5), followed by the United States (n=1) and South Korea (n=1). Notably, all of the included studies were observational. One study was reported as a longitudinal study, and another as a prospective pilot study. None of the studies included a control group.

Participant Features

As depicted in *Figure 3.2.*, the sample size of the participants varied between 15 and 117, with a mean of 63.0 and a standard deviation of 41.7. The mean age of the participants across all studies ranged from 79.9 (SD 11.2) years old to 84.0 (SD 6.1) years old. The age of the participants in most studies was around 80 years old. Overall, the mean age of the total participants averaged approximately 82.5 years old, with a standard deviation of 6.7 years old. Except for one single-sex studies,[32] all other studies include both sexes, with a total of 230 (52.2%) males and 211 (47.8%) females. The target users in the included studies are primarily people with all stages of dementia and those with mild cognitive impairments. Only one study included dementia caregivers to the intervention.[22]

Intervention Duration and Settings

Among the seven included studies, three distinct interventions were identified. The majority, 71.4% (n=5), were covered by the Minder program from the United Kingdom, also known as the "Technology Integrated Health Management (TIHM)" intervention. The other two interventions were the "Real-time Locating System" (n=1) from the United States and the "Smart Diaper System" funded by South Korea. In *Figure 3.2.*, we present the distribution of intervention durations, which ranged from 4 to 3864 days. The mean duration was 804.3 days (SD = 1264.5 days), indicating a wide range in the duration of interventions across studies. In terms of the intervention settings, 71.4% (n=5) of the interventions were installed in participants' homes, while 14.3% (n=1) were conducted in hospital wards, and another 14.3% (n=1) were carried out in long-term care facilities. The length of the interventions in the trials included in this study varied widely. Forty-three percent (n=3) of the studies had an intervention length of

over a year, while 57% (n=4) had an intervention lasting less than a year, with one study lasted less than a week and only tested a system, not the long-term effect of the technology.

Synthesis of the results

Research Question 1: What types of digital interventions and devices were described and tested in the current scientific literature for persons living with dementia and their caregivers to manage or prevent UTI occurrences? This subsection along with *Table 3.1.* and *Table 3.2.* describe three types of digital interventions summarized from the included studies, methodology used in each study, and types of devices utilized in current scientific literature to assist the prevention and management of UTIs in persons living with dementia and their caregivers.

The Minder program [33–37] was funded by two institutions: the England National Health Service (NHS), and Innovate UK, the Technology Strategy Board, the United Kingdom's innovation agency. This program utilized Technology integrated health management (TIHM) for Dementia System of Care, an Internet of Things (IoT) technology to monitor individuals with dementia. Five studies utilized data from this intervention. This program collected data through environmental sensors and Bluetooth-enabled medical devices that tracked daily activities and vital signs (see *Table 3.2.*) in persons with dementia. The environmental sensors included two passive infrared (PIR) sensors (installed in the hallway and living room), four motion sensors (one in the kitchen, one on the pill box/drawer, and two on the bedroom and bathroom doors), two pressure sensors (placed on the bed and the chair), one main entrance door sensor, and one central energy consumption monitoring device. Participants recorded physiological data twice a day using Bluetooth-enabled medical devices (e.g., blood pressure monitor, smart scale, heart rate monitor, thermometer). This information was relayed to a monitoring team via a computer-

based alert system that used machine learning to identify health and social care concerns. The monitoring team contacted the patient or their caregiver to provide advice, and Dementia Navigators offered support for non-emergency issues. Participants were monitored 24/7 for six months or more. This intervention incorporated diverse AI algorithms, with aimed to promptly alert clinicians to patients' UTI risks and facilitate early detection of UTI occurrences.

The Real-time locating system[32] *(RTLS)* was a longitudinal study approved by the Department of Veterans Affairs (VA) Research and Development Office in United States of America which integrated real-time data from technology and machine learning techniques to classify motor behaviors among long-term care residents with cognitive impairment or dementia for up to 18 months. The system consists of a wrist-worn tag (required for tracking multiple residents) and ceiling-mounted sensors to triangulate location in and around a unit and provided x, y, and z coordinates. The RTLS intervention aimed to utilized motor behavioral data to predict falls, delirium, and UTIs in persons living with dementia.

The Smart Diaper System [22] was a detection technology which utilized a smart diaper with conductor sensor devices to measure current flow, frequency, and integrated the information with an app that notified caregivers to change the diaper and measured voiding volume automatically. This system aimed to identify occurrences of incontinence-associated dermatitis (IAD) or aggravation of bed sores, conditions that may predispose patients to urinary tract infections (UTIs), within acute care settings.

Sensor Technology and Artificial Intelligence (AI) algorithms. Overall, sensors technology and integration with AI algorithms were applied in all the digital interventions (see Table 1 & Table 2) of our included studies. The devices included infra-red (PIR) sensor, motion sensors, door sensor, pressure sensor (e.g., sleep tracking mattress, urine flow), location sensors

(coordinate), and a diaper sensor. Also, Bluetooth/Wi-Fi-enabled medical devices such as smart scale, thermometer, BPM Connect (a Wifi-blood pressure monitor) were widely used in 70% of the studies. While Cho et al.[22] did not specify any algorithm used in the smart diaper system, Ramazi et al.[32] described their use of a deep learning algorithm to classify motor behavioral data collected from RTLS, identifying falls, delirium, and UTIs. Several AI algorithms had been incorporated into TIHM studies for UTI risk analysis and prediction of UTI occurrence. Enshaeifar et al.[35] introduced an unsupervised algorithm, Non-negative Matrix Factorization (NMF), to extract and analyze environmental and physiological data, along with a pattern analysis algorithm, Isolation Forest (iForest), to detect UTI occurrences. Li et al. (2021) presented a deep learning model for the early detection of UTIs or agitation in persons with dementia by providing predictions based on selected time points and features from raw observation and measurement data. Additionally, Li, Kolanko, et al.[37] proposed a semi-supervised approach that leveraged the benefits of adaptive Deep Neural Network (DNN) algorithms and supervised probabilistic model. In a separate study, Li, Rezvani, et al. [37] introduced attention-based, deep learning models to continuously learn from routinely collected in-home observation and measurement data to predict UTI risks in persons with dementia. Bijlani et al.[33] developed a Contextual Matrix Profile (CMP), an unsupervised learning-based algorithm that detects anomalies (representing adverse health conditions) using activity changes in PLWD to better evaluate the risks of UTIs and hospitalization. Capstick et al.[34] proposed a machine learning model that calculated UTI risk and stratifies scores to support clinical translation. This model alerted clinicians to UTI risk in patients, enabled early detection and improved screening for treatment.

Research Question 2: What outcome variables were included and what were the key findings in current digital interventions for UTI prevention and management in persons living with dementia and their caregivers? This subsection along with *Table 3.1.*, *Table 3.2.*, and *Figure 3.3.* describe the outcome variables measured in each intervention, results, and the key findings in each study.

Outcome Variables: In studies involving TIHM intervention, the outcome variables were divided into two categories: environmental data and physiological data. The environmental data referred to information collected by sensors installed in participants' homes, including activity patterns of their daily routines and nighttime sleep patterns.[33–37] These data were primarily gathered using motion, pressure, and door sensors. Each study developed its algorithms and models based on the sensory data utilized. For example, Bijlani et al. focused solely on PIR data, as it was the least missing, most reliable, and available with the finest granularity across the cohort,[33] while other studies[34–37] used combined sensory data to run their models. The physiological data collected by the medical devices were blood pressure, heart rate, body temperature, weight, and hydration readings. These measurements were taken by participants twice a day and uploaded from the Bluetooth/WIFI-enabled medical devices installed in the participants' homes.[35] The RTLS study employed unique type of location sensors that were worn on the wrist to track the participants' coordinates for motor behavior analysis.[32] The Smart Diaper System also utilized sensor-equipped diaper to detect physiological data such as urine flow rates, urine frequencies, and urine outputs, to further predict the occurrence of IAD.[22]

Outcomes of UTI Prediction Models and Key Findings: Figure 3.4. summarizes the outcomes of UTIs prediction models across different studies. Among the seven included studies, six studies reported the outcomes of seven UTI prediction models [32–37] while one study only reported the outcomes in IAD. The **sensitivities** (recall or true positive rate) of UTI prediction

models varied significantly, ranging from 65.2% to 91% (mean sensitivity = 80.6%, SD = 9.4). This variation suggests that while some models are highly effective in identifying UTIs, others need refinement. The **precision** (positive predictive value) of these models also showed substantial variability, from 63.5% to 86% (mean precision = 75.4%, SD = 8.1). These metrics indicate a moderate to high capability of the models to correctly identify true positives, but with room for improvement in reducing false positives. **Specificity,** or the true negative rate, varied from 70.9% to 88%, with a mean specificity of 79.5%. This indicates that the models were generally effective in correctly identifying individuals who did not have UTIs, though there is some variability in performance across different studies. Overall, Li, Rezvani, et al.s'[37] attention-based, deep learning model and Ramazi et al.s'[32] deep learning model achieved the highest sensitivity (91%) in UTI prediction, while Li, Kolanko, et al.s'[37] semi-supervised (DNN+ probabilistic) model attained the highest precision (86%). Both Capstick et al.s'[34] risk stratified machine learning model and Enshaeifar et al.[35] supervised (NMF & iForest) model achieved the highest specificity (88%) in correctly identifying patients without UTIs. Additional data included a 5.1% alert rate from Bijlani et al.[33]when their model was evaluated for UTIs and hospitalization. The RTLS program also reported a high sensitivity and high specificity model (sensitivity range = 0.88-0.91; specificity range = 0.71-0.88) for predicting falls, delirium, and UTIs.[32] In contrast, the Smart Diaper System showed a sensitivity of 32.8% in detecting urine voiding. Overall, the UTI prediction models reported in the TIHM and RTLS study outperformed the Smart Diaper System while exhibiting higher sensitivity, specificity, and precision, alongside a low alert rate in UTI predictions.

Discussion

This scoping review identified seven studies exploring digital interventions aimed at managing or preventing UTIs in persons living with dementia and their caregivers. The review's objectives were to categorize the types of digital interventions and devices used and to summarize the outcome variables and key findings regarding UTI prevention and management in this population. Our main findings were as follow. First, only three digital interventions were identified among the seven studies, all of which centered on sensor-based research primarily aimed at detecting occurrences of UTIs. Additionally, 86% (n=6) of the studies incorporated AI algorithms, primarily utilizing sensory data collected via the IoT or sensor devices integrated with AI algorithms. Second, the outcome variables from the three interventions were categorized into two types: environmental data and physiological data. And third, we summarized the outcomes and key findings of seven UTI detection models reported across the studies, comparing them based on their sensitivity, specificity, and precision.

The TIHM for Dementia Care of Care employed a comprehensive array of sensors, including PIR sensors, motion sensors, and pressure sensors, to collect extensive environmental and physiological data. This multi-sensor approach allowed for a robust monitoring system that could identify subtle changes in the participants' health status. On the other hand, the RTLS intervention utilized wrist-worn tags to monitor motor behavior through location tracking. This approach, while more focused, was effective in predicting falls and delirium. The Smart Diaper System, in contrast, used conductor sensor devices within a diaper to measure urine flow and frequency, aiming to detect incontinence-associated dermatitis (IAD) and bed sores, which are conditions that may predispose patients to urinary tract infections (UTIs). The contrast between these methods highlights the trade-off between breadth of data collection and focus on specific

health indicators. While the TIHM system provides a wide-ranging overview of various health parameters, the RTLS and Smart Diaper System focus on specific behaviors and conditions, respectively. Future research could explore combining these approaches to enhance overall monitoring accuracy, integrating broad environmental and physiological monitoring with targeted behavioral and condition-specific tracking.

While TIHM, RTLS, and Smart Diaper System employed various technological components such as sensors, conductors, WIFI/Bluetooth devices, and wearable devices, they shared two common features: 1) all interventions incorporated sensor-based technology while 80% of the interventions were incorporated with AI algorithms, and 2) their primary objective was early detection of UTIs in persons living with dementia. The features of sensor-dominant technological interventions observed in our study were unexpected and did not entirely align with existing digital interventions for other populations challenged with UTIs. For instance, Vellinga et al.[38] developed a smartphone diary app to help users record their UTI symptoms using the concept of an electronic diary. While the app demonstrated an efficient and acceptable means of collecting data on the natural course of UTIs,[38] it primarily included symptom tracking without providing UTIs preventive knowledge. The app's primary user base consisted of young women with a mean age of 29.7 (SD 14). Similarly, Le et al. [39] in 2021 introduced two digital knowledge translation tools aimed at helping parents of children with urinary tract infections. These tools proved to be useful mediums for sharing health information, with their users having a mean age of approximately 40 (SD 13).[39] More recently, Pat et al.[40]developed a telemedicine tool, myRUTIcoach, aimed at providing knowledge on UTI preventive measures. This digital intervention successfully enhanced effectiveness and self-management among its users. However, Pat's intervention primarily targeted women with recurrent UTIs, with a mean age of

57.9 (SD 19).[40] In contrast, our study's sensor-dominant interventions target a different demographic and aim to address the specific needs of persons with dementia and their caregivers. This demographic significantly differs from those in the aforementioned studies, with a mean age of 79.9 (SD 11.2), highlighting the need for tailored digital solutions in this population.

Our findings demonstrated that sensor technology is increasingly employed in predicting diseases and analyzing symptoms. This observation is consistent with several studies on digital interventions that integrate sensors, the IoT, and AI algorithms. For example, in the field of cardiovascular diseases, IoT and AI have been used to analyze real-time sensor data, helping in the early detection and management of heart conditions.[41,42] Similar applications are found in the management of diabetes, where continuous monitoring and predictive analytics improve patient outcomes.[43–45] Additionally, sensor technology is also used in predicting falls, delirium, agitation, and cognitive status in people with dementia.[44,46,47] This alignment highlights the growing role of sensor-based interventions in healthcare research.

We reported two types of outcome variables in this review. **Environmental data** refers to information collected from sensor-based systems, smart home devices, or IoT technologies; this includes data from various sensor devices such as infra-red (PIR) sensors, motion sensors, location sensors, pressure sensors, door sensors, smart plugs, and central energy consumption monitoring devices.[32–37] **Physiological data** encompasses measurable biological information that reflects the functioning of the body's systems, collected via wearable, Bluetooth, or WiFi-enabled medical devices, or current flow sensor device. Common physiological data include blood pressure, heart rate, body temperature, weight, hydration readings, urine volume, and frequency.[22,32–37] The integration of these types of data in digital interventions for UTIs detection

and management is significant. Environmental data, such as activity patterns and motor behaviors, can provide early indicators of health issues, including UTIs, by highlighting deviations from normal behavior.[48,49] Physiological data offers direct measures of the body's response to potential infections, such as changes in vital signs or urine characteristics, which are crucial for timely and accurate diagnosis.[7] These findings feature the potential of digital interventions in enhancing UTIs screening and monitoring in demented populations.

Finally, seven UTI prediction models were collated over the six studies (*Figure 3.3.*) in regard to their sensitivity, specificity, and precision of UTI detection. In studies regarding TIHM and RTLS interventions, the UTI prediction models demonstrated average levels of 80.6% sensitivity, 79.5% specificity, and 75.4% precision. These interventions provided practical digital solutions for: 1) effective early detection of UTIs events with minimized the false alarm and higher accuracy; 2) and identification of changes in daily activity patterns in persons living with dementia; 3) alerting clinicians and caregivers and enhanced screening when considering treatment. A retrospective study developed an early warning model for UTIs in patients with neurogenic lower urinary tract dysfunction, demonstrating good discrimination ability and consistency, with lower sensitivity (62.5%), but higher specificity (100%), and accuracy (90%).[50] Another literature review published in 2022 summarized the use of AI algorithms in UTI diagnosis among all age groups, providing an overview of various AI models in UTI diagnostics.[51] The average sensitivity and specificity reported in their study were 84.2% and 82.6%, respectively. Although both studies presented slightly higher specificity, sensitivity, and accuracy in their UTI detection models, they relied on clinical data and biomarkers, which are more intrusive and require clinical settings with healthcare provider involvement. In contrast, our

included studies utilize home-setting, non-intrusive sensor technology which might be able to provide safe and effective care for persons with dementia and their caregivers.

Limitations in Study characteristics and Research Biases

The inclusion of a limited number of studies highlights several gaps and limitations in this review. As presented in the results and depicted in Figure 2, all the included studies were observational, focusing on PLWD. Furthermore, 72% of these studies were home-based and conducted in the United Kingdom. The **small number of studies** included in this review (less than 10) significantly restricts the ability to draw comprehensive and generalizable conclusions. This limited sample size points to a need for more research in this area to establish a robust evidence base. The **predominance of observational studies** poses a limitation in terms of the strength of evidence. This finding aligns with a systematic review published in 2019, which evaluated the current state of home-based digital biomarker technologies for monitoring cognitive functions in individuals with cognitive impairment and Alzheimer's disease.[52] That review similarly noted that all 26 included studies were observational and took place at home with community-dwelling older adults. Observational studies can indicate associations but are less capable of establishing causality due to potential confounding factors.[53] This reliance on observational data underscores the necessity for more rigorous study designs, such as randomized controlled trials (RCTs), which can provide stronger causal inferences in UTI prevention and management.[53] Conducting RCTs in this domain would offer more definitive guidance on strategies for preventing UTIs and managing dementia-related challenges, thereby benefiting both persons with dementia and their caregivers. Moreover, with 72% of the studies conducted in the United Kingdom, there is a clear **geographical bias**. This regional concentration limits the generalizability of the findings to other countries with different

healthcare systems, cultural contexts, and population demographics. Future research should aim for a more geographically diverse sample to ensure the findings are applicable across various settings. These settings might include clinical environments such as hospitals and clinics, in-home settings where patients receive care within their own residences, and long-term care facilities such as nursing homes and assisted living communities. By including participants from these varied contexts, research can better account for the different challenges, resources, and patient needs that each setting presents, ultimately leading to more comprehensive and universally applicable findings.

The gender ratio of the participant population reveals another important bias. Specifically, the studies included a total of 230 males (52.2%) and 211 females (47.8%); with one of the studies only recruited male participants. Despite this, it is well-documented that women are more commonly affected by both dementia and UTIs than men.[54] For instance, almost two-thirds of Americans with Alzheimer's are women.[55] Similarly, in the United Kingdom, 65% of the PLWD are women[56] and for patients older than 70 years old, women have a 1.5 times higher chance of developing UTIs compared to men.[57] The overrepresentation of males in our study samples introduces a **population bias**, suggesting that the findings may not be fully representative of the broader population, particularly females. Addressing this bias in future research is crucial to developing interventions that are effective across all gender groups. Moreover, it is essential to consider the perspectives and health needs of LGBTQ+ individuals, who often face unique healthcare challenges and disparities. Research has shown that LGBTQ+ populations may experience higher rates of certain health conditions, including mental health issues, which can intersect with conditions like dementia.[58] Furthermore, transgender individuals, in particular, may encounter barriers to healthcare and may have different experiences with

conditions such as UTIs due to anatomical differences and hormone therapies.[59] Including a diverse range of gender identities and sexual orientations in future studies will help ensure that findings and interventions are inclusive and applicable to the entire population, thereby enhancing the equity and effectiveness of healthcare solutions.

From a Clinical Perspective

We want to highlight two critical points from the lens of clinical care. Firstly, there is a lack of theoretical foundations of the included studies and interventions. The digital interventions in this study were solely designed with the concept of detections and predictions of the UTIs diagnosis rather than offering prevention strategies for their users. The interventions were not informed with theory, framework, or follow the UTIs protocol or guideline such as Infectious Diseases Society of America (IDSA) or European Association of Urology (EAU). While sensor-based technology plays a crucial role in the early detection and management of UTIs, offering continuous, real-time data collection for timely identification of risk factors and early signs of UTIs,[37,43] its strength lies primarily in diagnosis. However, sensor-based interventions fall short in delivering comprehensive strategies to resolve the underlying risk factors and shift outcomes in UTIs. Additionally, it lacks mechanisms to actively alleviate UTIs symptoms or promote healthy behaviors to prevent the onset of the disease. Thus, while the technology excels in diagnosis, it lacks the essential elements required for a holistic approach to UTIs management and prevention. Interventions that encompass behavioral change theory, UTIs framework, or protocols, such as educational content on hygiene practices,[18] lifestyle modifications, and behavioral interventions,[60,61] are crucial for mitigating UTIs risk factors and promoting overall urinary health in persons with dementia. For example, education campaigns can raise awareness

about the importance of hydration, proper hygiene practices, and timely voiding habits, which can significantly reduce the likelihood of UTIs occurrence.[7,11]

Secondly, caregiver involvement as users in digital interventions can significantly aid in reducing UTI occurrence in persons with dementia. PLWD often struggle with maintaining proper hygiene, recognizing the need to hydrate, and remembering to void regularly, which are critical factors in preventing UTIs.[7,11] Digital interventions that include caregivers as active participants can provide caregivers with timely reminders and instructions for these essential activities, ensuring consistent adherence to preventive measures.[46] Caregivers can improve the effective use of technology[17,60] such as monitoring and interpreting health data collected by digital tools, such as fluid intake and voiding patterns, enabling them to promptly address any irregularities. Furthermore, caregivers can implement recommended hygiene practices and make necessary lifestyle adjustments based on the insights provided by digital interventions.[62] By integrating caregiver support into digital health solutions, the management of UTIs in PLWD becomes more proactive and personalized, ultimately reducing the frequency and severity of infections.

Conclusions

This scoping review explored current digital interventions for managing and preventing UTIs in PLWD and their caregivers. Our results revealed three key aspects: the predominance of sensor-based interventions, the categorization of outcome variables into environmental and physiological data, and the comparative analysis of UTI detection models. Despite the promise shown by these digital interventions, the review identified significant gaps and limitations, including a small number of studies, observational study designs, geographical biases, and an overrepresentation of male participants.

Digital interventions in this review primarily employed sensor-based technology integrated with AI algorithms, with a focus on early UTI detection. Nevertheless, these interventions were deficient in theoretical underpinnings and preventive strategies. This highlights the necessity for comprehensive interventions that not only identify but also prevent UTIs, necessitating more active involvement of caregivers to enhance compliance with preventive measures. Future research should broaden its scope to encompass diverse geographical locations and demographics, ensuring the generalizability of findings and strengthening causal inferences through RCTs. Incorporating preventive strategies into digital interventions grounded in clinical guidelines and behavioral change theories can enhance UTI management for persons with dementia, offering comprehensive education on hygiene practices, lifestyle modifications, and proactive behavioral interventions. Active involvement of caregivers in these interventions, supported by training programs and access to real-time monitoring capabilities, can alleviate the burden on caregivers and improve their effectiveness in managing UTIs. By leveraging advanced technologies such as AI and IoT integration, continuous monitoring and early detection of UTI symptoms can be facilitated, leading to timely

interventions and improved health outcomes in both persons living with dementia and their caregivers. These developments hold promise for enhancing healthcare system efficiency and improving the quality of life for persons living with dementia and their caregivers while reducing healthcare costs associated with UTI management.

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Tables

Table 3.1. Aim, Intervention, Method, and Key Findings.

Authors/ Year	Aim	Data Source (Intervention)/ Method	Key Findings
Capstick et al., 2024	To propose a machine learning method that alerts clinicians to UTI[a] risk in subjects, enabling early detection and improved screening for treatment.	Minder Program: TIHM[b] for Dementia System of Care. Use **machine learning techniques** to calculate UTI risk and perform stratification on scores to support clinical translation and allow control over the balance between alert rate and sensitivity and specificity.	1. The proposed UTI model achieves a sensitivity of 65.3% (CI[c] 64.3–66.2) and specificity of 70.9% (CI 68.6–73.1) when predicting UTIs on unseen participants and after risk stratification, a sensitivity of 74.7% (CI 67.9–81.5) and specificity of 87.9% (CI 85.0–90.9). 2. This machine learning model alerts clinicians of UTI risks in subjects, enabling earlier detection and enhanced screening when considering treatment.
Bijlani et al., 2022	To develop an online unsupervised approach to detect UTIs and hospitalizations.	Minder Program: TIHM for Dementia System of Care Propose **CMP[d]**, an unsupervised learning–based algorithm to detect anomalies representing adverse health conditions using activity changes in people living with dementia.	1. The CMP yielded, on average, 84.3% recall with 5.1% alert rate, offering the best balance of recall and relative precision when evaluated for UTIs and hospitalization. 2. This study proposed a high sensitivity and low alert rate model to detect anomalies and anomaly biomarkers in people living with dementia.
Ramazi et al., 2022	To develop and test how motor behaviors, delivered from location and movement sensor tracking data, may be associated with falls, delirium, and UTIs.	Real-time locating system Utilize **real time location system** data and **DL[e] techniques** (which are a family of advanced machine learning methods) to classify motor behaviors among LTC[e] residents with cognitive impairment or dementia for up to 18 months.	1. Motor behavior classifications were sensitive and specific to falls, delirium, and UTI predictions 1 week before the week of the event (UTI sensitivity = 0.91 (SD[f] 0.09); specificity range =0.71 (SD 0.04); precision = 0.76 (SD 0.04)). 2. Study findings suggest that falls have behavioral precursors that may be used to identify those in need of more timely exercise interventions. Study findings also support the idea that UTIs and delirium may be identified sooner in LTC through an objective study of changes in motor behaviors, which may improve treatment outcomes in this vulnerable population.

Table 3.1. Aim, Intervention, Method, and Key Findings.

Authors/ Year	Aim	Data Source (Intervention)/ Method	Key Findings
Cho et al., 2021	To evaluate the applicability of the smart diaper system for urinary detection, and its effect on IAD[g] occurrences in an acute care hospital.	Smart Diaper System The diaper has an absorbent liner inside and conductive lines on the outside connected to a sensor. When urine is absorbed, it increases electrical flow between the lines, allowing the sensor to detect and measure the amount of urine. This data is sent to a smartphone via Bluetooth. If the urine volume below/exceeds set limits (50 mL to 500 mL in this study), a caregiver is notified through a dedicated app. No algorithm reported.	1. The smart diaper system's voiding detection rate was lower than expected at 32.8%. However, it still promptly notifies caregivers of urination, aiding in timely diaper changes to prevent or improve incontinence-related issues like IAD and bed sores. 2. The smart diaper system functions effectively with researchers' assistance, but older caregivers may find it challenging to learn to use the system within the study's short three-day period.
Li, Rezvani, et al., 2021	To propose an attention model by using environmental sensors to predict incidents of UTI events and agitation in people with dementia.	Minder Program: TIHM for Dementia System of Care. Introduce an **attention-based**, **DL model** that can identify the important time steps and features and utilize long-distance dependencies to make better predictions. The proposed model provides a prediction based on the selected time points and the selected features from the raw observation and measurement data.	1. The proposed model provides a recall of 91% and precision of 83% in detecting the risk of agitation and UTIs. 2. This model can be used for early detection of conditions such as UTIs and managing of neuropsychiatric symptoms such as agitation in association with initial treatment and early intervention approaches.
Li, Kolanko, et al., 2020	To propose a semi-supervised model to make predictions of UTIs in dementia.	Minder Program: TIHM for Dementia System of Care Utilize a semi-supervised model (adaptive **DNN**[h] algorithms and **supervised probabilistic models**) that continuously learn from routinely collected in-home observation and measurement data. This model can process highly imbalanced and dynamic data to make robust predictions in analyzing the risk of UTIs in dementia.	1. The proposed model (semi-supervised model) achieves 85% recall with 86% precision. It proves that this model performs better than other existing models on detecting UTIs events.

Table 3.1. Aim, Intervention, Method, and Key Findings.

Authors/ Year	Aim	Data Source (Intervention) /Method	Key Findings
Enshaeifar et al., 2019	To propose an unsupervised algorithm to detect UTI occurrence from environmental data and physiological data collected via in-home sensory devices.	Minder Program: TIHM for Dementia System of Care. Develop algorithms (**NMF[i] & iForest[j]**) to detect UTIs: 1) extract latent factors from raw observation and use them for clustering and identifying the possible UTI cases. 2) detect changes in activity patterns to identify early symptoms of cognitive decline or health decline in participants.	1. The unsupervised machine learning model (NMF) is 10% more effective than the baseline model (SVM[k]), reducing false positive alerts for UTIs; the iForest presents 85% sensitivity to night-time activity. 3. This study proposed algorithms that enables: 1) early detection of UTIs; 2) identification of changes in daily activity patterns in people living with dementia.

Note:
[a]UTIs: urinary tract infections.
[b]TIHM: Technology Integrated Health Management.
cCI: Confidence Interval.
[d]CMP: Contextual Matrix Profile.
[e]DL: Deep Learning.
[e]LTC: Long term care.
[f]SD: standard deviation.
[g]IAD: incontinence-associated dermatitis.
[h]DNN: Deep Neural Network.
[i]NMF: Non-negative Matrix Factorization.
[j]iForest: Isolation Forest.
[k]SVM: Support Vector Machine.

Table 3.2. Intervention name, description, outcome variables, dosage, and technological devices involved in the intervention.

Name	Description	Outcome Variables	Dosage	Types of Technological devices
Technology Integrated Health Management (TIHM) [33–37]	A digital platform routinely collects longitudinal, observational, and measurement data, within the home and apply machine learning and analytical models for the detection and prediction of adverse health events affecting the well-being of persons living of dementia.	• Environment data from sensors • Physiological data (blood pressure, heart rate, body temperature, weight, hydration reading, urine samples)	-24/7* -Twice a day	• Sensor devices (infra-red (PIR) sensors, motion sensors, pressure sensors, door sensor, central energy consumption monitoring device) • Blue-tooth enabled medical devices (physiological monitoring devices that are used for submitting daily measurements of vital signs, weight and hydration) • Smart power plugs
Real time locating system (RTLS) [32]	A system which uses real-time data from technology consists of a wrist-worn tag (required for tracking multiple residents) and ceiling-mounted sensors to triangulate location in and around a unit and provide x, y, and z coordinates.	• Motor behaviors (location coordinates x, y, z)	-24/7*	• Wrist-worn tracking tag • Location sensor (ceiling-mounted)
Smart Diaper System [22]	A smart system that integrates a sensor-equipped diaper with a mobile app. The diaper collects urinary data, uploads the information to the app, and notifies caregivers.	• Urine record (volume& frequency) • Accuracy of urine output assessment, • Occurrence of IAD • User experience	-24/7* -24/7* -Once per Day	• Diaper with conductors • Sensor devices (current flow and pressure) • Smartphone with app

Note: 24/7*: 24 hours a day, 7 days a week; IAD: incontinence-associated dermatitis.

Figures

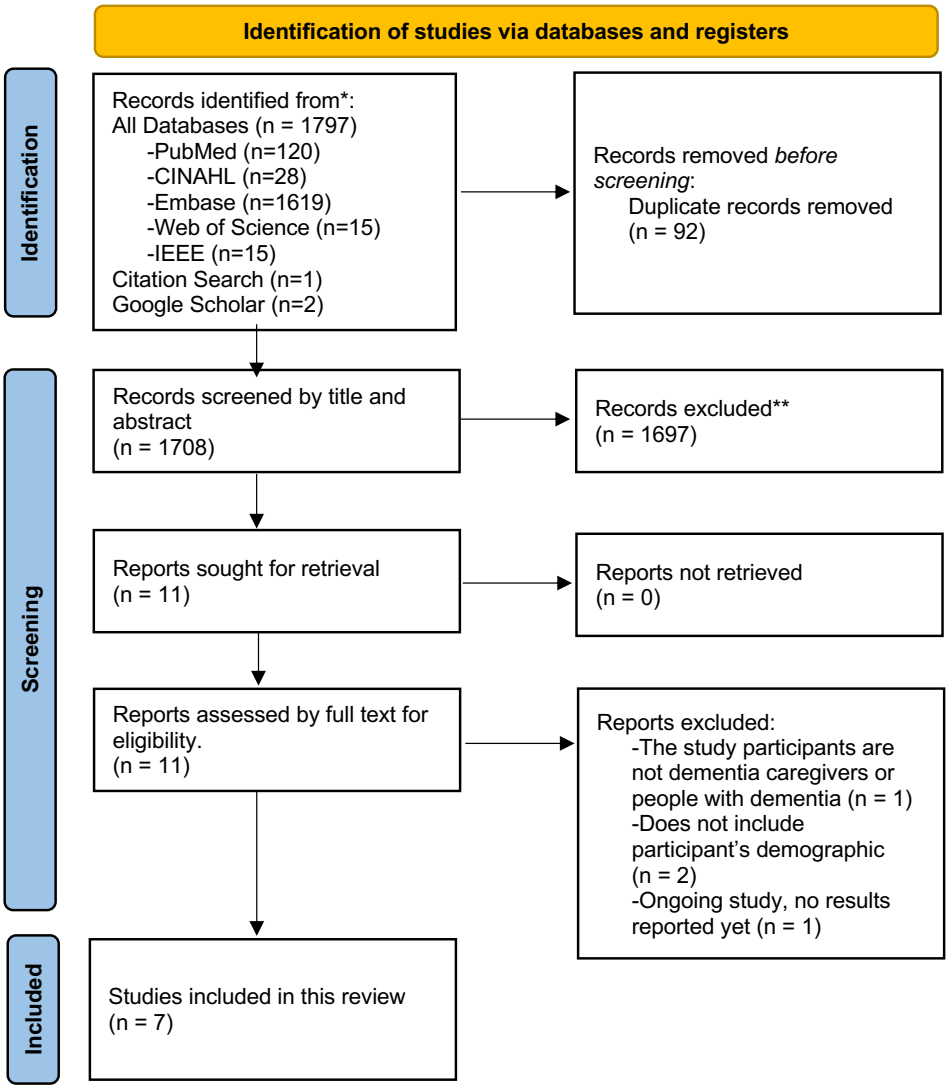

Figure 3.1. Prisma-ScR flow chart. The PRISMA-Scr (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) flow chart describes the process of selecting studies for inclusion in this scoping review.

Study						Participant			Intervention		
#	Year	Authors	Country	Design	Sample Size	Mean Age (SD)		Users	Program	settings	Duration (Days)
1	2024	Capstick et al.		Observational	117	83.5 (5.9)	52% 48%	Dementia & MCI	Minder (TIHM)	Home	238
2	2022	Bijlani et al.		Observational	15	84.0 (6.1)	47% 53%	Dementia	Minder (TIHM)	Home	624
3	2022	Ramazi et al.		Longitudinal Observational	23	79.9 (11.2)	100% 0%	Dementia	RTLS	LTC	540
4	2021	Cho et al.		Prospective Observational Pilot	35	81.5 (7.6)	52% 48%	Dementia & Caregiver	Smart Diaper System	Hospital ward	4
5	2021	Li, Rezvani, et al.		Observational	88	82.0 (6.5)	53% 47%	Dementia	Minder (TIHM)	Home	180
6	2020	Li, Kolanko, et al.		Observational	110	83.0 (6.0)	54% 46%	Dementia	Minder (TIHM)	Home	3864
7	2019	Enshaeifar et al.		Observational	53	81.1 (6.1)	30% 70%	Dementia	Minder (TIHM)	Home	180

Note: MCI: mild cognitive impairment; TIHM: Technology Integrated Health Management; RTLS: Real-time locating system; LTC: long-term care.

Figure 2. Characteristics of the included studies, participants, and interventions

Figure 3.2. Characteristics of the included studies, participants, and intervention.

The figure provides detailed information for each study, including the sample characteristics of the participants and the intervention details.

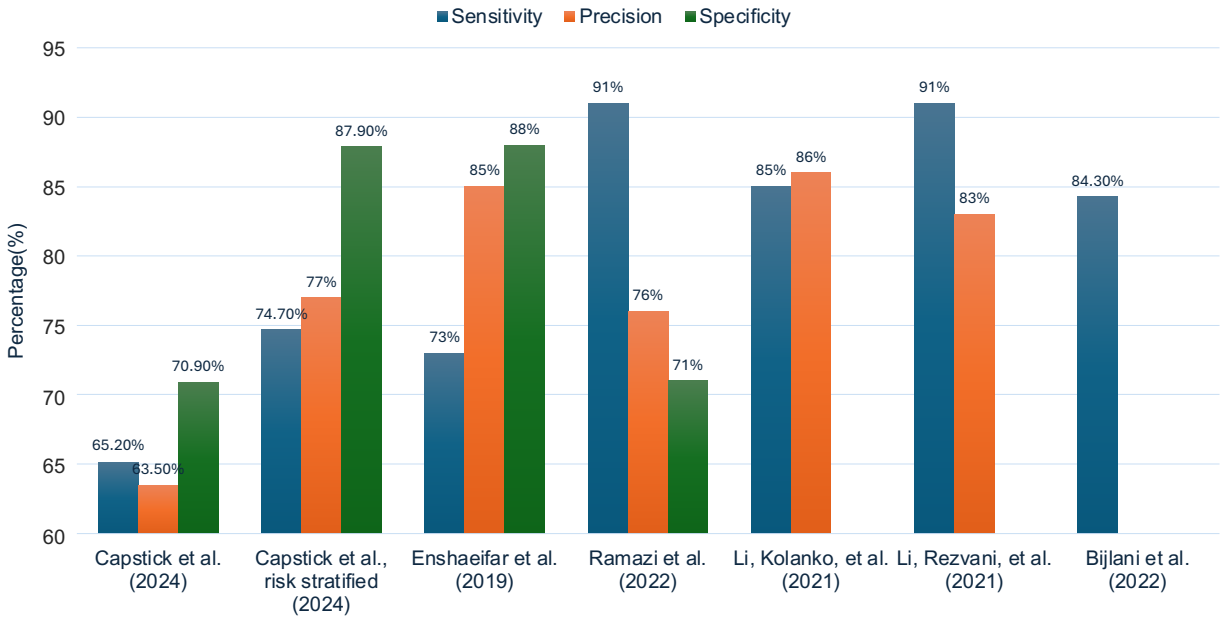

Figure 3.3. Outcomes of UTI prediction models across studies. This bar chart presents the sensitivity, precision, and specificity percentages reported in included studies in this review. These studies evaluated different AI models or algorithms for the clinical prediction of urinary tract infection (UTI) occurrence, emphasizing their performance metrics.

Appendix

Multimedia Appendix 3.1. Search Terms

PubMed

("Mobile Applications"[Mesh] OR "Computers, Handheld"[Mesh] OR "Internet"[Mesh] OR "Telemedicine"[Mesh] OR "Internet-Based Intervention"[MeSH] OR "Self-Help Groups"[Mesh] OR "Social Media"[Mesh] OR social media OR smartphone OR telehealth OR telemedicine OR health app OR mHealth OR eHealth OR eMedicine OR internet-based intervention OR web-based intervention OR online intervention OR computer OR internet OR "app based" OR “self help group” OR “support group”) AND (UTI OR urinary tract infection OR bacteriuria OR "Urinary Tract Infections"[Mesh]) AND ("Aged"[Mesh] OR "older adults" OR "elderly" OR "geriatric" OR "aging") ("Brain Diseases"[Mesh] OR "Neurocognitive Disorders"[Mesh] OR dementia OR cognitive impairment OR Alzheimer's OR brain disease OR cognitive disorder OR cognition disorder)

IEEE

(social media OR smartphone OR telehealth OR telemedicine OR health app OR mHealth OR eHealth OR eMedicine OR internet-based intervention OR web-based intervention OR online intervention OR computer OR internet OR "app based" OR “self help group” OR “support group”) AND (UTI OR urinary tract infection OR bacteriuria) AND (aging OR older adults OR elderly OR aged OR geriatric OR senior)

CINAHL

(MH "Mobile Applications" OR MH "Computers, Hand-Held+" OR MH "Internet-Based Intervention" OR MH "Internet+" OR MH "Telemedicine+" OR MH "Social Media+" OR social media OR smartphone OR telehealth OR telemedicine OR health app OR mHealth OR eHealth

OR eMedicine OR internet-based intervention OR web-based intervention OR online intervention OR computer OR internet OR "app based") AND (MH "Urinary Tract Infections+" OR UTI OR urinary tract infection OR bacteriuria) AND (MH "Brain Diseases+" OR MH "Cognition Disorders+" OR MH "Delirium, Dementia, Amnestic, Cognitive Disorders+" OR dementia OR cognitive impairment OR Alzheimer's OR brain disease OR cognitive disorder)

Embase

('mobile application'/exp OR 'mobile phone'/exp OR 'web-based intervention'/exp OR 'Internet'/exp OR 'telehealth'/exp OR 'social media'/exp OR smartphone OR telehealth OR telemedicine OR health app OR mHealth OR eHealth OR eMedicine OR ‘internet-based intervention’ OR ‘web-based intervention’ OR ‘online intervention’ OR computer OR internet OR ‘app based’) AND ('urinary tract infection'/exp OR UTI OR ‘urinary tract infection’ OR bacteriuria) AND ('brain disease'/exp OR 'cognitive defect'/exp OR 'dementia'/exp OR dementia OR ‘cognitive impairment’ OR Alzheimer OR ‘brain disease’ OR ‘cognitive disorder’)

Web of Science

(smartphone OR telehealth OR telemedicine OR health app OR mHealth OR eHealth OR eMedicine OR internet-based intervention OR web-based intervention OR online intervention OR computer OR internet OR "app based") AND (UTI OR urinary tract infection OR bacteriuria) AND (aging OR older adults OR elderly OR aged OR geriatric OR senior)

Chapter 4. Assessing Caregiver Needs and Requirements in Digital Solutions for UTI Prevention and Management in Dementia Care

Abstract

Background: Family caregivers (FCGs) of persons living with dementia (PLWD) face significant challenges in managing urinary tract infections (UTIs) in their care recipients. These challenges indicate the need for digital health interventions tailored to the specific requirements of FCGs.

Objectives: To systematically identify user contexts, needs and requirements to create digital tools for FCGs of PLWD.

Methods: Eleven dementia caregivers participated in the semi-structured interviews during December 1, 2023, to June 26, 2024. Caregivers were invited to share their experiences regarding UTI care in PLWD and their perspectives regarding digital solutions. The interview data were recorded, transcribed, and analyzed following the six-step inductive coding framework proposed by Braun and Clarke.

Results: The interviews revealed four main themes: 1) identified UTI signs and symptoms in PLWD; 2) comprehensive approach to UTI management in routine care for PLWD; 3) challenges in caregiving and leveraging digital technology for enhanced health management in PLWD; and 4) key design considerations for personalized digital solutions: integrating user requirements, tech preferences, and engagement strategies. These themes informed the design considerations of user context, challenges, needs, and requirements in digital solution.

Conclusion: This study provided insights from dementia caregivers and gathered the foundation for future phases of intervention development utilizing HCD principles to improve UTI care

quality in PLWD. Ultimately, this approach seeks to empower caregivers to better manage UTI prevention and care for PLWD, and to improve the quality of life for both caregivers and PLWD.

Introduction

Urinary tract infections (UTIs) are one of the most common causes of preventable hospitalizations in this population for older persons living with dementia (PLWD).[1,2] People with dementia were 3.4 fold more likely to be admitted to the hospital for urinary tract infection than patients without dementia.[3] Hospitalization due to UTIs can lead to a range of negative outcomes, including increased cognitive decline, delirium, and a higher risk of mortality.[1,4] For dementia caregivers, these hospitalizations not only disrupt the continuity of care but also exacerbate the emotional and physical burden of caregiving.[5,6] The stress of managing a loved one's health crisis, combined with the challenges of navigating the healthcare system, can lead to caregiver burnout, social isolation, and a decline in their overall well-being.[7,8]

Dementia caregivers often face significant challenges caring for PLWD with UTI.[9–11] UTIs can provoke delirium in PLWD, leading to behavioral changes or cognitive decline such as agitation, increased confusion, or withdrawal symptoms.[10,11] Other physiological symptoms in this population include dysuria, fever, suprapubic pain, gross hematuria, costovertebral angle tenderness, and new or worsening urgency or urinary incontinence.[4,11] As UTIs progress, they may exacerbate the progression of dementia and increase the likelihood of hospitalization. Moreover, people with moderate- and late-stage dementia may struggle to communicate their symptoms,[12] leading to more severe UTI complications, such as renal failure or septic shock.[13] These challenges create additional caregiving burdens and result in harmful outcomes, higher societal costs, and financial strain on both PLWD and their caregivers. [2,14–16] Therefore, efforts should be made to avoid unnecessary hospitalizations, prevent future admissions, and promote the well-being of PLWD and their family caregivers.

Current digital technologies, such as smartphone applications, sensor-based technology, wearable devices, and telehealth platforms,[17,18] have the potential to provide UTI detection, monitoring, and adherence to preventive measures and treatment regimens.[19–22] However, there are significant gaps in current digital solutions for UTI management in PLWD. First, digital solutions reported in current literature rely heavily on sensor-based technologies and AI algorithms designed for early UTI detection.[18] Second, these digital solutions mainly focus on the technical aspects, such as tracking movements and monitoring vital signs, without incorporating infection preventive strategies or caregiver involvement.[18,23] Last, these solutions lack a solid theoretical foundation,[24] making them less effective in addressing the broader context of caregiving. These gaps strengthen the need of a holistic approach that integrates clinical guidelines and considers the caregiver's role in developing UTI management digital interventions for PLWD.

This study aimed to address existing gaps by establishing a list of design considerations of digital solutions focused on the user needs and requirements of family caregivers (FCGs) of PLWD. We adopted the initial two phases of a human-centered design (HCD) framework to develop digital solutions for UTI management in PLWD. The HCD framework, as defined in DIN EN ISO 9241-210, involves four key activity phases: 1) understanding user needs and context; 2) specifying user requirements; 3) producing design solutions; and 4) evaluating designs against requirements. These phases are conducted iteratively, as shown earlier in *Figure 1.1.*,[25] until specific usability objectives are met. HCD emphasizes understanding the needs, experiences, and challenges of the end users—in this case, dementia caregivers—throughout the design process. By involving caregivers in the development of these tools, we can create solutions that are not only technically robust but also intuitive, practical, and aligned with the

realities of caregiving. This approach ensures that digital interventions are user-friendly, accessible, and tailored to the specific context of caregiving, ultimately leading to better health outcomes for PLWD and reducing the burden on caregivers. Understanding caregivers' needs and use of context, requirements, and preferences in technology, is crucial for developing effective digital interventions that can significantly enhance the quality of care and improve the overall well-being of both caregivers and PLWD.

Methods

Study Design

This study used a qualitative research approach, conducting semi-structured interviews via Zoom to explore dementia caregivers' perspectives on using digital tools for preventing and managing UTIs in dementia care. The study received the Institutional Review Board (IRB) exempt approval from University of Washington Human Subject Division (HSD) under ID: STUDY00017259. The research follows the first two phases of the HCD process, as defined in DIN EN ISO 9241-210: understanding user needs and specifying user requirements for designing digital interventions that assist caregivers in managing UTIs in PLWD.

Setting

The study was conducted at the University of Washington, School of Nursing. The interviews took place online using Zoom videoconferencing. Dementia caregivers participated from their home settings, both due to their preference for a familiar environment and because they were unable to leave their homes while caring for their family members.

Participants

Participants in this study were family caregivers of people with moderate to severe dementia. They were recruited from caregiver support groups, online forums, and community

organizations. The inclusion criteria required participants to be family caregivers: 1) age 18 or older; 2) be the primary family caregiver for at least six months to a PLWD at stage 2 or 3 on the Clinical Dementia Rating Scale[26] (CDR) or with a Mini-Mental State Examination[27] (MMSE) score less than 20; 3) have experience in caring for PLWD with UTIs; 4) have experience with digital health tools; and 5) with internet access. Participants would be excluded for: 1) a major psychiatric diagnose; and 2) initiation of any psychological treatment within the previous 3 months; 3) unable to provide informed consent. Initial contact was made via email, where potential participants were provided with detailed information about the study and invited to participate. Eleven participants were chosen based on their willingness and availability. As a token of appreciation for their time, each participant received a $10 Amazon gift card via email, sent one week after completing the interview.

Data Collection Procedures

The researcher recruited promising participants through the Alzheimer's Disease Research Center (ADRC) caregiver support groups, online forums, and community organizations (e.g., senior centers) and used snowball sampling with participated caregivers. Participant were contacted with phone calls or emails to assess their eligibility based on predefined inclusion and exclusion criteria. Caregivers who met the criteria were invited to participate in an hour-long online interview via Zoom, a Health Insurance Portability and Accountability Act (HIPAA) compliant platform provided by the University of Washington. Prior to the scheduled interview, eligible participants received detailed email instructions, including potential questions and topics to be discussed, along with the Zoom meeting invitation, one week in advance.

Participants provided informed consent electronically and completed a series of demographic surveys via the Research Electronic Data Capture (REDCap) system. The

interviewer (KCW) then re-introduced the study's purpose and addressed any participant concerns. Upon obtaining permission to record the session, the interviewer proceeded with the interview, guided by eight topic areas (see Appendix A): (1) caregiver background, (2) caregiving experiences and challenges, (3) current UTI care practices, (4) attitudes toward technology and accessibility, (5) specific user needs and requirements, (6) engagement and motivation, (7) support and communication, and (8) data privacy and security concerns.

The interview contents were recorded and automatically transcribed by Zoom's audio transcription service. This system generates transcripts with timestamps and organizes the text into sections. The researcher (KCW) manually reviewed and edited the transcripts to ensure accuracy by correcting any discrepancies, such as misheard words, and adding appropriate capitalization and punctuation. Transcripts were stored securely on a cloud storage service provided by the University of Washington.

Data Analysis

The qualitative data analysis followed the six-step inductive coding framework proposed by Braun and Clarke: (1) familiarizing with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report.[28]

Inductive thematic coding was chosen as the primary analytical approach for this study due to its suitability for uncovering patterns, themes, and insights directly from the data.[28–30] This method aligns with the study’s objective of assessing caregiver needs and requirements in digital solutions for UTI prevention and management in dementia care. Inductive analysis allows for a data-driven exploration of participants' experiences, ensuring that the themes and categories identified are grounded in the caregivers’ own narratives, rather than being imposed by pre-

existing theoretical frameworks. This approach facilitates a more nuanced understanding of the diverse challenges and preferences that caregivers face, ultimately guiding the development of user-centered digital interventions.

Transcripts were imported into the ATLAS.ti software to aid the analysis process (ATLAS.ti 7 Windows). To ensure rigors in the coding, two independent coders (KCW and CST) initially coded the same transcript independently to identify key themes and categories. The two coders then integrated their coded transcripts and utilized ATLAS.ti to calculate the **inter-coder agreement (ICA)**. The **Krippendorff's alpha coefficient** from ICA yielded a high-reliability score of **0.942**, indicating substantial agreement between the coders. After the initial coding, two coders individually coded the remaining transcripts. The text was independently coded by CST and KCW into categories and were later exported into Excel spreadsheet to be further broken down into subcategories based on the depth of the responses. The two coders then analyzed the codes and categories to identify key themes based on their interpretations. The themes were later named and defined to finalize the results and condensed into a list of design considerations, focusing on user needs, context, and requirements.

Data Accuracy and Review Process

To ensure data accuracy, a third researcher (OZ) reviewed the audio before transcription to ensure there were no instances of leading questions or bias in the interviewer's approach. All interviewed contents were automatically transcribed using Zoom's cloud-based audio transcription service, which generates a separate VTT file for each recorded session. These transcripts include timestamps and can be edited to improve accuracy. After the transcription, KCW manually reviewed all the transcripts to correct any errors in the automatic transcription and to ensure the accuracy of the participants' responses.

Elaboration Process

During the interviews, caregivers were encouraged to elaborate on their responses when needed. The interviewer used techniques such as repeating caregiver's responses or asking follow-up questions to prompt further clarification. This approach ensured a thorough exploration of participants' perspectives, enriching the data collected.

Data Consistency and Trustworthiness

To ensure the consistency and trustworthiness of the data, two coders (CST and KCW) met weekly to discuss the codes, resolve any differences in interpretation, and continued to refine the codebook as new themes surfaced in the data. A third experienced qualitative researcher (OZ) was consulted regularly to get an outside perspective and feedback to validate the analysis. Throughout the project, we kept detailed records of our research decisions and analytical process, ensuring transparency and rigor in the analysis.

Results

Participant Characteristics

Eleven interviews were conducted through December 1, 2023, to June 26, 2024, with each session lasting approximately 60-70 minutes. A total of 11 dementia caregivers for persons with moderate to severe dementia participated in online surveys and interviews. Of these, 36% (n=4) were female, and 64% (n=7) were male. Participants' ages ranged from 42 to 82 years, with a mean age of 68.74 years (SD = 11.41). The majority of participants were White (55%, n=6), retired (82%, n=9), and well-educated, with 90% (n=10) holding a bachelor's degree or higher. Spousal caregivers accounted for 64% (n=7) of the sample. Most caregivers (45%, n=5) had 3-5 years of experience caring for persons with dementia, and 60% spent 40 or more hours per week providing care. Additionally, 80% of the care recipients were at the moderate stage of dementia. Further demographic details and sample characteristics are presented in *Table 4.1.* and *Table 4.2.*

Overview of Themes

Four major themes were determined: 1) Identified UTI Signs and Symptoms in PLWD; 2) Comprehensive Approach to UTI Management in Routine Care for PLWD; 3) Challenges in caregiving and leveraging digital technology for enhanced health management in PLWD; 4) Key Design Considerations for Personalized Digital Solutions: Integrating User Requirements, Tech Preferences, and Engagement Strategies. Each main theme includes three to four subthemes and each subthemes contain two to seven codes that characterize the experiences and perspectives of caregivers in managing UTIs in PLWD. The identified themes provide insights into both the

signs and symptoms of UTIs and the challenges and opportunities for improving care through digital technology. Below, we summarize the key findings from the thematic analysis.

Identified UTI Signs and Symptoms in PLWD

Caregivers reported various signs and symptoms that alerted them to potential UTIs in PLWD. These were grouped into three primary subthemes:

Behavior Changes. Caregivers frequently observed sudden shifts in the behavior of PLWD, including ***abnormal or unusual behaviors*** (e.g., being repetitive or acting strangely) and displaying ***disruptive behaviors*** such as yelling or becoming aggressive. For example, one participant described the unusual behavior of PLWD: "And she had a UTI... she was sort of acting a little strange" (U01). Another participant mentioned disruptive behaviors: "He's being a little bit more repetitive than usual or yelling out and being aggressive" (U03). These behavioral changes were often the first indicators of a possible UTI.

Cognitive Changes and Psychotic Episodes. Over half of the caregivers (55%, n=6) reported that ***cognitive decline***, episodes of ***confusion or delirium***, and several ***psychotic episodes*** often coincided with UTI onset, suggesting a relationship between UTIs and worsening dementia symptoms in PLWD. For instance, a caregiver noticed confusion as the main sign of a UTI in PLWD, "You know, he was, just not understanding quite what was going on around him, and unable to make his body move. It's not quite like himself, and he'd been definitely more confused, much more confusing usual. And that was the main sign" (U04). These cognitive and psychotic symptoms often prompted caregivers to seek medical attention for potential UTIs.

Physical Symptoms. Common physical indicators included ***fever, changes in urine odor or color, and increased frequency of urination,*** and ***pain and discomfort in urination***. One

caregiver explained how frequent urination and a burning sensation impacted the PLWD: "Normally, it's the burning sensation during urination that bothers her. It's a problem. So far, her only symptoms are peeing frequently and also the burning sensation" (U09). Two other caregivers shared observations about increased body temperature and changes in urine color in PLWD: "And if the temperature is high, you can't prevent it. The only thing is that when you find a fever, you know that he is infected" (U09), and "As far as cloudiness and all that, you're supposed to look for it" (U04). Most caregivers agreed that physical symptoms like these were often clear indications of a developing UTI in their care recipients.

Comprehensive Approaches to UTI Management in Routine Care for PLWD

Caregivers of PLWD face multiple responsibilities in managing general health and preventing complications such as UTIs. Their approach involves both routine care and specific actions aimed at UTI management, often supported by tools, resources, and a range of supports and communication methods. Below are four identified subthemes that highlight these comprehensive approaches.

Routine Care. Routine care refers to the daily tasks necessary to maintain the overall health and well-being of PLWD. Caregivers described two primary codes as their caregiving routines: ***personal hygiene and care*** and ongoing ***medical and health management activities***. Personal hygiene includes activities such as bathing or showering, dressing, and ensuring cleanliness in areas like oral/facial care, toilet routines, and diaper changes. For instance, one caregiver shared her mother's shower routine: "They usually do have a planned shower time for hygiene, and so that's usually twice a week. However, she often needs more than that because she might get stool from her colostomy" (U01). Medical and health management includes encouraging hydration, providing special care (e.g., ostomy care, suprapubic catheter care), and

assisting with medication and supplements. One caregiver explained how he encourages his wife to stay hydrated: “Well, I give her 8 ounces of water in a glass, five times a day” (U02). Notably, within the Personal Hygiene and Care code, body hygiene (including showering or diaper changes) and toilet routine were mentioned by 73% (n=8) of the interviewees, highlighting the importance of these tasks in routine care.

UTI Care. UTI care focuses on the strategies caregivers mentioned while managing or preventing UTIs in PLWD. This subtheme consists of four codes: ***Hygiene and Care Practices, Lifestyle and Behavioral Modifications, Medical Intervention, and Monitoring and Assessment***. Caregivers emphasized the importance of hygiene practices, such as hand hygiene, perineal care, and sterile techniques for UTI prevention. 73% (n=8) of caregivers highlighted the importance of perineal care, and 82% (n=9) stressed the value of hydration as a key preventive measure. For example, a caregiver mentioned how she maintained perineal care in PLWD: “Use the diaper and check it every 2 to 3 hours to keep the area clean, especially the urinary area” (U11). Caregivers also reported employing the lifestyle and behavior modifications to reduce PLWD’s UTI risks, such as using cranberry supplements, promoting exercise, and ensuring hydration. One caregiver shared how she encouraged her mom to get hydrated: “Sometimes you remind her to get hydrated. You ask her to drink something, drink water, drink milk” (U01). When UTIs occurred, caregivers commonly turned to medical interventions like antibiotics. Additionally, a caregiver mentioned how she performed monitoring and assessing by tracking urine IO (intake/output) and taing notes to detect early signs of infection in PLWD, “You have to monitor it. For example, even though he doesn't like it, you introduce him to IO every day, always write down how much he drinks and what happens” (U08). These strategies showcase the comprehensive approach caregivers take to manage UTI risks in PLWD.

Tools/Resources Used in Care Caregivers rely on various tools and resources to support their caregiving tasks. ***Technology-based tools***, such as apps for reminders, calendars, and health tracking, along with emails and smart devices (e.g., wearable devices and smart speakers) and ***online resources***, assist caregivers in managing daily routines and monitoring the health of PLWD. A caregiver mentioned how he benefited from Alexa, the smart speaker, "We have an Alexa, an echo device in every room. It reminds us to drink water and take medications" (U02), while another shared how she learned from online videos, "I love YouTube. I was trying to find out more about ostomy care, so I went online. And there are so many great Youtube videos about people their own experiences, you know, people who have their own ostomy are sharing their success, or what works and what doesn't. Those videos are really helpful" (U01). ***Traditional organizational tools*** are widely accepted in caregivers like checklists, whiteboards, and pillboxes help provide structure and improve the efficiency of caregiving tasks. A caregiver shared her experience in utilizing whiteboard: "I've several whiteboards around the house. You wanna talk about digital technology. I use whiteboards. We have one for downstairs, one for the middle room, the land, and one for upstairs, and it's just a matter of me having to erase them and put the news on it" (U07). ***Hygiene and comfort tools***, including bidet toilet seats, diapers, and flushable wipes, play an essential role in maintaining cleanliness and comfort in PLWD. Additionally, ***healthcare resources*** such as healthcare providers and medical supplies (e.g., hormone creams) are crucial in addressing more specific health needs. Notably, ***technology-based tools*** and ***online resources*** were used by 82% (n=11) of caregivers, while 55% (n=6) reported familiarity with using diapers and pads as part of their hygiene and comfort practices. These tools and resources are integral to supporting caregivers in delivering effective and efficient care to PLWD.

Supports/Communications. Supports and communications were methods and resources through which individuals receive emotional, social, or practical assistance and maintain connections with others. ***Attitudes towards support groups*** vary among caregivers; while some find them beneficial, the majority (73%, n=8) reported negative experiences: “So I used to. I started in also another group earlier on. And it wasn't as useful” (U03). ***Online support***, including digital tools like chatbots, Zoom, and online support groups, offers caregivers flexibility and access to exchange valuable information. In fact, 73% (n=8) of caregivers mentioned participating in online support groups. A caregiver described how she joined the dementia Facebook group : “We have, like Facebook groups, dementia caregiver groups, and online Zoom meetings” (U06). There were 46% of caregivers rely on ***in-person networks***, including family, friends, and local community members, to share caregiving duties and receive emotional support. Despite these resources, most caregivers (73%, n=8) still heavily depend on ***professional support***, such as healthcare providers and paid caregivers, for expert advice and caregiving assistance. Two caregivers stressed how a paid caregiver relieved their burden of care in UTI: “I have a caregiver who comes 3 days a week for 8 hours...Once I had a caregiver come in regularly. It took a lot of the stress off from of me" (U03); "We had the paid caregiver doing the cleaning that reduced the number of UTIs" (U05). Some caregivers also brought up how ***telephone-based support systems***, like helplines, provided them a quick and reliable source of guidance when needed.

Challenges in caregiving and leveraging digital technology for enhanced health management in PLWD

This theme highlights the difficulties caregivers encounter in their roles and their perceptions of digital technology’s role in supporting caregiving:

Caregiving Challenges. Dementia caregivers encounter a variety of challenges in their daily routines, with ***caregiving burden and emotional strain*** being one of the most prominent. All of our caregivers (100%) expressed felt overwhelmed by the physical toll of caregiver responsibilities and tasks and emotional strain. 91% (n=10) of the caregivers described their affected lifestyles from caregiving responsibilities and tasks such as be PLWD's brain, the cleaning responsibilities, continuous supervision in dementia care, caring routines, monitoring nutrition intake and medication schedule, providing physical supports and ensure patient's safety. One caregiver emphasized the time commitment: "You have to live with him and take care of him 24 hours a day" (U05). Furthermore, 36% (n=4) reported feeling socially isolated, with limited opportunities for "adult time." A husband caregiver shared, "I don't have any adult-type interaction with her… it's like I'm locked in the house with a child, with no adult company" (U02). Two caregivers reported struggling to adjust to the caregiving lifestyle, while one expressed frustration over the lack of external support. The second and third most significant challenges are ***patient communication and autonomy*** and ***knowledge gaps and diagnostic challenges***. As PLWD gradually lose the ability to express their needs and make independent decisions, 73% (n=8) of caregivers find it difficult to understand their loved ones' thoughts and desires. One caregiver expressed her frustration with this communication breakdown: "I tried to brush her teeth, and she would shake her head vigorously, preventing me from brushing. It was an awful situation because she couldn't communicate with me verbally, so I didn't know why she was acting that way" (U03). Additionally, 64% (n=7) of caregivers reported challenges in ensuring compliance with medication, personal hygiene, and daily routines as PLWD increasingly lose control over self-management. One caregiver noted, "She has a hard enough time. She won't wash her hands unless I tell her" (U01). Another caregiver described how her

mother had lost the ability to live independently: “The obstacles and challenges were that she couldn't manage to live on her own, which requires my full support and care” (U05). Moreover, 55% (n=6) of the caregivers reported ***knowledge gaps and diagnostic challenges***, making it difficult for them to identify symptoms that require immediate intervention. As one spouse caregiver explained, “I actually don't know what to do to prevent UTI or know if she has a UTI other than what our doctor said sometimes” (U03). These knowledge gaps can delay critical care. Another challenge reported was ***resource and service accessibility***. Two of the caregivers expressed that they found it difficult to access the necessary care resources and support services, which adds to the heavy burden of caregiving tasks such as personal care, medical management, and emotional support. Also, one spousal caregiver highlighted the challenge of ***managing expectations and the progressive decline in PLWD***. Caregiver must balance hope for stability with the reality of worsening conditions, which can be emotionally taxing. Lastly, ***health and medical challenges*** such as recurrent UTI, or multiple comorbidities and complex medication regimens present further difficulties. “Under this very unwilling situation, their UTI situation often keeps repeating for several months and comes back again” (U08). In summary, dementia caregivers face a range of challenges, including difficulties with communication and autonomy, emotional and physical strain, resource limitations, and gaps in medical knowledge, all of which complicate their ability to provide effective care for PLWD.

Current Challenges of Using Technology. This subtheme reveals the challenges and obstacles that caregivers encountered when interacting with technology relevant to their health. Most of the challenges were usability issues such as ***hard to access*** the digital tools, ***no clear instructions*** on how to effectively operate the technology, leaving caregivers frustrated and unsure of how to use the devices or apps. One caregiver specified, “I didn't understand the

process of how I was gonna get in there. It wasn't clear about the process, so I didn't save the password, and then I had to make a new password, and by then I was like, it's not worth it. So I gave up" (U01). One of the participants noted that the current digital solutions on the market were ***not meeting their needs***, failing to provide the specific features or resources required for managing PLWD's health issues. Additionally, ***password settings and logins*** posed a recurring issue, with two caregivers expressing the complex characters to set up passwords, difficulty in logins or encountering overly complicated security protocols. A caregiver expressed her frustration in setting up passwords for online caregiver group: "It's so hard to create a password meeting the rules, but then it just didn't work. I just probably think the password requirement is too complex, like they want, like an upper class, a lower class" (U01). ***Technical issues***, such as device malfunctions and compatibility, further hindered their ability to rely on these tools. Lastly, caregivers emphasized the importance of a ***user-friendly interface*** since many available platforms lacked intuitive designs, further complicating their usability experience, and making it hard to integrate these technologies into their caregiving routines.

Tech Comfort and Access. This subtheme encompasses users' comfort, attitudes, and accessibility issues related to technology and its various applications. In summary, caregivers display mixed comfort levels and attitudes toward technology, influencing their willingness to adopt tech-based solutions. The ***attitudes toward technology*** were mainly positive, with 75% (n=8) of caregivers expressing favorable views, 25% (n=3) being neutral, and 8% (n=1) showing negative opinions. A caregiver shared, "Yeah, I like technology. It's kind of my friend that's so good to know" (U02). However, when it comes to specific technologies, the responses are more varied. For instance, ***apps*** are generally well-received, with five out of eight people who mentioned apps expressing positive attitudes. However, caregivers are divided over ***online***

support groups or programs, with four caregivers holding positive views, four having negative opinions, and three being neutral. Despite these mixed feelings, caregivers are gradually recognizing the potential benefits of digital tools in enhancing care management.

Key Design Considerations for Personalized Digital Solutions: Integrating User Requirements, Tech Preferences, and Engagement Strategies.

Participants highlighted several design considerations for developing personalized digital solutions to support UTI management in PLWD. We concluded with four subthemes:

Specific User Requirements. Dementia caregivers expressed their distinct needs for digital health management tools, requiring specific functionalities to manage health and interactions effectively. We identified six key user requirements. ***Reminders and notifications*** emerged as the top priority, with all eleven participants emphasizing its importance. 91% (n=10) of caregivers requested reminders for medication, water, or urination, while 55% (n=6) highlighted the need for prompt alerts and notifications. As one caregiver explained, "I think we need a reminder for medication and reminder for water, reminder for toileting" (U05). ***Health management and problem-solving*** was the second most emphasized need, with 91% of participants wanting educational content or a "knowledge piece" included in the digital solutions, and 46% (n=5) asking for UTI screening tools to assist in preventing hospital admissions. Three participants mentioned the needs of involving integrated health management with guided problem-solving functions. A spousal caregiver expressed that: “It should provide a solution to help us identify UTI symptoms, precautions, and some knowledge piece regarding UTI information” (U04). ***Customization and personalization*** was highly valued, with caregivers expressing the need for the ability to customize features, edit data, and tailor the app to their

specific needs. A participant brought up, “So it's good to have the ability to edit, because something, you know, being able to customize would be a good feature” (U01). ***Automated solutions and monitoring*** was another key requirement, where caregivers desired automated health situation categorization, assistance, and mood reading functionalities to help them manage care more efficiently. One participant explained the automated solution and situation categorization as: “There is a system available to guide me. It will help me determine whether the condition should be monitored, if I need to see a doctor, or if I should take specific actions, with different levels of intervention based on the situation” (U10). In terms of ***support and resources***, caregivers emphasized the importance of external resources such as websites, associations, and groups, as well as the involvement of healthcare providers and other caregivers for comprehensive support. Worth mentioning, 46%(n=5) caregivers stressed the needs of technical support for the digital solution or devices. Finally, ***data management and analytics*** was seen as critical, with 73% (n=8) caregivers asking for tools that could track and analyze data, generate reports, record real-time information, and show trends, helping them make informed decisions regarding the care of PLWD.

Tech Preferences. This subtheme includes three codes that reflect caregivers’ desired features, design elements, and overall experience with the technology. In terms of ***device preferences and compatibility***, all caregivers (n=11) expressed a preference for using an “app” as the primary digital solution for managing UTIs while 46% (n=5) mentioned their interest in incorporating smart devices, such as sensors, smart speakers, and wearables, into their UTI management routines. For example, one participant stated: “It would be great to use an app with tailored features, like setting reminders for UTI routines that integrate with my Alexa (smart speaker)” (U05). Others suggested the potential benefits of using online video conferencing or

creating a comprehensive "UTI ecosystem" to better support caregivers in managing UTIs. Over half of the caregivers stressed the importance of ***user interface and experience*** for the UTI management tool, highlighting several key elements. Two out of third caregivers (64%, n=7) requested an intuitive and simple interface while over half (55%, n=6) of the caregivers inquired the inclusion of graphics to aid in understanding. “If I were to use a tool, it would need to be something that easy to apply, straight forward and simple. And that would be something I would use” (U06). Features like big fonts, bright colors, and a clear interface were seen as critical for ensuring accessibility and ease of use. Furthermore, 34% (n=4) expressed a desire for a color-coding function to help users quickly identify different sections or tasks. “I think the app should have a color-coding feature to show the likelihood and severity of UTIs. Like, if it's red, that means it's urgent and I should contact a doctor. If it's green, it means everything's safe, and if it's yellow, I should watch out for some signs that might need attention” (U10). Instructions were demanded by 34% (n=4) of caregivers, suggesting that providing clear guidance within the app could enhance usability. Some participants mentioned drawing inspiration from the interfaces of other popular apps, while others advocated for a cute, dynamic design to make the experience more engaging. Caregivers also highlighted the preference of ***interactive elements and communication*** features within the UTI management tool. Four participants desired for having access to a human instructor or facilitator to guide them through the app’s features and offer support when needed. A participant specifically described her fear of making mistakes without a human instructor, “You know, you really do want some hands on instruction when you look at an app to do something…if you're actually working on another human's body, it's pretty big fear factor there that you're gonna do something wrong for lack of knowledge. So I feel like you can't do it without a human” (U04). A chat line was also suggested as a valuable addition, enabling

direct interaction with professionals or fellow caregivers in real time. The option to opt-in or opt-out of specific features, such as reminders or notifications, was deemed important in personalizing the experience. Additionally, three participants noted that having pop-up knowledge pieces providing useful tips or relevant information, would enhance the learning process and support ongoing education about UTI management: “The knowledge piece should be pop out in functions” (U11).

User Engagement and Motivation. This subtheme portrays factors and strategies that might stimulate user’s participation and sustain their interests in the digital solution. ***Ease of use and efficiency*** (91%, n=10) emerged as a top priority for long term engagement. Caregivers emphasized the need for the tool to be easy, intuitive, and quick to set up. Another factor to encourage engagement is simple and time-saving interface just as one spousal caregiver shared: “It has to be easy. And my motivation is, I don't have any time, and so whatever saves me time and provides more help than it requires in, you know, time to set it up. And it works” (U02). ***User connection*** (64%, n=7) which allow multiple user accounts to connect and interact was highlighted by caregivers as another critical factor of engagement. Features that enabled peer comparison or data sharing were seen as enhancing a sense of community and support, and keep users engaged. One participant suggested, “what it does is it compares me to my peers. Hi, you know you're drinking, you know you're drinking more water than 80% of your peers. Good job!” (U02). ***Reporting and feedback*** (46%, n=5) were seen as another engagement feature, with participants appreciating instant reports on progress and positive feedback or affirmation from the app. One participant envisioned the app providing daily positive reinforcement, stating, "It should pop up daily compliments or affirmations for users! It's always good to receive positive reinforcement. This is hard work—no question about it" (U08). Additionally, ***rewards and***

incentives were suggested as effective strategies to drive engagement. Participants recommended offering discounts in groceries and providing interactive milestone rewards or multimedia incentives. Some even mentioned the potential for monetary rewards to enhance motivation. To maintain relevance, ***comprehensive and updated information*** was seen as a necessary feature. Caregivers wanted access to the latest data and updates to ensure the tool remained useful over time.

The top motivating factor was focused on ***problem-solving*** (91%, n=10), as caregivers expressed the desire for the tool to provide practical solutions, such as early detection of UTIs and tangible ways to assist PLWD. “So what motivates me is it solves a problem I have today. I guess if it's if it's useful and helpful, and not a burden right.” (U09). Caregivers found the tool most motivating when it was deemed useful in solving real-world problems. Lastly, ***caregiver support and burden reduction*** was a significant code for motivation, as 64% (n=7) participants expressed the need for the tool to be relatable to caregivers (CGs) and help alleviate their burdens. As a participant summarized, “The first one is the person you are taking care of will be improved. His condition will be better. Secondly, he will reduce my load” (U10). Reducing the caregiving workload was a strong factor in sustaining user interest and engagement.

Data privacy. Data privacy for dementia caregivers focuses on their concerns and preferences regarding the protection of sensitive information when using digital solutions. Several key aspects were identified as important considerations in the design phase. Caregivers’ general ***attitudes toward data privacy*** were neutral (55%, n=6). “I don't think there's any risk here. Everything about us is on the Internet. Medical hacks happen all the time on the Internet, right? So it's like, why should I be concerned?” (U02). In addition to personal attitudes,

authentication and access control (64%, n=7) emerged as a priority, with caregivers advocating for robust security measures to ensure only authorized users can access sensitive information. Caregivers believe that features like **biometrics protection** (e.g., thumbprints), **customized passwords**, **device control**, and **data sharing and access control** are essential for holding up the security of their personal data. A participant specifically described how sharable feature would benefit the data privacy: "If there's a way to limit the time someone has access, that would be huge for me. For example, I'd like to say, 'Okay, paid caregiver is with John (her husband) now, so she can access the app and see what's been happening, but only during certain hours'" (U05). Furthermore, **2-factor authorization** and **username settings** were seen as key components in safeguarding access and minimizing the risk of breaches. A participant mentioned 2 factor authentication: "So there's probably like 2 factor authentication something like that" (U06) while the other described the concept of the device control: "I can only do this on my phone. They only give you. You can only do it on one device so that they have more control over your privacy and security" (U01). ***Regulatory compliance*** was also a significant concern, with caregivers stressing the importance of digital solutions that **follow security protocols and regulations**. They believed that working with **government or long-term care (LTC)** facilities is critical to ensure that the digital solution aligns with existing data privacy laws and best practices, thereby offering peace of mind regarding the protection of sensitive caregiver and care recipient information. For example, a participant mentioned: "You should be referencing and following the privacy protocol of government or big organizations. There will be many beneficiaries" (U08).

Discussions

This study applied the first two steps of the HCD framework to explore the experiences of dementia caregivers in managing UTIs in PLWD and their perspectives on utilizing digital solutions to support care. The primary objective was to understand the user context, needs, and requirements, particularly the challenges in caregiving, with an ultimate goal to generate a list of design considerations for digital tools tailored to the needs of caregivers in UTI prevention and management for PLWD, and guiding the next steps in prototyping. Four key themes emerged regarding context of use in UTI digital solutions, caregivers' needs, requirement, and technological preferences for personalized digital tools. Out findings underscore the complexity of caregiving for PLWD, especially in identifying UTIs, and highlight the need for personalized, caregiver-centered digital solutions.

Context of Use in UTI Digital Solutions

Our findings informed the context of use for UTI management in PLWD, as described by their caregivers. The context of use refers to the real-life, day-to-day observations and actions caregivers take when they suspect a UTI in PLWD.[31]Through the UTI signs and symptoms, and comprehensive approach in UTI management and care, we can better understand the context in designing digital health solutions that fit seamlessly into the routines and environments of both caregivers and PLWD.

The first theme, **Identified UTI Signs and Symptoms in PLWD**, reveals that behavioral and cognitive changes were two key indicators of urinary infection in PLWD. Behavioral shifts, such as increased aggression; and cognitive changes, such as confusion or psychotic episodes, were among the first signs caregivers noticed. The findings are consistent with previous reviews

reporting that PLWD usually presented infections through neuropsychiatric and behavioral symptoms since their inability to communicate physical discomfort directly.[32,33] The altered behaviors and cognitive deterioration in PLWD required caregivers to take extra monitoring and providing further assistance in care. The extra efforts in care created caregiving burdens, strengthening the key point of real-time awareness in caregiving contexts. This finding highlights the need for reliable, easy-to-use diagnostic tools that can help caregivers detect UTIs early.

The second theme, **Comprehensive Approach to UTI Management in Routine Care**, covers a broader context of dementia care with various strategies or resources caregivers applied to facilitate the UTI care in PLWD. Caregivers reported how they maintained PLWD's personal hygiene through perineal care, engaged PLWD in medical and health management activities, promoted lifestyle and behavioral modifications such as ensure hydration, and utilization of various tools and supports to manage and prevent UTI occurrences in PLWD. The strategies practiced by our caregivers align with several studies that identified dehydration as a key issue,[34,35] highlighted the importance of hygiene management[36] and noted the lack of a person-centered, integrative approach to dementia care.[37] A digital health solution that integrates routine care reminders, educational content, and telehealth features could potentially address this caregiving context. The digital tool could support caregivers in adopting preventive measures and seeking timely medical assistance. To be more specific, hydration reminders tailored to the care recipient's needs could reduce UTI risks by promoting consistent fluid intake, the toilet reminders could enhance the hygiene by ensuring timely perineal care in PLWD. Digital tools designed to resolve hydration status or integrative hygiene protocol raised in caregiving context could significantly benefit caregivers by helping them to reduce the likelihood of infection in PLWD and enabling timely intervention when early symptoms emerge.

Caregivers' Needs, Requirement, and Technological Preferences for Personalized Digital Solutions

An effective digital solution to assist caregivers in UTI management in PLWD must tailor the design with the caregivers' specific needs, requirements, and technological preferences.[38] In our third theme, ***Challenges in caregiving and leveraging digital technology for enhanced health management in PLWD***, caregivers described the unique challenges they encountered. Lastly, **Key Design Considerations for Personalized Digital Solutions,** encompasses the desired features based on user requirements, technological preferences, engagement strategies, and data privacy considerations from dementia caregivers.

Caregivers' Needs. Dementia caregivers face significant challenges, particularly in communication and supporting autonomy as PLWD lose their ability to express needs and make independent decisions. In this study, 73% of caregivers struggled to understand their loved ones' thoughts, with some expressing frustration over communication challenges during routine care. Communication barriers were similarly reported in two recent studies that explored caregiver interactions with their loved ones.[39,40] Additionally, 64% of caregivers reported difficulties in managing medication, hygiene, and daily routines as PLWD lost the ability to self-manage. This result aligns with a recent study that highlighted how cognitive decline in PLWD impacts autonomy and their activities of daily living (ADL).[41] Another challenge brought up by caregivers was significant time contribution, the physical, and emotional strains in caregiving. This finding aligns with studies exploring the potential of digital health interventions to alleviate caregivers' burdens and workloads.[42–44] These insights underscore the need for digital tools that support monitor and guidance in PLWD care, to reduce, rather than add to caregivers' workload.

User Requirements. Dementia caregivers specifically identified ***reminders, notifications, and integrated health management systems*** as essential requirements in considering a digital solution. Reminders such as medication, hydration, and urination, were brought up most frequently by caregivers, underlining the need for tools that simplify caregiving tasks. These requirements resonate with two recent studies that designed mHealth solutions to address the needs of dementia caregivers. In both studies, dementia caregivers described how personalized calendar and reminder functions played a critical role in their caregiving conetxt[45,46] but also enhance the well-being of PLWD [46] by promoting timely medication and hydration. The need for ***health management and problem-solving tools*** emerged as another key user requirement. Caregivers sought educational content on UTI prevention and detection, along with integrated screening tools to manage potential complications early and reduce unnecessary hospitalizations. This request for comprehensive health monitoring tools and educational resources concurs with findings from recent studies that explored and designed specific features in digital assistive tools for dementia caregivers [21,47]. Holt Clemmensen et al. (2021) identified four subthemes from dementia caregivers' self-reported needs, including informational content, knowledge sharing, and the monitoring of daily living, as well as behavioral and psychological symptoms. Similarly, Castillo et al.[47] reported that caregivers valued mHealth themes related to informativeness, visual appeal, layout, and facilitated monitoring of behaviors and symptoms that assist with health management.

Tech Preferences. All eleven caregivers in this study expressed strong preferences for an ***app-based solution*** as the primary solution for UTI management. In addition, half of the caregivers mentioned incorporating ***smart devices***, such as sensors, smart speakers, and wearables, into their routines. The preferences of apps and other smart devices from dementia

caregivers in our study align with the most recent mHealth and digital assistive tool studies.[44,46,48] For other desired features, participants emphasized the importance of a ***user-friendly interface***, ***intuitive*** and ***easy-to-use*** interface followed by ***color coding, large fonts, and clear navigation***. Caregivers' suggestions on "ease-of-use" and "intuitive" design with large fonts and graphics were also a central theme in Castillo et al.,[47] which explored how mobile apps meet the needs of dementia caregivers. The resonance of our results to Castillo's study indicates the values of considering accessibility and simplicity in digital solutions designed to support caregiving tasks, particularly for elderly dementia caregivers. Caregivers also envisioned the integration of ***interactive elements***, such as access to ***human support*** and a ***live chat feature*** in designing digital solutions. The needs in human support and live chat features align with findings from both Castillo et al. and Rathnayake et al,[46,47] proven their significance in caregiver-focused digital tools.

User Engagement, Motivation, and Data Privacy. The success of digital health tools for dementia caregivers depends on effectively balancing user engagement and motivation with strong data privacy protections while offering intuitive, problem-solving features that safeguard sensitive information. 91% of the caregivers assumed a simple, ***ease-of-use*** interface could improve their engagement in digital tools. In contrast, 64% believed ***user connections*** that value peer comparison and data-sharing options pertain to their use commitment. Caregivers expected themselves to continuously commit to a digital tool that is easy to set up and offers peer interaction and data sharing. Our findings resemble three recent studies that describe how ease-of-use, intuitive interface, and data-sharing capabilities in smart wearable devices could significantly promote user engagement.[49–51] Over half of the caregivers considered "***problem-solving"*** and **"*caregiver support and burden reduction"*** as two major motivators as they sought

practical solutions to assist in managing their caregiving tasks. Our findings are consistent with Dombestein et al.,[52] who discovered that strengthening problem-solving skills is directly linked to reduced caregiver burden and enhances caregivers' autonomous motivation and well-being. As for reducing the risks in data privacy breaches, 55% (n=6) of caregivers suggested including ***access control*** features such as biometric protection, customized passwords, 2-factor authentication, and device control. Our findings imply the need for secure, user-friendly designs in health management tools, which echo the results from a previous study that examined the significance of privacy in caregiving technologies.[46]

Clinical Implications

This study has four clinical implications. First, healthcare providers should integrate behavioral assessments into routine evaluations for PLWD since they increase the likelihood of early UTI detection and improve treatment outcomes. Second, incorporate interdisciplinary collaboration and comprehensive approach to achieve the best health outcome in UTI care for PLWD. Healthcare providers, including primary care physicians, nurses, and social workers, should work closely with caregivers to develop personalized care plans that address both prevention and early intervention strategies. Regular screening, hydration management, and hygiene maintenance are comprehensive approaches that could help reduce the incidence of UTIs and decrease the reliance on antibiotics in older adults since they are at high risk for antibiotic resistance. Third, clinicians should advocate for the use of caregiver-centered digital tools that facilitate real-time monitoring of symptoms, medication adherence, and behavioral changes. These tools could serve as an extension of clinical care, allowing caregivers to track key health indicators and share updates with healthcare providers. As digital health becomes more integrated into healthcare systems, clinicians can leverage these technologies to enhance

care coordination and provide more personalized interventions for PLWD. Finally, given caregivers' interests in data sharing and concerns about privacy and data security, healthcare providers must be proactive in addressing these issues when recommending digital solutions. Clinicians should educate caregivers on the importance of safeguarding personal health information and help them choose technologies that comply with data privacy regulations, such as HIPAA in the United States. By ensuring that caregivers feel confident in the security of digital tools, clinicians can promote wider adoption and utilization of these technologies, ultimately improving the quality of care for PLWD.

Limitations and Future Research

This study contains several limitations. ***Generalizability*** is a primary concern due to the participants' small sample size and homogeneity. The sample was predominantly male (64%), highly educated, and older adults (mean age of 68.7 years). Participants were mainly spousal caregivers (64%) and identified as either Caucasian (55%) or Asian (36%), with a lack of representation from the Black community. The lack of a Black community may restrain the applicability of the findings to a broader caregiver population. Future studies should consider incorporating a minority population or a more diverse group of caregivers in age, ethnicity, education, and LGBTQ+ to better capture the full spectrum of caregiving experiences and challenges. Another limitation falls on the ***missing viewpoints of PLWD***. It would be worthwhile to include people with early- to moderate-stage dementia who can still express their thoughts and needs. Voices from PLWD would allow a more extensive understanding of the care dynamics. Last but not least, further research is needed to prototype and evaluate the effectiveness of digital health solutions in real-world settings. By understanding and specifying user requirements, the study completed the first two steps of the Human-Centered Design and Engineering (HCDE)

process. Next, we will develop prototypes and design solutions based on these requirements, and we will evaluate them through iterative design methodologies. It would be helpful to refine and validate a UTI prevention and management prototype for dementia caregivers and people with disabilities through usability testing and pilot studies.

Conclusion

This qualitative study explored the needs and requirements for digital tools to support dementia caregivers in managing and preventing UTIs in PLWD. The four themes identified from this study emphasize the perplexing nature of UTI management in PLWD and highlight the potential for digital health solutions to support dementia caregivers. The next step of this study will work on designing UTI digital solutions that address caregivers' needs and challenges: early identification of signs and symptoms, integrating personalized care in PLWD, and ensuring usability and privacy in developing UTI digital solutions. The ultimate goal is to reduce caregiver strain, enhance caregiving effectiveness, improve overall care quality in PLWD, and reduce the risk of hospital admissions associated with UTIs. Future research will involve collaboration between more dementia caregivers, healthcare providers, HCD experts, and digital technologists on an innovative, effective, user-centered digital solutions that meet the unique needs of PLWD and their caregivers.

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Tables

Table 4.1. Participant Demographics.

Table 1. Participant Characteristics

Variable	N = 11[1]
Patient Age, yrs	68.73 (11.41)
Ethnicity	
NOT Hispanic or Latino	11 (100%)
Race	
Asian	4 (36%)
More Than One Race	1 (9.1%)
White	6 (55%)
Gender	
Female	4 (36%)
Male	7 (64%)
Education	
Bachelor's degree	5 (45%)
Master's degree	3 (27%)
Doctoral degree	1 (9.1%)
Professional school degree	1 (9.1%)
Some college, no degree	1 (9.1%)
Employment Status	
Retired	9 (82%)
Uemployeed	1 (9.1%)
Working	1 (9.1%)
Marital Status	
Divorced	1 (9.1%)
Married	10 (91%)

[1] Mean (SD); n (%)

Table 4.2. Caregiver Characteristics provides detailed caregiving information (types of caregiver, years of being a caregiver, total hours of care provided per week), and the care recipient's dementia stage.

Table 2. Caregiver Characteristics

Variable	N = 11[1]
Caregiver Types	
Children	3 (27%)
Nursing Home Caregiver	1 (9.1%)
Spouse of Partner	7 (64%)
Dementia Stage	
Moderate	9 (82%)
Severe	2 (18%)
Years of Being A Caregiver	
1-3 Years	2 (18%)
3-5 Years	5 (45%)
More Than 5 Years	4 (36%)
Total Hours of Care Provided in A Week	
20-39 Hours/Week	3 (27%)
40 Hours or More	7 (64%)
9-19 Hours/Week	1 (9.1%)

[1] n (%)

Table 4.3. Identified Themes, Subthemes, and Exemplar Quotes

Themes/ Subthemes	Exemplar Quotes
Theme 1. Identified UTI Signs and Symptoms in PLWD	
Behavior Changes	
Abnormal or unusual behaviors	"And she had a UTI... she was sort of acting a little strange." (U01)
Disruptive behavior	"He's being a little bit more repetitive than usual, or yelling out and being aggressive." (U03)
Cognitive Changes and Psychotic Episodes	
Cognitive decline	"…That (PLWD's cognition) is generally there, and when it gets worse. Is when he really seems to be off mentally." (U04)
Confusion or delirium	"You know, he was, just not understanding quite what was going on around him, and unable to make his body move. It's not quite like himself, and he'd been definitely more confused, much more confusing usual. And that was the main sign." (U04)
Psychotic episodes	"…one time she was just sort of having a psychotic episode, and she went to the hospital and they (physicians) found that she had an UTI…" (U01)
Physical Symptoms	
Changes in urine color & smell	"And then, you know, as far as cloudiness and the bad smell in her urine and all that kind of thing you're supposed to look for." (U04)
Fever	"It means that you have done a good job, but the urine still cannot come out smoothly. And if the temperature is high, you can't prevent it. The only thing is that when you find that it has a fever, you know that he has UTI." (U10)
Frequent urination	"It's a problem. but so far, like her, only symptoms are like peeing frequently..." (U09)
Pain and discomfort in urination	"Normally, it's the burning sensation during urination that gets her off. It's a problem. but so far, like her, only symptoms are like peeing frequently, and also like sensational burning." (U09)

Themes/ Subthemes	Exemplar Quotes
Theme 2. Comprehensive Approach to UTI Management in Routine Care for PLWD	
Routine Care	
Personal hygiene and care • Body hygiene (shower, diaper change) • Grooming and dressing • Facial/ oral hygiene • Toilet routine	"They usually do have a planned shower time for hygiene, and so that's usually twice to twice a week." (U01) "I could do diaper change every 3 to 4 hours." (U05) "If I take her to the toilet, she'll often urinate or have a ball movement." (U03)
Medical and health management activities • Hydration • Ostomy care • Suprapubic catheter care • Take Medication • Take Supplements	"Well, so she gets at least 5 (glasses) of 8-ounce glass of water a day." (U02) "Because she might get stool from her colostomy all over the all over body, so it's just easier to cleaner with the shower." (U01) "His unique circumstance is that he has a suprapubic catheter, and I change that catheter form about every 2 to 2 and a half weeks." (U04) "I pretty much manage her medications and supplements. She's on 7 medications and numerous supplements daily, and she can't keep track of it." (U09)
UTI Care	
Hygiene and care practices • Hand Hygiene • Perineal Care • Sterile Technique in Care	"As for peeing, we usually wash our hands before eating and then go to the toilet." (U08) "Use the diaper and check it every 2 to 3 h to keep the area clean. The urinary and perineal area." (U11) "Using a pair of gloves to prepare, and then SEP over a pair of surgical gloves, and then pulling the outer gloves off, did the procedure." (U04) SEP SEP
Lifestyle and behavioral modifications • Cranberry products • Exercise • Hydration	"I let her drink a lot of cranberry juice, got rid of it (UTI) myself." (U07) "After eating, 10 to 20 minutes later, we walk for exercise and then go to the bathroom." (U08) "Sometimes you kind of remind her to get hydrated. You ask her to drink something, drink water, drink milk." (U01)

Medical intervention	"She has to take antibiotics from the doctor's prescription." (U05)
Monitoring and assessment • Monitor vital signs • Monitor urine input/output	"We just take our temperature and blood pressure every day…" (U08) "You have monitored it. For example, even though he doesn't like it, you have introduced him to IO (intake/output) every day, always saying how much he drinks, and then what happens." (U08)
<u>Tools/Resources used in care</u>	
Technology Based Tools • **App** (calendar, reminders, timer, health app) • Emails • Smart devices (smart speaker, wearable devices, tracking devices) • **Online resources** (Google, ChatGPT, YouTube, medical portals)	"So I use my timer on my iPhone, something like that." (U11) "I prefer receiving email from our personal trainer so I can keep updated about his progress." (U07) "We have an Alexa echo dot (smart speaker) in every room." (U02) "I love YouTube. There are so many great YouTube videos about people their own experience sharing their success, or what works and what doesn't. Those videos are really helpful!" (U01)
Traditional organizational tools • Checklists, whiteboards, pillboxes	"I've several whiteboards around the house. You wanna talk about digital technology. I use whiteboards. We have one for downstairs, one for the middle room, the land, and one for upstairs, and it's just a matter of me having to erase them and put the news on it." (U07)
Hygiene and Comfort Tools • Bidet Toilet Seat • Diapers and Pads • Flushable Wipes • Water Spray	"It's it's bidet of the day. So, it just washes everything away after you defecate." (U02) "Changing the diaper, you know, actively, or using a pad inside the diaper." (U05) "So our caregiver and I both use a lot of flushable wipes." (U03) "Water spray. I filled it with water and sprayed and clean his perineal area." (U10)
Healthcare Resources • Medical supplies (Hormone cream) • Professional support	"We did end up using hormone cream to try to strengthen the area (perineal area) there." (U05) "I have a caregiver who comes 3 days a week for 8 hours" (U03)

(Health care providers, Professional caregivers) • Specialized protocols (Bredesen protocol)	"And then roughly, 2 years ago. we discovered a program called the Bredesen Protocol and it helped us a lot."
<u>Supports/Communication</u>	
Attitudes and perceptions towards support groups	"So I started in also another group earlier on. And it wasn't as useful." (U01) "It would be a trouble...There are a lot of things, and when you listen to them, it's not support, it becomes stress to you." (U10)
In-personal networks • Family and Friends (spouse/family/friends) • Local Community (neighbors/community/in-person support group)	"So we're just at the point we're starting to get a little bit of outside help. We've got a friend of hers coming in once a week for about 5 hours at a time." (U09) "We do have 2 or 3 neighbors who bring meals over once in a while." (U02)
Online support • Digital Tools (e.g., chatbox, live chat, Zoom) • Online Resources (Websites, Associations) • Online Support Groups	"Because it's embarrassing to talk about his issue to a person so it would be great to get something like a chat box" (U04) "We have, like Facebook groups, dementia caregiver groups something like that." (U11)
Professional support • Health Care Professional • Paid/Professional CGs	"I didn't really have a support group, so I guess it was talking to the professional caregivers. You know, they (professional caregivers) had good tricks, and I think I also consulted the doctor for my husband. He definitely supported my works." (U05)
Telephone-based Supports	"…and he started with another guy, a chat line. But it was a computer chat line, so that it wasn't a verbal. I mean, it wasn't talking. It was completely anonymous." (U04)

Themes/ Subthemes	Exemplar Quotes
Theme 3. Challenges in caregiving and leveraging digital technology for enhanced health management in PLWD	
Caregiving challenges	
Caregiving burden and emotional strain • Caregiver responsibilities and tasks • Emotional strain • Physical strain • Lack of support • Social isolation • Time commitment	"The most significant is making sure he eats 3 meals a day, cause he seems to have sort of lost his appetite and sense about whether he's eaten or not." (U04); "He can't clean his bathroom. He has absolutely no idea what to do. So his bathroom gets dirty because of this constant team. And it's just hard. It's very hard."; "I'm very high anxiety, in fact, anxiety disorder. To tell you the truth and depression sometimes." (U07) "He and I have been going through at least a couple of months of just trying to find somebody who could give us a straight answer about how to treat it. We just weren't finding the right people." (U04) "I don't have any adult-type interaction with her… it's like I'm locked in the house with a child, with no adult company"; "I don't have time to get away. I can't leave her, and if she comes with me that can be difficult." (U02) "You have to live with him and take care of him 24 hours a day." (U05)
Patient communication and autonomy • Challenges in ensuring compliance in PLWD (medicine, personal hygiene, daily routine) • Unable to communicate with PLWD	"She has a hard enough time. She won't wash her hands unless I tell her." (U01) "The obstacles and challenges were that she couldn't manage to live on her own, which requires my full support and care." (U05) "I tried to brush her teeth, and she would shake her head vigorously, preventing me from brushing. It was an awful situation because she couldn't communicate with me verbally, so I didn't know why she was acting that way." (U03)
Knowledge gaps and diagnostic challenges • Difficulty in UTI Symptom Identification	"I wonder how would I know she has a UTI if she can't communicate with me, you know she's losing words now." (U09)

• Lack of UTI Caregiving Knowledge	"I actually don't know what to do to prevent UTI or know if she has a UTI other than what our doctor said sometimes." (U03)
Managing expectations and progressive decline	"So the biggest challenge is trying to adjust my expectation that this is now my life." (U02) "But Mom was getting more feeble, so it wasn't as easy." (U05)
Resource and service accessibility (e.g., medical resources, supplies)	"It takes a long time to get an appointment." (U04) "…you know, the supplies with a challenge. Even getting gloves were a challenge back." (U05)
Health and medical challenges in PLWD	"Under this very unwilling situation, their UTI situation often keeps repeating for several months and comes back again." (U08)
<u>Current Challenges of Using Technology</u>	
Accessibility barriers	"It's a pain in the butt to use it. You have to open it up. It's just if I have to pick up a phone and go to an app. Or I have to be near the phone so it can remind me it will not work. It just won't." (U02)
No clear instructions	"I didn't understand the process of how I was. Gonna get in there (the online support website). It wasn't clear about the process." (U01)
Not meeting their needs	"There was a huge gap between what I expected and what I got." (U10)
Password settings	"It's not hard to create a password, but then it just didn't work. I mean, I just probably think the password requirement is too complex, like they want, like an upper class, a lower class." (U01)
Technical issues	"I don't know how to get rid of it. That's why I want to hire somebody. I just need help." (U07)
User-interface	"It didn't really work. It's not user friendly. See? It wasn't user friendly." (U01)
<u>Tech Comfort and Access</u>	
Attitudes Toward Technology	"Yeah, I like technology. It's kind of my friend that's so good to know." (U02)

Attitudes Toward Specific Technologies (Apps, online programs, social medias)	"I use that (reminder) on my iPhone all the time. Oh yeah, it helped a lot!" (U05) "Those videos are really helpful. So with dementia, the only thing that I looked up online is the Alzheimer's website and FB support groups." (U01)

Themes/ Subthemes	Exemplar Quotes
Theme 4. Key Design Considerations for Personalized Digital Solutions: Integrating User Requirements, Tech Preferences, and Engagement Strategies	
Specific User Requirements	
Reminders and notifications	"For at least make the announcements, for the reminders." (U02) "A reminder for medication and reminder for water reminder for toileting." (U05) "Something that would remind me or notify me to do something would be good." (U06) "But the reminder should be daily since you need to do the hydration every 2 to 3 hours. The medication parts." (U09)
Health management and problem-solving • Integrated health management and guided problem-solving • Provide knowledge piece or training materials for caregivers • UTI Checklist or screening tool	"The first thing it will remind you to check, for example, whether the urine is too yellow. And the second thing is that after you look at these things, it will tell you whether it is urgent or not. And then the next step is that if it is urgent, it can connect you to a professional, or someone, and let them tell you what to do next." (U10) "It should provide a solution to help us identify UTI symptoms, precautions, and some knowledge piece regarding UTI information." (U04)
Customization and personalization	"I think that being able to customize when they are and what they are. You will be able to have multiple reminders to water, toilet, medication" (U05) "So it's good to have the ability to edit, because something, you know, something devices and all that smart." (U01)
Automated solutions and monitoring	"There is a system available to guide me. It will help me determine whether the condition should be monitored, if I need to see a doctor, or if I should take specific actions, with different levels of intervention based on the situation." (U10)

Support and resources • External resources (websites, associations, caregiver support groups) • Health care providers and professional caregivers • Technical support (for Devices)	"And you know, and maybe that's an app that also links you to the Alzheimer's Association or AARP's dementia caregiver webpage." (U02) "I was thinking like, if it's an app, then probably you can probably have, like a regular link to a meeting or to health healthcare professionals." (U09) "Make sure to get a technical support line!" (U08)
Data management and analytics • Tracking and recording • Able to take notes • Provide reports of real-time data, analytic data, and show trends	"It should track anything you log in the app for a certain amount of time, like a week"; "I think a place to record and take notes would be really important." (U05) "It should collect and generate real-time data and establish a baseline report and show trends. If the daily report is different than the baseline. Then, you know, when to contact healthcare provider"; "It shows (report) in different ways. So, there's a graph, and it shows long-term trends and short-term trends." (U01)
<u>Tech Preferences</u>	
Device preferences and compatibility • **App** • Smart Devices (sensors, speakers, wearable devices) • Zoom, tutorial video • UTI ecosystem (internet of things)	"They just need a place to put like a note or something like, and a button to push when there is a UTI so it should be like a tailored app." (U05) "It would be great to use an app with tailored features, like setting reminders for UTI routines that integrate with my Alexa (smart speaker)" (U05). "If you have a smart device (sensors) that can detect and leveled seriousness of UTI. At this point you can see a doctor and prescribe medication early in your speech." (U10)
User interface and experience • **Clear and simple interface (big fonts, bright colors, graphics)** • **Intuitive and easy-to-use** • Dynamic User Interface (cute design and customized settings) • Color-coding function • Provide clear instructions	"So you something that has a clear interface." (U06) "Simplicity is the point. So probably the easier to operate." (U05) "In large font, or probably have a magnified glasses on the app." (U11) "…as you were saying about actually using it, I think it just has to be pretty seamless and intuitive." (U01) "If it is an app, of course the color should be brighter, because many caregivers are women. Women know that

	they are a little emotional, and if they look cute, they will be in a cheerful mood and more willing to use it." (U08) "So if you can same sort of color coding in the system. Use the color to code the level of seriousness of UTI" (U10)
Interactive elements and communication • **human instructor or facilitator** • Chat line • Opt-in/-out Function • pop-up knowledge pieces	"It's more like a support line, a support line that is always staff. But everybody calls and talks. It's not like a group that's gonna meet every week to talk about your questions, and somebody will gonna answer your questions." (U04) "I was thinking like, if it's an app, then probably you should have a regular link to a meeting or a regulator to facilitate discussion." (U08) "It would be nice to maybe as a character if I clicked on a an opt in function. Then, having something that was text it to me every 4 hours, it says something like, here's a reminder to make sure that you hydrated your wife." (U05) "The knowledge piece should be pop out functions." (U11)
<u>User Engagement and Motivation</u>	
Ease of use and efficiency	"It has to be easy and intuitive to keep me engaged." (U01) "So my motivation is, I don't have any time, and so whatever saves me time and provides more help than it requires time to set it up." (U02) "It has to be easy. Quick." (U05)
User connection • Peer Comparison • Sharable data	"What it does is it compares me to my peers. Hi, you know you're drinking, you know you're drinking more water than 80% of your peers. Good job!" (U02) "I guess the part should be like the data should be shareable. It can be export into a chart or file like there's a trajectory of how things change." (U05)
Reporting and feedback (instant report or provide positive feedback/affirmation)	"It should pop up daily compliments or affirmations for users! It's always good to receive positive reinforcement. This is hard work—no question about it." (U08)

Rewards and incentives • Discount or monetary reward • Interactive milestone reward • Multimedia reward	"I was thinking, if there is an encouraging assumption, if you use it every day, then in the second month, you may get a coupon or a little bit of a discount in grocery." (U03) "…when you reach certain milestones, it will give you something like money or there will be some kind of interaction with you or something like that." (U08) "It would be nice to get, you know, every time you know, every time we drink water we get 10 cents in the account, and we can buy something, you know." (U02) "We want it to make some sounds or say that he has achieved his goal, and then there will be a cute sound, and there must be a piece of music and a cartoon video, which can be equivalent to the elders' rewords. He has achieved his goal, so we want to share this joy with him, so his gift may be a cartoon video." (U08)
Comprehensive and updated information	"Make the app to send an updated information about UTI every day or when I'm using the app. It'll help us engaging with the app." (U08)
Caregiver support and burden reduction	"The first one is the person you are taking care of will be improved. His condition will be better. Secondly, he will reduce my load." (U10)
Problem solving	"So what motivates me is it solves a problem I have today. I guess if it's if it's useful and helpful, and not a burden right. I'll engage" (U09)
<u>Data Privacy</u>	
Attitudes toward data privacy	"I don't think there's any risk here. Everything about us is on the Internet. Medical hacks happen all the time on the Internet, right? So it's like, why should I be concerned?" (U02) "There is no security. I can tell you that anyone can crack it now." (U10)
Authentication and access control • Biometrics protection (e.g., thumbprint) • Customized username and passwords • Device control	"I want to be able to use my thumbprint to open to access my account without having to type a password name." (U02) "We have to customize our own username and passwords." (U03)

• Data sharing and access Control • 2 factor authorization	“I can only do this on my phone. They only give you. You can only do it on one device so that they have more control over your privacy and security.” (U01) “I guess the part should be like the data should be shareable. It can be export into a chart or file like there's a trajectory of how things change"; "…if there's a way, the main user will be able to add other caregivers and limit the time of their accessibilities, and that to me would be huge. So she (professional caregiver) has access to see what's been happening. She can get into the app, but only between these hours.” (U05) “So there's probably like 2 factor authentication something like that.” (U03)
Regulatory Compliance (Cooperate with government or long-term care facilities)	“You should be referencing and following the privacy protocol of government or big organizations. There will be many beneficiaries.” (U08)

Appendix

Appendix 4.1. Interview Guide

Part 1. Introduction

Thank you for meeting with us and offering to provide your insights and perspectives. My name is Kuan-Ching Wu. I am a doctoral student at UW SON conducting a study for my dissertation. My study involves developing a digital intervention to reduce the incidence of emergency department visits or hospitalization due to urinary tract infections (UTIs) for people living with dementia. Users of this intervention will be people living with dementia and their caregivers. Before we start, may I have your permission to record our interview? This would be a valuable documentation for my study. The recording will be saved and stored safely. The written transcript will have all names removed.

[START RECORDING]

This interview aims to understand the caregivers' needs for this digital intervention to help with urinary tract infection prevention and management in community-dwelling people living with dementia. When I use the term digital what I mean is programs and devices using digital technology, such as computers, smartphones, or any device that can be connected to the internet. Any questions before we start?

Part 2. Interview (35 min)

1. Caregiver's Background
   - Can you tell us your name, your relationship to person with dementia, and your background?
2. Caregiver Experience and Challenges:
   - What are the most significant challenges you face while caring for someone with dementia?
   - How do you currently manage or prevent urinary tract infections (UTIs) in the individual you care for?
   - What difficulties or obstacles do you encounter in preventing or addressing UTIs?
3. Understanding Current Practices:
   - Can you describe the daily routine or caregiving practices related to hygiene and health maintenance for the individual with dementia?
   - What tools, resources, or methods do you currently use for managing the health and hygiene of the person with dementia?
4. Technological Comfort and Access:
   - How comfortable are you with using digital tools or technology to assist in caregiving activities?
   - What kind of digital tools or applications have you used in the past for managing health concerns of the person with dementia?
5. Specific Needs and Preferences:
   - What specific features or functionalities would be most helpful in a digital intervention aimed at UTI prevention and management?
   - Are there any preferences regarding user interface design or accessibility features that would enhance your experience with such a tool?

6. Engagement and Motivation:
    - What motivates you to engage with digital interventions regularly?
    - How can the intervention maintain your interest and encourage consistent use?
    - Are there any interactive elements or gamification strategies that might enhance engagement?

7. Support and Communication:
    - How important is it for you to have access to support networks or communication channels through a digital intervention?
    - Would you find value in a platform that connects you with other caregivers facing similar challenges or offers guidance from healthcare professionals?
8. Privacy and Security:
    - How concerned are you about your privacy while using a digital intervention?
    - What measures should be implemented to ensure the security of your personal health data?

These questions can serve as a starting point for understanding the needs, challenges, and preferences of dementia caregivers in the context of developing a digital intervention for UTI prevention and management. Adjust and expand upon them as necessary based on the specific focus of your research or the particular aspects of caregiving you wish to explore.

Part 3. Conclusion (2 min)

This is the end of our interview. Are there any questions you have for us or is there anything you would like to discuss that we haven't addressed?

Chapter 5. Conclusion and Mock-up Prototype

Introduction

The overall purpose of this dissertation was to prototype a digital intervention aimed at supporting dementia caregivers in providing better urinary care, reducing UTI-related hospital visits in PLWD, and subsequently alleviating caregiving burden while improving the well-being of both caregivers and their loved ones. This chapter will summarize the findings, discuss the broader implications, and outline the next steps in this research journey.

Summary of Findings

Chapter 1: The Impact of UTIs in PLWD

In Chapter 1, we recognized the critical issue of UTIs among PLWD, highlighting the negative health outcomes and the burden they impose on caregivers. UTIs are one of the most common health complications faced by PLWD, significantly increasing hospitalizations and adding to the caregiving burden. Three specific aims were proposed to prototype a digital intervention that could potentially prevent or manage UTI occurrences, specifically targeting caregivers of PLWD. This study is unique in being the first to focus on the development of a digital solution designed specifically for this population, with the dual aims of tracking and preventing UTIs through the integration of clinical guidelines and behavior change techniques.

Chapter 2: Development of the Conceptual UTIP Framework

In Chapter 2, we employed the CDC's Social Ecological Model of Health as a foundation to develop the conceptual UTIP framework. This framework facilitates the assessment of UTI symptoms, risk factors, outcomes, and non-pharmacological prevention strategies in community-dwelling PLWD. A critical insight gained from the literature review was the significant role that modifiable factors such as lifestyle and behavior, particularly hydration and personal hygiene,

play in UTI prevention. Modifiable factors at the individual and interpersonal levels were identified as having the most potential to prevent UTI occurrences in PLWD, emphasizing the need for interventions targeting these areas.

Chapter 3: Review of Existing Digital Interventions for UTI Prevention

Chapter 3 reviewed existing digital interventions for UTI prevention and management in PLWD. Among the 1,800 articles reviewed, only three sensor-based interventions were identified, all of which primarily focused on UTI detection rather than prevention. These interventions often utilized AI algorithms to analyze sensor data collected via IoT devices, but lacked comprehensive strategies for managing underlying risk factors or following established UTI guidelines, such as those from the Infectious Diseases Society of America (IDSA) or the European Association of Urology (EAU). Additionally, the review pointed to the absence of stakeholder involvement, particularly the input of caregivers and PLWD, in the design and implementation of these interventions.

Chapter 4: Needs Assessment of Dementia Caregivers

In Chapter 4, we applied the first two stages of the HCD approach by conducting semi-structured interviews with dementia caregivers, which revealed four key themes. First, caregivers identified a wide range of UTI signs and symptoms in PLWD but reported challenges in detecting these early. Second, caregivers stressed the need for a comprehensive approach to UTI management, highlighting the importance of integrating prevention, early detection, and treatment into routine care. Third, while caregivers showed interest in using digital tools, they noted challenges such as technological literacy and the availability of user-friendly devices. Lastly, caregivers emphasized the importance of personalized digital solutions that incorporate user preferences, promote caregiver engagement, and offer consistent support. These findings

underscore the complexity of UTI management in PLWD and demonstrate the potential of digital health solutions to provide meaningful support to caregivers.

Implications for Research and Practice

The findings from this dissertation contribute to the growing body of literature on the use of digital health interventions to manage chronic conditions among PLWD. Specifically, the development of a digital intervention for UTI prevention and management addresses a critical gap in both dementia care and urinary health. By integrating evidence-based clinical guidelines with behavior change techniques, the proposed intervention aims to empower caregivers, improve PLWD's quality of life, and reduce unnecessary hospital visits due to UTIs.

Additionally, the use of HCD principles underscores the importance of involving caregivers in the design process to ensure that the final product meets their specific needs and preferences. This approach can serve as a model for future digital health interventions in dementia care, emphasizing user-centered solutions that are practical, accessible, and sustainable.

Next Steps: Design Solutions and Prototyping

The next phase of this research involves transitioning from the assessment stage to the design and development of a digital intervention that meets the specific needs of dementia caregivers. Leveraging the insights from both previous studies and caregiver interviews, we will create design solutions that address the identified preferences and challenges. The core of this process will be the development of the GUTI App, a prototype aimed at supporting caregivers in preventing and managing UTIs in PLWD. Key features of the GUTI App will include the following (see *Table 5.1.* for design considerations):

Reminders and Notifications: The app will offer customizable reminders for essential routines such as drinking water, taking medication, and using the toilet. These notifications will help ensure that caregivers can maintain a consistent care schedule for PLWD, promoting urinary health and reducing UTI risks.

Health Management and Problem-Solving Tools: The app will include UTI symptom tracking and screening tools, as well as a comprehensive UTI checklist. These features will allow caregivers to monitor symptoms, address potential issues early, and streamline the management of UTI prevention in their daily caregiving routines.

Data Management and Analytics: Caregivers will be able to track and record health-related data, take notes, and generate reports. The app will provide real-time data, analytics, and trend visualization, empowering caregivers with actionable insights into the health status of PLWD and enabling more informed decision-making.

Support and Resources: To enhance caregivers' knowledge and problem-solving abilities, the app will provide daily tips, access to external online resources, and training videos. These features will offer caregivers continuous education and immediate access to valuable information.

Clear, Intuitive, and Simple Interface: The app will prioritize ease of use by incorporating large fonts, bright colors, and intuitive graphics. These design elements are intended to save caregivers time and effort, making the app accessible even to those with limited technological experience.

Interactive Elements and Communication: The app will feature interactive components, such as a human instructor or facilitator option, to provide caregivers with a

personal touch. This will encourage engagement and ensure that caregivers feel supported throughout their experience.

Authentication and Access Control: Security will be a primary concern, with features like biometric protection (e.g., thumbprint), customized usernames and passwords, and two-factor authentication. Caregivers will also have control over data sharing and access permissions, ensuring that sensitive information is protected.

User Connection: The app will foster caregiver connections by allowing peer comparisons and data sharing, providing caregivers with a sense of community and support. This feature will enable them to share experiences and gain insights from others in similar situations.

Once the design solutions are finalized, the next critical step will be to develop mockup prototypes of the digital intervention. These prototypes will serve as early versions of the final product, allowing us to conduct iterative testing and refinements based on real-world feedback. To facilitate this, we used Figma, a collaborative web-based design tool widely employed for creating user interfaces. Figma allows for real-time collaboration, making it ideal for developing, sharing, and revising design prototypes.

We have created several detailed mockup screenshots using Figma, including key elements such as the login page (see *figure 5.1.*), a color-coded warning homepage that signals UTI risk levels (*figure 5.2., figure 5.3., figure 5.4.*), a reminder system (*figure 5.5., figure 5.6.*), a tracking diary (*figure 5.7.*), the educational content (*figure 5.8.*), and an input feature for logging symptoms (*figure 5.9., figure 5.10.*). These prototypes will be shared with caregivers and other stakeholders to gather valuable insights and ensure the design meets their expectations and caregiving needs. Through this process, we aim to refine the usability, functionality, and overall user experience, ensuring that the final product is both intuitive and seamlessly integrates into

daily caregiving routines. Feedback from this phase will be instrumental in shaping the final version of the digital intervention.

Conclusion

This dissertation has laid the groundwork for the development of a novel digital intervention aimed at supporting dementia caregivers in preventing and managing UTIs in PLWD. Through a comprehensive review of existing literature, the development of the UTIP framework, and a thorough needs assessment with caregivers, we have identified key gaps and opportunities in the current landscape of digital health solutions. The next phase of this research will focus on translating these insights into tangible design solutions, with the ultimate goal of improving the lives of both caregivers and PLWD. By addressing a critical health issue, this work holds the potential to reduce caregiving burden, enhance the well-being of caregivers and PLWD, and transform how UTI prevention is managed in the context of dementia care.

Tables

Table 5.1. Design Considerations of the GUTI App Prototype

Features		Examples
1	Reminders and notifications	• Water/medicine/toilet routine reminders
2	Health management and problem-solving	• UTI symptom tracking tool • UTI screening tool • UTI checklist
3	Data management and analytics	• Tracking and recording • Able to take notes • Provide reports of real-time data, analytic data, and show trends
4	Support and Resources	• Daily knowledge piece/tips • External link to online resource • Training videos
5	Clear, intuitive, and simple interface (Ease of use, saves time)	• Big fonts, icons • Bright colors • Graphics
6	Interactive elements and communication	• Human instructor or facilitator
7	Authentication and access control	• Biometrics protection (e.g., thumbprint) • Customized username and passwords • Device control • Data sharing and access Control • 2 factor authorization
8	User connection	• Peer comparison • Sharable data

Figures

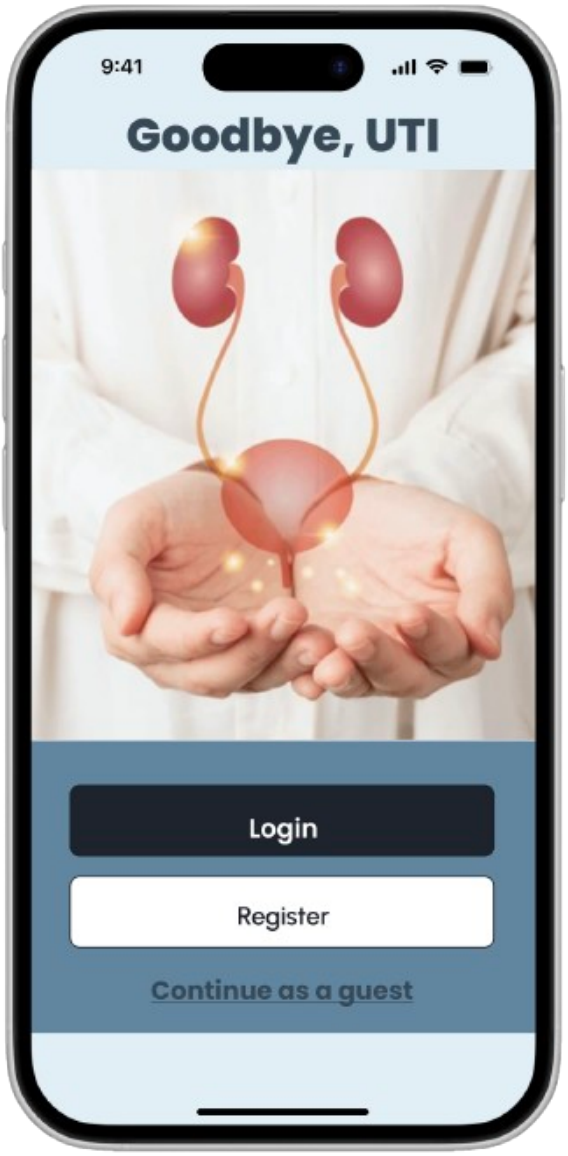

Figure 5.1. GUTI App Login Page.

Figure 5.2.

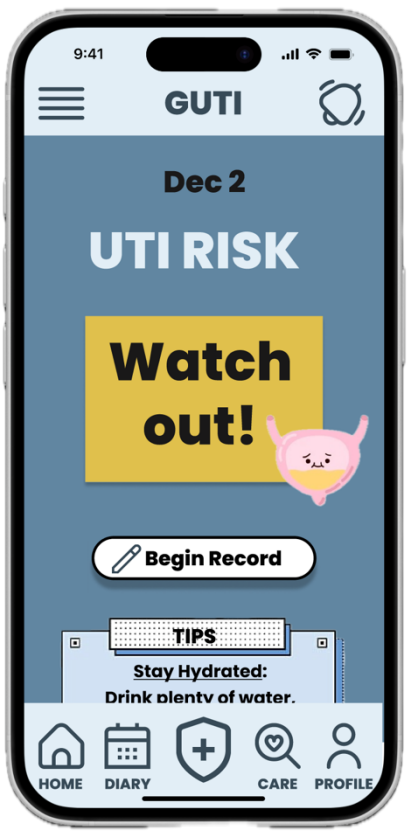

Figure 5.3.

Figure 5.4.

Figure 5.2. GUTI App Home Page—Doing Great! (Left)
Figure 5.3. GUTI App Home Page—Watch Out! (Middle)
Figure 5.4. GUTI App Home Page—Seek Help! (Right)
The color-coded warning dashboard displays the risk of UTIs in persons living with dementia (PLWD) by integrating daily symptoms recorded by users. It is divided into three colors: red indicates a high risk of UTI, suggesting users seek medical assistance; yellow signals a moderate risk, advising caregivers to monitor for additional symptoms; and green means the PLWD is symptom-free and at relatively low risk of a UTI.

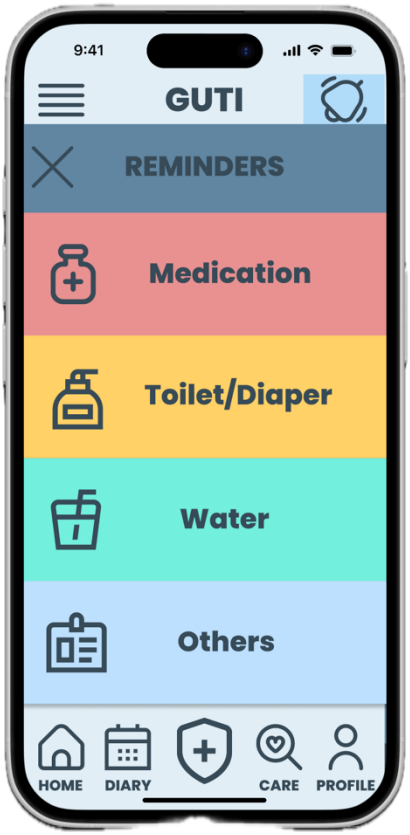

Figure 5.5.

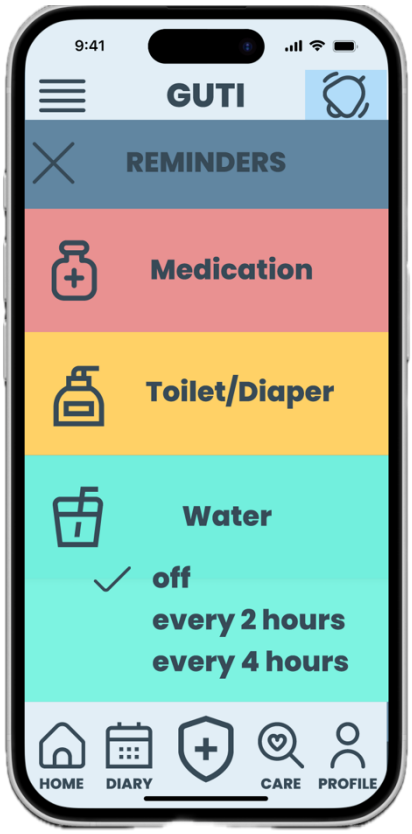

Figure 5.6.

Figure 5.5. GUTI App Reminder Page. (Left)
Figure 5.6. GUTI App Reminder Page—set up water reminder. (Right)
The reminder page includes prompts for medications, toilet/diaper changes, hydration, and other customizable reminders. Users can select from a dropdown menu to easily toggle reminders on and off, with the option to set specific time intervals.

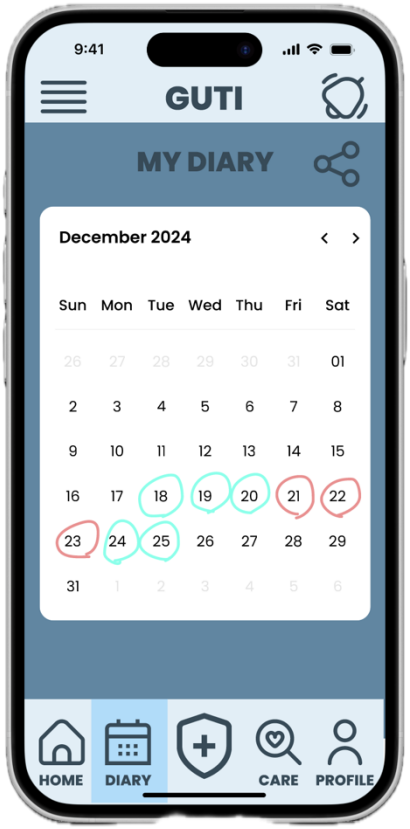

Figure 5.7.

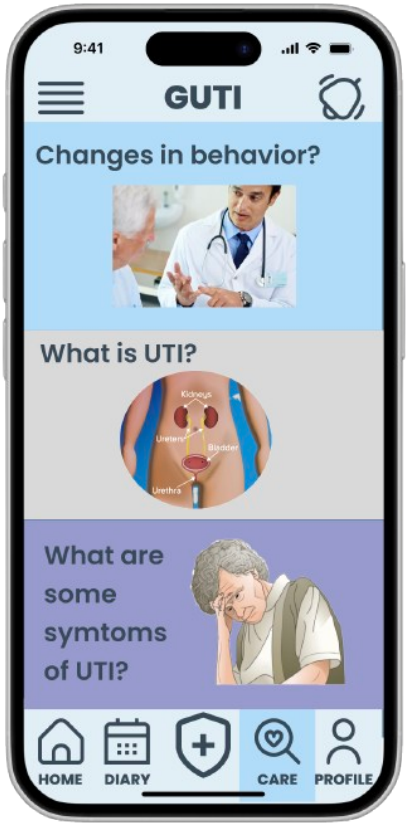

Figure 5.8.

Figure 5.7. GUTI App Tracking Diary Page (Left)
The tracking diary allows caregivers to monitor and record the care details of persons living with dementia (PLWD). Caregivers can share the recorded data via Facebook, Instagram, or email. A "share" icon is conveniently located in the upper-right corner of the app, next to the "My Diary" section.
Figure 5.8. GUTI App Care Page (Right)
The care page provides educational content on UTIs, including caregiving tips and UTI protocols. It also offers links to external resources such as the Alzheimer's Association, Dementia Society, and Alzheimer's Disease Research Center (ADRC), among others.

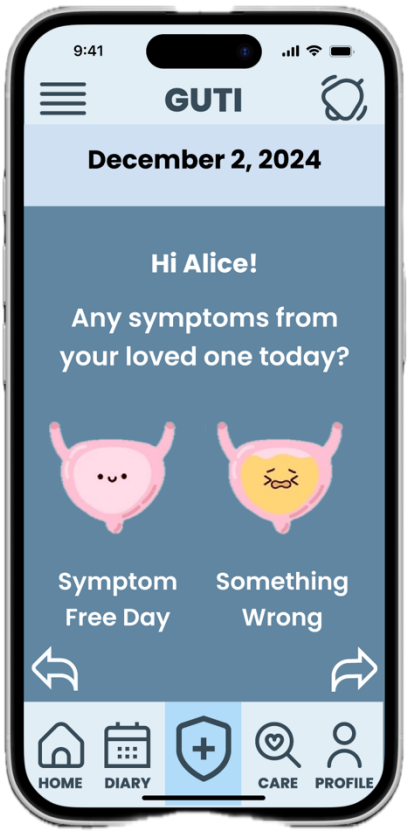

Figure 5.9.

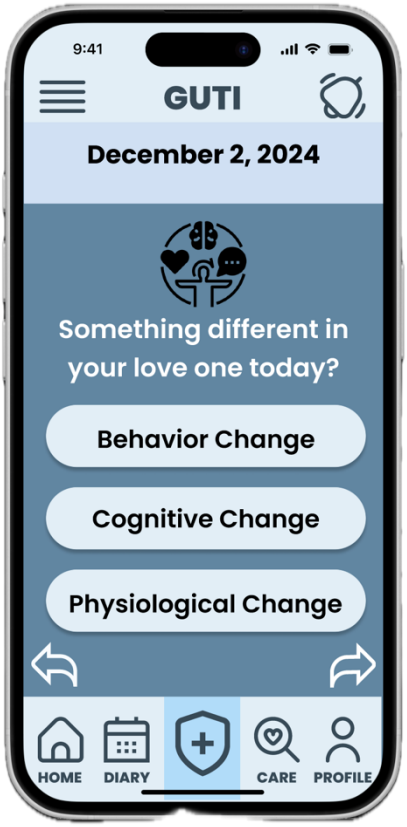

Figure 5.10.

Figure 5.9. GUTI App Recoding/Symptom Tracking Page.
Figure 5.10. GUTI App Recoding/Symptom Tracking Page (continued).
The symptom tracking and recording page enables caregivers to log urinary-related information for persons living with dementia (PLWD), such as UTI symptoms, diaper changes, dietary supplements, water intake, and bowel movements.