

Candidate number: 10010

Exploring the User Experiences of People with Dementia and their Caregivers Interacting with Mental Health Chatbots for Dementia Care, Treatment and Follow-up: A Scoping Review

Bachelor's thesis in Psychology
Supervisor: Lucas Bietti
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PSY2900 Bachelor's thesis

In-Depth Research in Psychology

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NTNU Dragvoll, spring 2023

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PREFACE AND SELF-DECLARATION

The framework of this study occurs within a theoretical research project planned by the project supervisor, called "PSY2900 - In-Depth Research in Psychology - BA13: Mental health chatbots: A scoping review". The research project focuses on user experiences of mental health chatbots in relation to specific disorders, where the undersigned and four other fellow students from an associated research group were each able to choose a different mental disorder for each individual assignment. The majority of the literature in the thesis I have found myself through various search engines, but some literature regarding methodological guidance for the conduct of scoping reviews (ScR) has been recommended by the supervisor.

The research group of students associated with this bachelor's project has not previously carried out extensive literature searches on their own, so some information and joint training was given under the guidance of the supervisor, before the final literature search based on each student's selected topic was carried out individually. The search terms in the current ScR were suggested by the supervisor, with the possibility of further narrowing the search individually if necessary.

The selection of evidence sources was carried out by using independent fellow students from the associated research group as second and third reviewers during the screening process. Also, on 20% of the selected publications, relevant data were extracted and coded by two reviewers independently. The rest of the work on the thesis was done individually, including defining the ScR research question and objectives, developing the charting table for mapping data extractions, extraction and coding of relevant data, identification and elaboration of the themes, and finally discussing the results, limitations of the ScR process, and conclusions. The thesis is designed in accordance with APA 7th standard.

I would like to thank the fellow students in the associated research group for valuable discussions, especially around the actual execution of the ScR, and the writing process. One student in particular stood out for her continuous willingness to discuss and evaluate details and issues that arose along the way. I would also like to thank the supervisor for being available and answering questions at all times. Thanks to my good friend who took the trouble to proofread the thesis before submission. In addition, I would also like to express enormous gratitude to my boyfriend and my son for their patience and support throughout the entire semester, and especially during the periods when I was very much in the "writing bubble".

With this said, I declare this work to be my own.

ABSTRACT

Background: The global trend of an increasing ageing population means that the number of people suffering from dementia will gradually increase in the future, and at the same time there will be a shortage of healthcare personnel. The use of chatbots can bring great benefits to people with dementia (PwD) by complementing existing pharmacological and non-pharmacological dementia care, treatment and follow-up.

Objective: This Scoping Review (ScR) aims to explore user experiences of PwD and their caregivers interacting with mental health chatbots regarding dementia care, treatment and follow-up. And finally provide recommendations for future research and application of chatbots, based on observed gaps in the literature.

Methods: This ScR was carried out by conducting and analyzing an extensive literature search. Considering the novelty of the field, the literature was analyzed using a modified thematic analysis to map predefined themes related to user experiences, while also searching for any new emerging themes.

Results: Of 258 publications initially identified, 12 were included in the ScR. Seven themes were identified and elaborated after analysis of the publications; Application areas, Attractiveness, Usefulness, Adaptability, Safety, Research frameworks, and Limitations.

Conclusion: Mental health chatbots are found to have the potential to be useful tools for PwD and their caregivers in dementia care, treatment, and follow-up. However, further research need to be aware of the limitations, and address challenges to better meet the needs and preferences of individual users.

Key Words: *chatbots; conversational agents; dementia; caregiving; user experience.*

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Background

The global population is experiencing a trend of increased longevity, with a concurrent rise in the number and proportion of older adults in all countries. This population ageing phenomenon began in high-income nations, but is projected to increasingly affect low- and middle-income countries. By 2030, one in six people worldwide will be over 60 years old, with the number of people aged 60 or older projected to double from 1 billion in 2020 to over 2 billion by 2050. As a result, healthcare and social systems will face major challenges to accommodate this demographic shift adequately (World Health Organization, 2023).

As the world's population ages, there is a heightened risk of dementia development due to advancing age. This trend will lead to an increase in the number of older adults with various types of dementia, and consequently, an increased demand for healthcare services. Currently, over 55 million people worldwide live with dementia, and nearly 10 million new cases occur annually. Dementia is a leading cause of disability and dependence among older adults globally, ranking as the seventh leading cause of death worldwide. Dementia's effects can be overwhelming and extend beyond those diagnosed with it, impacting their families, caregivers, and society as a whole. Dementia care often faces challenges of stigma, awareness, and diagnosis barriers (WHO, 2023). At the same time WHO estimates a projected shortage of 10 million healthcare personnel by 2030, mainly in low- and lower-middle-income countries (WHO, n.d.).

To help this situation, the use of mental health chatbots (MHCs) may reduce the pressure by reducing the need for physical personnel. However, it is unclear what kind of information is available in the existing literature about user experiences (UX) of people with dementia (PwD), their caregivers and healthcare personnel interacting with MHCs regarding dementia care, treatment and follow-up. Based on this, a scoping review (ScR) was conducted in order to systematically map the research done in this area, and from this identify any gaps in existing knowledge about how the use of chatbots contributes to helpful support for everyone involved in the management of dementia.

Dementia

Dementia is a common designation used to describe a wide range of symptoms associated with a reduction in cognition and functional capacity, including memory loss, communication difficulties, mood swings, behavior, confusion, spatial orientation, learning, judgement, motivation, and other symptoms that significantly impair the performance of daily life. It is typically associated with ageing, with exponential risk of developing dementia as the individual grows older. Dementia can result from various underlying diseases and injuries that primarily or secondarily affects the brain, such as Alzheimer's disease (AD), Parkinson's disease (PD), Huntington's disease, stroke, head injury, infections, medications, or vitamin deficiencies (WHO, 2023).

Risk factors, causes and prevention

As previously mentioned, ageing is the most important risk factor for dementia. Other non-modifiable risk factors includes genetic factors like female gender and ethnicity (Arvanitakis et al., 2019). Modifiable risk factors includes hypertension, diabetes, diet (e.g.

nutrients, fatty acids), body mass index >30, smoking, alcohol consumption, medication usage, exposure to environmental factors like aluminum and possibly several other metals (e.g. iron, copper and zinc), lower education level, and limited physical, social, and cognitive activities (Arvanitakis et al., 2019; Chen et al., 2009). The risk of developing dementia can also be related to comorbidity with a variety of diseases like HIV, hepatitis C, traumatic brain injury, stroke, infections, and depression (Chen et al., 2009). Risk and protective factors appear to vary with age, but in the absence of prophylactic treatment, it seems likely that maintaining a healthy lifestyle may be the best option for preventing dementia (Peters, 2009). Currently there are several ongoing trials testing the effectiveness of electronic health (eHealth) and mobile health (mHealth) interventions in high-risk individuals (Eggink et al., 2019).

Symptoms and diagnosis

Through the natural development of dementia, each individual will experience the personal change in different ways, depending on the underlying causes, additional diagnoses and health conditions, and the individuals cognitive functioning before the cognitive and behavioral symptoms of dementia appear. As people age, some degree of cognitive slowing is to be expected due to loss of healthy working neurons in the brain, resulting in lack of contact between brain cells. Suffering from dementia, often denoted as a neurodegenerative disease, patients experience a far greater decline than what is expected from normal ageing (National Institute on Aging, 2022).

There are some common early symptoms that may appear prior to a possible diagnosis of dementia, including memory loss, difficulties concentrating and/or conducting familiar daily tasks, struggles to follow a conversation or to find the right words, confusion

about time and place, and mood swings. These early symptoms are usually mild and may worsen gradually over a long period of time, and are often called "mild cognitive impairment" (MCI) as the symptoms are not of sufficient severity to be diagnosed as dementia (National Health Service, 2020). Further symptoms may appear as poor judgement, impaired spatial orientation ability (e.g. wandering and getting lost in familiar environments), problems handling money responsibly, repeating questions, lack of interest in usual activities, excessive impulsivity, inappropriate behavior, apathy or insensitivity, losing balance and/or having problems with movement or walking, hallucinating, delusions, paranoia, difficulties recognizing relatives and friends, diminished personal hygiene, aggression, dyspnea, pneumonia, episodes of fever, eating problems, stress, anxiety, and depression (Cerejeira et al., 2012; Mitchell et al., 2009; NIA, 2022; WHO, 2023).

In the process of setting a potential diagnosis, the challenge is to identify whether the individuals changes are clinically significant. Dementia is usually diagnosed when the cognitive impairment has become sufficient enough to compromise social and/or occupational functioning, and interfere with independence in daily life activities. MCI is a state between normal cognition and dementia. Functional abilities is mainly preserved, but still represents a decline from a previously higher level of functioning, and should be documented through both history and objective evaluation (Hugo & Ganguli, 2014).

MCI may appear to be a preliminary stage of developing dementia of some sort, but it is not certain that dementia will occur as the symptoms of MCI may remain the same or even improve over time. Nevertheless, more people with MCI than people without it will eventually develop dementia, where about 10-20% of people aged 65 or older with MCI develop dementia within a one-year period (NIA, 2021). The signs and symptoms in the course of the disease can be divided into three phases; (1) Early stage: is often overlooked

because of the very gradual onset, and includes mostly forgetfulness, losing track of time, and getting lost in familiar places. (2) Middle stage: signs and symptoms become more apparent, and may include confusion, behavior changes, repeated questions, and problems communicating. (3) Late stage: is near total dependence and inactivity, with serious disturbances in memory and severe physical signs (WHO, 2023).

The International Statistical Classification of Diseases and Related Health Problems - Tenth Version (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition (DSM-V) define the core features of dementia by chronic, acquired loss of at least two or more cognitive abilities caused by brain disease or injury, including memory. The recently updated DSM-V state that dementia can also be present with severe impairment in only one single domain (Arvanitakis et al., 2019; Cerejeira et al., 2012).

First of all, the process of considering possible dementia requires obtaining the medical history focusing on cognition and functioning, retrieved from both the patient and close relatives, friends, and caregivers. This is considered the most important diagnostic tool, and is very useful because the patients may not be able to tell their story thoroughly enough by themselves. In addition, a short outpatient or bedside examination is carried out, and if necessary a neuropsychological testing. This medical history also forms the basis of the etiology of dementia, in addition to physical examinations (e.g. neurologic and pertinent systemic signs), laboratory testing (e.g. thyroid function, vitamin B₁₂ level, and other indicated metabolic, infectious, or autoimmune tests), structural brain imaging (CT or MRI), and in some cases neurophysiologic (EEG), vascular (MRA or CTA), or cardiac (ECG) tests (Arvanitakis et al., 2019). The etiological subtypes most likely to be seen in geriatric psychiatry settings is AD, Vascular Dementia, Frontotemporal Dementia, Dementia with Lewy bodies, Neurocognitive disorders due to PD or Prion disease (Hugo & Ganguli, 2014).

AD is the most common type of dementia, and accounts for approximately 60-70% of the cases (WHO, 2023).

Self-care

PwD can take measures to help manage their symptoms. These include maintaining physical activity, consuming a healthy diet, abstaining from smoking and drinking alcohol, creating memory aids, engaging in hobbies and other activities, exploring new methods to maintain cognitive stimulation, socializing with friends and family, joining local support groups, receiving regular check-ups with healthcare providers, and planning ahead for future decision making. Trusted individuals should be identified to provide support in decision making and communication of preferences, and identification with address and emergency contacts should be carried when leaving home (WHO, 2023).

Self-awareness

PwD frequently experience a condition known as "loss of insight" or "anosognosia", where they are unable to identify neurological symptoms within themselves. Anosognosia for cognitive and behavioral impairment that occurs in dementia is clinically relevant, and has important consequences for compliance with treatment and burden of caregivers. For PwD on the frontotemporal spectrum, anosognosia for behavioral disturbances may be a consequence of their inability to evaluate other people's responses to their own inappropriate behavior, reflecting a dysfunction of fundamental mechanisms involved in self/others knowledge (Zamboni et al., 2010). Empirical data indicates that in AD, despite the presence of impairment in higher-level autobiographical awareness, lower-level facets of

self-awareness such as bodily ownership and the capacity for independent action endure, thus facilitating a prolonged sense of self-awareness (Mograbí et al., 2021).

Comprehending the phenomenon of anosognosia is crucial in developing efficacious MHCs supporting dementia care. It highlights a significant barrier to delivering effective dementia care and treatment, as anosognosia can prevent patients from adhering to treatment plans, placing a greater burden on their caregivers. Therefore, understanding the potential of MHCs to support dementia care and treatment is critical, as chatbots can offer education and support to both PwD and caregivers, and address the challenges associated with anosognosia.

Impact on caregivers

In 2019, informal caregivers like family members and friends on average spent five hours a day providing care for PwD, which obviously can be pretty overwhelming. About half of the global cost of dementia is attributed to informal care (WHO, 2023). Caregivers of early onset PwD experience high levels of stress and depression, facing a range of psychosocial problems, including conflicts and difficulties within relationships, families, and at the workplace, financial problems, lack of social support, and negative experiences during the diagnostic process. These problems are partly related to their life phase due to, for instance, changed future expectations, a disruption of the life course, and changes in and loss of roles (Van Vliet et al., 2010).

Lindeza et al. (2020) conducted a comprehensive review of caregiving experiences for PwD. Positive aspects of caregiving include the opportunity to engage in meaningful activities with loved ones and access to disease-related information. However, caregiving also presents challenges such as emotional distress, social isolation, and difficulty balancing

caregiving responsibilities with personal life and work. The importance of early diagnosis of dementia is emphasized, as it leads to improved care and relief for caregivers. Caregivers may benefit from pharmacological and psychological support, and formal resources such as healthcare professionals. Difficulties in communication with healthcare services, and managing social care services were reported, highlighting the need for improved support for caregivers (Lindeza et al., 2020).

Social and economic impact

Cipriani & Borin (2015) state that the sociocultural context of dementia shapes its experience, and its conceptualization varies across cultures. Dementia is often stigmatized in modern Western societies due to the emphasis on high cognitive function. This stigma can have a social and economic impact on affected individuals and their families. Cultural factors, including those specific to minority populations, may affect the recognition and treatment of dementia. The lack of understanding of dementia among ethnic minority groups may exacerbate existing health disparities (Cipriani & Borin, 2015)

Dementia has significant social and economic implications in terms of informal care costs, social care costs and direct medical costs. The estimated total global societal cost of dementia was \$1.3 trillion in 2019, and this cost is expected to more than double by 2030 as both the number of PwD and the cost of care increase (WHO, 2023).

Management, treatment and care

Currently, there exists no treatment available to cure dementia. Yet, much can be offered to support and improve the lives of PwD and their caregivers and families. The main principle for dementia care is early diagnosis in order to promote optimal management at an

early stage of the disease. Understanding and managing behavior changes can be helped by providing information and long-term support to caregivers (WHO, 2023). The management of dementia is multifaceted, as it depends on the specific symptoms and underlying causes, and may include lifestyle changes, therapy, and/or medication. Due to the complexity of symptoms, personalized approaches tailored to each individual patient and caregiver are required (Kales et al., 2015).

Incorporating various components such as information dissemination, didactic instruction, role-playing, problem-solving, skill training, stress management techniques, and telephone support can be effective in alleviating caregiver burden and depression, delaying nursing home admission, and improving the quality of life for PwD. The management of PwD requires a holistic approach that involves collaboration between healthcare professionals, doctors, and families. Caregivers who are vulnerable to negative consequences can be identified and targeted for interventions (Brodaty & Donkin, 2009).

Overall, the primary objective is to prevent any deterioration in the quality of life that may arise due to cognitive impairment and other symptoms, while simultaneously delaying the advancement of cognitive decline. Both non-pharmacological and pharmacological modalities can accomplish this objective (Arvanitakis et al., 2019). Non-pharmacological interventions are preferred, with the involvement of family caregivers being the most evidence-based approach. However, pharmacological treatments, specifically antipsychotics, may be necessary in some cases despite the associated risk-benefit concerns (Kales et al., 2015).

Pharmacologic management

According to Tible et al. (2017), the use of pharmacologic management for dementia symptoms should be approached with caution due to the increased vulnerability PwD have to medication side effects, as well as the complicating factors of multimorbidity and polypharmacy. The majority of medications used for dementia symptoms are not approved for such use and are therefore used off-label. Prior to initiating medical therapy, a detailed clinical and laboratory examination, including medical history and ECG, should be conducted.

The use of psychotropic medication should be limited, and gradually reduced when symptoms improve. Elderly patients typically require lower dosages of psychoactive medication due to altered medication metabolism. Examples of medications include cholinesterase inhibitors, memantine, antidepressants, antipsychotics, mood stabilizers, benzodiazepines, hypnotics, and sedatives (Tible et al., 2017).

Non-pharmacologic management

A recent review on the diagnosis and management of dementia suggested that referral to specialists such as clinicians, social workers, occupational or speech therapists may be beneficial for patients with complex manifestations of dementia (Arvanitakis et al., 2019). The authors also suggest potential advantages of non-pharmacological treatment in dementia, which are generally safe and inexpensive. Cognitive training, reminiscence therapy, physical exercise, social activities, and a brain-healthy diet may improve cognition and function, psychological well-being, and cardiovascular health.

Palliative care may be useful in the terminal phase of dementia. Caregivers should monitor patient safety at home and outside, receive education and clinical attention. Behavioral problems such as physical aggression are associated with poor outcomes and can

potentially be addressed by redirecting the patient's attention to something they enjoy (Arvanitakis et al., 2019).

According to Tible et al. (2017), biological interventions such as light therapy and electroconvulsive therapy could be considered as potential treatments for dementia-related symptoms. Morning light therapy and a combination of light therapy and melatonin at bedtime may prove beneficial in addressing sleep or circadian rhythm disturbances, since sleep deprivation can exacerbate symptoms of dementia, potentially leading to increased agitation. Electroconvulsive therapy may also be applicable in selected cases, while repeated transcranial magnetic stimulation may hold promise as a potential therapeutic approach. However, further research is required to fully evaluate the efficacy of these interventions for addressing dementia symptoms (Tible et al., 2017).

Chatbots

In this thesis, as often elsewhere, the word "chatbot" is used as a common and interchangeable term for both *chatbots* and *conversational agents* (Io & Lee, 2017). These are both types of computer software designed to simulate human conversation. However, it can be stated that all chatbots are conversational agents (CAs), but not all CAs are chatbots. Hence, there are some differences between the two (Chatbot Business Framework, 2020).

CAs is software designed to simulate human conversation through text or voice interactions, often over the internet, and uses natural language processing (NLP) and machine learning algorithms to understand and respond to user requests in a human-like manner. CAs can either be rule-based where they follow a set of predefined rules to respond to user requests, or they can be powered by artificial intelligence (AI) where they use machine learning to learn from user interactions and improve their responses over time. CAs

can be integrated into various communication channels such as messaging platforms, websites and mobile apps. They are used for various purposes, including customer service, lead generation and marketing automation. CAs can be goal-oriented with a pre-programmed conversation structure where the CAs controls the conversation flow by asking targeted questions to direct the flow. In case of dialog confusion, the CAs will ignore user input that does not answer the question. Therefore, there is not much flexibility for the user to control which way the conversation goes (CBF, 2020).

On the other hand, a chatbot is a type of CAs designed to handle full conversations, allowing for the context switching and unstructured dialogue that can occur in human to human conversation. In short, a *chatbot* is a specific type of CAs designed to respond to user requests, while *conversational agents* is a broader term that includes any computer program designed to simulate human conversation (CBF, 2020).

Embodiment

A type of CAs that combines NLP and AI with robotics or animation technology to simulate human-like social behavior and interaction is called embodied CAs (ECAs). ECAs have a physical embodiment, such as an animated pet, avatar, or robot, which enables them to use non-verbal behaviors and gestures to communicate with users in a more natural and engaging way than traditional chatbots (Bickmore & Cassell, 2005; Cassell, 2000). ECAs are designed to engage in social dialogue with users, which involves understanding the user's intentions, emotions and social context, and responding appropriately using verbal and non-verbal cues (André & Pelachaud, 2010).

Objective

The objective of this ScR was to provide an overview of the existing research literature on the use of MHCs in relation to dementia, examine how research is conducted, and identify key characteristics and factors related to the field. This review aims to explore the UX of PwD, their caregivers (both formal and informal) interacting with MHCs regarding dementia care, treatment and follow-up. And finally, based on the observed knowledge gaps in the literature, provide recommendations for future research and application of chatbots.

METHODS

Protocol

To achieve the abovementioned objective, a ScR was conducted, which is defined as an initial exploration of the available research literature which follows a systematic method in order to map evidence on a certain area and identify its scope, size, and nature. This ScR followed the updated methodological guidance for conducting systematic ScR published by the Joanna Briggs Institute (JBI) (Peters et al., 2017; Peters et al., 2020), supported by the use of the Preferred Reporting Items for Systematic reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018).

Eligibility criteria

This ScR only assessed primary research, encompassing peer-reviewed publications, dissertations, and conference proceedings. Non-primary research such as reviews, conference abstracts, proposals, and editorials, were excluded.

The main focus in this ScR was to explore the UX of PwD and their caregivers and healthcare personnel interacting with MHCs regarding dementia management such as general care, implementation of treatment, complementing general treatment, monitoring and follow-up of the disease, and as support for caregivers. The research had to be conducted centered around persons diagnosed with some sort of dementia, PwD caregivers, and health personnel related to dementia patients. Although MCI is often closely linked to dementia, it was excluded because, as mentioned earlier, it is not a given that it will develop into dementia. Only chatbots that work on stand-alone software and web browser platforms were taken into consideration. Other non-chatbot applications such as robotics, serious games, SMS, and telephones, were excluded. Publications on the development process of chatbots, and chatbots related to general health or other diseases were also excluded. Eligibility criteria are summarized in Table 1.

Table 1

Eligibility criteria

Aspect	Inclusion criteria	Exclusion criteria
Population	Persons with dementia (PwD).	Mild Cognitive Impairment (MCI).
	PwD caregivers and healthcare personnel.	Other mental or general health care.
Concept	User experiences with mental health chatbots.	Robotics, serious games, SMS, telephones, and other non-chatbot applications.
	Chatbots that work on stand-alone software and web browser platforms.	The development process of chatbots.
Context	Interaction with chatbots regarding dementia care, treatment and follow-up.	Digital interventions without use of chatbots throughout treatment course
Publication type	Primary research findings: e.g. peer-reviewed articles, dissertations, conference proceedings, reports.	Non-primary research; e.g. systematic/scoping reviews, conference abstracts, proposals, editorials.

Information sources

For the purpose of the current ScR, the following six electronic databases were searched 16.-17. February 2023; Medline (EBSCO), IEEE Xplore, PubMed, Scopus, Web of Science, and Google Scholar. Medline was the only database with search on MeSH-terms. Only the first 100 citations from the Google Scholar search were included in this ScR, because Google Scholar usually retrieves hundreds of citations sorted by relevance to the search topic. As the field of chatbots is relatively new, no restrictions were set in relation to either year of publication, language or origin.

Search strategy

The search terms in the current ScR were suggested by the supervisor, based on the Population-Concept-Context (PCC) mnemonic as recommended by JBI (Peters et al., 2017). The searches were conducted in English as there are probably not many reports in other languages, and contained the exact same search-string on all databases:

("chatbot" OR "conversational agent*" OR "virtual agent*" OR "chatterbot*")
AND ("dementia*")*

Selection of included publications

The search results from each database were imported into Excel files, which in turn were merged into a compiled file that was cleaned of duplicates before further review. First, two reviewers independently screened the titles and abstracts of all retrieved studies to select potential relevant studies for the ScR. Next, the same reviewers independently

screened the full texts of the studies included from the first step for further selection. Any discrepancies between the reviewers were resolved by consulting a third reviewer.

Data extraction process and themes

Initially, data on publication characteristics were extracted, i.e. year of publication, location, type of publication, type of chatbot, study design, setting, sample size, sample type, mean age, sex, themes treated.

Further, as the conceptualization of the research question in this ScR is about UX, a user-centered research design questionnaire based on the System Usability Scale (SUS) (Brooke, 2013), and a short version of the User Experience Questionnaire (UEQ-S) (Schrepp et al., 2017), was used as foundations to propose potential themes when developing the charting table for mapping potential data that could be extracted from the included publications.

By perusal of the publications, a modified form of Thematic Analysis (TA), inspired by Braun & Clarke's (2006) framework for TA, was used as an a priori approach to search for the predefined themes, while also using an inductive approach searching for any new emerging themes and subthemes of interest to the objectives of the research question. On 20% of the selected publications, relevant data were extracted and coded by two reviewers, while the remaining material was processed independently.

Methodological quality assessment

Methodological quality or risk of bias of the included publications was not assessed, which is in accordance with guidance on conducting ScR (Peters et al., 2020).

Data synthesis

To examine the objective of how the execution of previous research has been conducted, and to identify key characteristics and factors related to the research question concerning the field of MHCs regarding dementia care, the extracted data were synthesized using a modified TA to search for the predefined themes, while also searching for any new themes. This was done by extracting text excerpts relevant to the research question from the publications connected to the predefined themes (i.e. usefulness, attractiveness, adaptability, safety, accessibility) and to the additional themes that emerged (i.e. application areas, research frameworks, limitations), in order to finally form an overview of what existing research has already mapped, and what has not been covered. The publication characteristics were summarized in a table and described narratively. Also, a narrative description of the main characteristics of each theme treated in the included studies was presented.

RESULTS

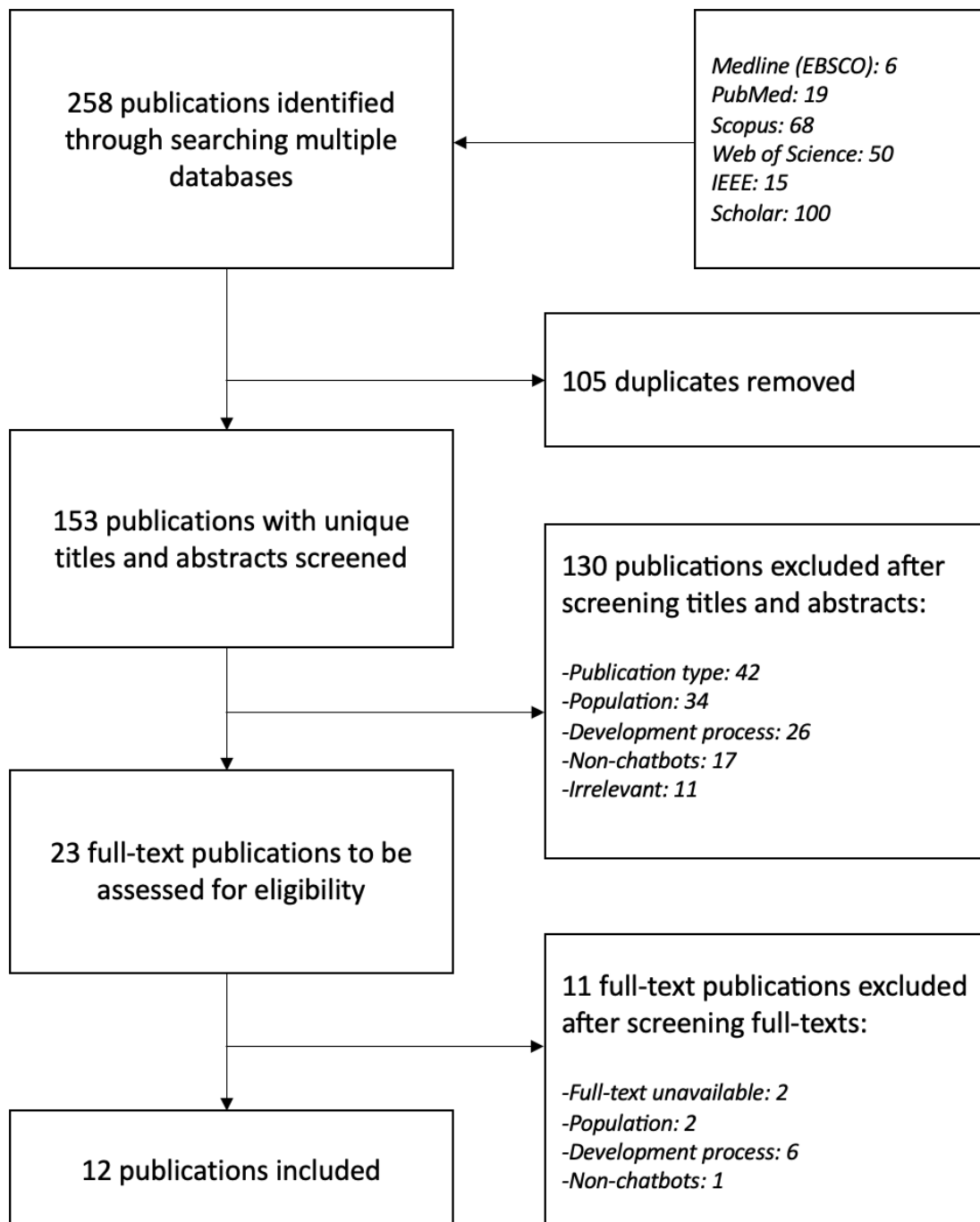
Selection of included publications

As shown in Figure 1, the literature search conducted by using six digital databases resulted in 258 publications, and a total of 105 duplicates were removed. After a relevance review of the remaining 153 unique titles and abstracts, 130 publications were excluded. After further eligibility assessment of the 23 potentially relevant full-text publications, in total 11 publications were excluded due to unavailable full-text (2), not meeting population criteria (2), dealing with development process handling (6), and non-chatbot application (1). Finally, 12 publications were included. The full list of included publications is shown in Appendix A.

Interrater reliability between reviewers in both steps of the screening process were assessed in SPSS using Cohen’s Kappa (McHugh, 2012), with respective outcomes of 0.86 and 0.91, indicating very strong agreement.

Figure 1

PRISMA-ScR Flowchart of the study selection process



Characteristics of included publications

As shown in Table 2, all publications are published quite recently, between 2018-2022. 58% of the studies were conference proceedings, and only two studies were conducted outside European countries. 58% of the publications handled non-embodied chatbots, 33% handled embodied chatbots, and one study handled chatbots in general. 58% of the studies used mixed research design, 42% were conducted in institutional settings, and 25% in home environment. 74% of the sample consisted of PwD, while the proportion of caregivers, professionals and healthy adults was fairly evenly distributed. Mean age of participants were reported in six studies, some of these reported from several groups, and the main body of participants was aged 65 and up. Sex was reported only in four studies, where the distribution was 63% females and 37% males. Almost all of the themes were treated in half or more of the publications, except for the predefined theme "Safety" that was treated in four publications (33%).

Relevant data within each included publication

After analyzing the included publications in relation to the research question and objectives, seven main themes and subthemes within each theme were identified: (1) Application areas, (2) Attractiveness, (3) Usefulness, (4) Adaptability, (5) Safety, (6) Research frameworks, and (7) Limitations. The predefined theme "Accessibility", which dealt with availability and findability, was covered to such little extent that the theme was chosen to be removed from further elaboration. Table 3 shows in which publications each theme is treated, and the frequency of each theme. Each of the themes identified is elaborated in the following subsections.

Table 2*Summary of the characteristics of the included publications (N = 12)*

Characteristics	Number of studies	
Year of publication	2022: 3 2021: 3 2020: 1	2019: 2 2018: 3
Location ¹	Italy: 4 Luxembourg: 3 Spain: 2 Netherlands: 2 Switzerland: 1	England: 1 Germany: 1 Japan: 1 France: 1 Malaysia: 1
Type of publication	Conference Proceeding: 7 Journal article: 4 Preprint: 1	
Type of chatbot	Non-embodied: 7 Embodied: 4 General: 1	
Study design	Mixed: 7 Field study: 2 Survey: 1	Experimental: 1 Focus groups: 1
Setting	Institutional: 8 Home: 2	Workshops: 1 Video conference: 1
Sample size ²	<10: 3 10-19: 3 20-29: 2	30-39: 2 >40: 1
Sample type	PwD: 150 Caregivers: 21	Healthcare professionals: 17 Healthy adults: 14
Mean age ³	<60: 1 60-65: 0 65-70: 2	70-75: 2 >75: 4
Sex ⁴	Female: 63% Male: 37%	
Themes treated ⁵	Research frameworks: 12 (100%) Application areas: 11 (92%) Limitations: 11 (92%) Usefulness: 10 (83%)	Attractiveness: 9 (75%) Adaptability: 6 (50%) Safety: 4 (33%)

Notes¹ Numbers do not add up as some studies was conducted in several countries.² Numbers do not add up as one study did not report sample-size.³ Mean age was reported in 6 studies, some studies reported from several groups.⁴ Sex was reported in 4 studies.⁵ Numbers do not add up as most studies treated several themes.

Table 3*Relevant data within each of the included publications (N = 12)*

Theme	Frequency	Publication ID ¹
Research frameworks ²	12 (100%)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12.
Limitations ²	11 (92%)	1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12.
Application areas ²	11 (92%)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11.
Usefulness ³	10 (83%)	2, 3, 4, 5, 6, 7, 8, 9, 11, 12.
Attractiveness ³	9 (75%)	1, 2, 4, 5, 6, 8, 9, 11, 12.
Adaptability ³	6 (50%)	1, 7, 8, 9, 11, 12.
Safety ³	4 (33%)	5, 8, 9, 10.
Notes	¹ ID-numbers given for each included publication as shown in Appendix A and Table 2. ² Emerged themes. ³ Predefined themes.	

Application areas

This theme deals with the chatbots content and areas of use in relation to dementia care, how it is intended to be used and application functions. This shows the versatility that can be achieved by being able to use chatbots as part of dementia care. This theme was treated in 11 (92%) of the publications.

Digital information and communication technology, especially touch screens, are seen as tools that can support cognitive functions. Assisting individuals with memory loss and cognitive impairment not only reduces the workload for their formal and informal caregivers but also promotes their ability to live autonomously in their own homes. Several application areas are mentioned in the publications included in this ScR; detection of cognitive impairment and dementia signs (De Arriba-Pérez et al., 2022; Mirheidari et al., 2019; Ujiro et al., 2018), reminiscence therapy (Carós et al., 2020), health and therapeutic monitoring (De Arriba-Pérez et al., 2022; Stara et al., 2021b), controlling home appliances (Wargnier et al., 2018), entertainment (e.g. news broadcast service, radio, listening to music, playing games) (De Arriba-Pérez et al., 2022; De Jong et al., 2018; De Jong et al., 2019; Stara

et al., 2021a; Stara et al., 2021b), telling the time (Stara et al., 2021a), scheduling and reminders about things that are typically forgotten by PwD (e.g. daily agenda, appointments, activities, medication, drinking water) (De Jong et al., 2018; Koebel et al., 2022; Stara et al., 2021b; Wargnier et al., 2018), promote social support and socialization (e.g. suggest contacting others by making phone calls or video calls via voice commands or touch screen) (Koebel et al., 2022; Stara et al., 2021b), motivate to activation (e.g. initiate dancing, playing an active game, or going for a walk) (De Jong et al., 2018; Koebel et al., 2022; Stara et al., 2021b), step-by-step task instructions to support everyday tasks (e.g. cooking, using the toilet, dressing, preparing a glass of water, measuring blood pressure) (Wargnier et al., 2018), replacement for human company (Müller et al., 2022), and as a tool for encouragement and effort rewards (Koebel et al., 2022).

Koebel et al. (2022) found that combining physical and cognitive exercises (such as in active games and multi-domain training) has positive effects, and experts believed that adding social components to such interventions could have an even greater effect. Some experts consider loneliness as one of the biggest problems for PwD that chatbots can help with, meaning that they not only support and entertain, but also improve social contact with other people. Along these lines, Müller et al. (2022) found that chatbots can help provide caregivers with some relief and improve self-efficacy by acting as social companions for PwD. This provides valuable help to older people as many live alone, and almost half of people over the age of seventy-five hardly speak to anyone on a daily basis. PwD who interact with the chatbot experience a virtual social companion, relieve their memories and learn a new technology that can in turn help them to master new digital challenges later on.

Automatic detection of dementia is another potential use for chatbots. For example, Mirheidari et al. (2019), Carós et al. (2020) and Ujiro et al. (2018) all propose different

variations of conversation analysis as methods for automatic dementia detection, but these are still under development before they can potentially be used as a supplement or tool for possible diagnosis via chatbot.

Attractiveness

This theme concerns whether the chatbot captures the users attention and interest, and includes desirability, valuableness, personalization and acceptance, and was addressed in 9 (75%) of the publications.

Attractiveness can be linked to the user experiencing similarity to natural settings, which can give a sense of closeness, friendliness and relationship with the chatbot. The attractiveness of the chatbot is a key factor in determining its potential impact, and can be achieved through interfaces that look like pets or humanoid avatars (De Arriba-Pérez et al., 2022; Stara et al., 2021b), using natural language (Carós et al., 2020; De Arriba-Pérez et al., 2022; De Jong et al., 2019; Koebel et al., 2022; Stara et al., 2021b), or through user customization of the chatbot (Koebel et al., 2022; Stara et al., 2021a; Wagnier et al., 2018).

De Arriba-Pérez et al. (2022) model their interface as an animated dog to make the chatbot appealing. They also combine dichotomous and essay questions to achieve similarity to natural everyday speech. Carós et al. (2020) focuses on the chatbot not only being able to generate grammatically correct questions, but also that the generated questions sound like they could be asked by a real person.

Several studies included in this ScR (De Jong et al., 2018; De Jong et al., 2019; Stara et al., 2021a; Stara et al., 2021b) deals with the embodied chatbot for dementia care, "Anne", which was developed, tested, and improved during the project "Living well with Anne" in Italy, the Netherlands and Luxembourg over a three year period between 2017-2020. Stara

et al. (2021b) emphasizes that "Anne" expresses emotions and uses natural language to provide information and emotional feedback. When the user speaks, "Anne" reacts by automatically generating nods, mouth movements, and acknowledgements. They found that the majority (40%) of PwD perceived "Anne" as a friend.

Wagnier et al. (2018) also use a similar interface, an ECA called "LOUISE" (*LOvely User Interface for Servicing Elders*), specifically targeting elderly with cognitive impairments. When an image is displayed, the chatbot avatar points and directs its gaze towards it by turning its eyes and head so that its body position is still facing the user. So when the image disappears, the character turns its head and eyes towards the user again. This is intended to direct the user's attention to the object of interest when necessary. More than half of the participants said they would like to be able to customize the appearance of the chatbot.

It has also been found that empathic chatbots that show improvement in their ability to empathize with the patient can increase compliance, but the chatbot's messages should also not trivialize the seriousness of a patient's condition. Rather, the chatbot should offer coping strategies that support the patient as well as caregivers and family members in managing the condition (Koebel et al., 2022).

Usefulness

Usefulness is about the quality of information and outputs that is appropriate, applicable, and practical, and may include aspects such as user satisfaction, quality, innovation. That is, relevance to fulfill the PwD and their caregivers needs, and the level of comfort by fulfillment of a need. This theme was treated in 10 (83%) of the publications. In general, most PwD and their caregivers confirm the usefulness of a chatbot as help and support for dementia care, although there are currently some technical problems which in

some cases may be due to the novelty of the systems used (De Jong et al., 2018; Stara et al., 2021b; Wagnier et al., 2018).

Koebel et al. (2022) state that perceived usefulness starts with psychological aspects, particularly that patients first of all need to acknowledge and accept their need for support. Some patients try to mask their cognitive decline, and refuse interventions. Others, mainly in advanced dementia, may not be aware of their condition and therefore lack willingness to cooperate.

De Jong et al. (2018) present a critical appraisal of the efficacy of individual functions of "Anne" at different stages of dementia and proposes that customization of these functions is necessary to cater to the unique needs of patients at each stage of the disease. Initially, the chatbot system is passive and is started by the user asking the chatbot to perform a task, while the chatbot just listens. If the user forgets how to ask a certain thing, or uses the wrong command, "Anne" will not respond correctly, leading to frustration, and even stress for the PwD. This is considered to be an emerging problem as the degree of dementia increases. Therefore, an active chatbot that takes the initiative to suggest specific activities is preferred.

Stara et al. (2021b) found "Anne" to be perceived as a useful tool to support memory and enjoyment needs, with medication and gaming functions as the most successful services. Nevertheless, a negative change in perceived usefulness was recorded during the period of use among both PwD and informal caregivers mostly due to technical problems related to speech recognition. Similar problems were also present when Wagnier et al. (2018) performed testing of "LOUISE", as the chatbot sometimes did not react to the users' answers when they did not speak loud enough, or when the users reacted to the chatbot's own speech. In many occasions the user tried to talk to the chatbot while it was not listening

to them. Still, "LOUISE" was found to be suitable for people with moderate dementia who are still able to speak, provided they do not have a severe hearing impairment, and to be most useful as a cognitive prosthesis for PwD, particularly to compensate for memory loss by performing reminders.

Adaptability

This theme is about how easy it is to get to know the chatbot and learn how to use it, whether PwD and their caregivers can solve their tasks without unnecessary effort, and whether the chatbot responds adequately to the users actions. Adaptability may be considered to consist of the changes in effectiveness and efficiency, which means ease of understanding, learning and remembering how to perform basic tasks, and how quickly a user can perform tasks. This theme was treated in 6 (50%) of the publications.

The needs of PwD vary as the disease progresses, encompassing support for memory and various aspects of daily functioning. In general, problems performing tasks were in most cases associated with system errors, not with user errors or too complicated user interfaces. This indicates that the chatbot technology proposed so far is adaptable to a large extent, and that most early and middle stage PwD are competent to use them.

Müller et al. (2022) found that dementia patients can spontaneously use digital devices and touch screens. Stara et al. (2021a) found it strategic to introduce technologies at early stages of dementia to increase the possibility of familiarity with new devices, and ensure the acquisition and/or improvement of digital competence as perceived difficulties become more pronounced as the severity of dementia symptoms increases. This forms a good basis for the technology-based interventions in the middle stage of dementia to move from preventive support to providing actual assistance and monitoring services, adapted to

seniors suffering from forgetfulness, enabling seniors to live independently at home for as long as possible.

Stara et al. (2021b) found discrepancies between perceived and measured adaptability. There was little to no perceived change during the test period of the chatbots, while measurements indicated that actions became effective and targeted after a period of usage. The test users perceived "Anne" as well integrated and easy to use, and people could quickly learn her most important functions.

Wargnier et al. (2018) found that 13/14 participants were able to interact with "LOUISE", and found the instructions easy or very easy to follow, except for one participant with severe cognitive impairment who appeared to be intimidated by the avatar.

While testing user interaction doing reminiscence therapy with chatbot "Elisabot", Carós et al. (2020) discovered that healthy users found it very easy to use and even a bit silly, due to some of the generated questions and comments. Users with MCI found it engaging and challenging due to the effort they had to make remembering the answers for some of the generated questions. However, all users enjoyed interacting with "Elisabot".

Safety

This theme concerns the user's personal security and perceived control over the interaction with the chatbot, whether it is experienced as safe and predictable. Ensuring the safety of chatbot interactions is critical in gaining the trust of users. Dependability, credibility, reliability, privacy and trustworthiness are critical aspects of safety. This theme was treated in four of the publications (33%).

Most people trust human counterparts more than digital solutions (Koebel et al., 2022). Therefore, it is crucial that users experience chatbots as reliable tools as part of

dementia treatment, since there are sometimes no other options in terms of resources. In some cases it may also feel safer for someone to use chatbots instead of human support for various personal reasons. Privacy and security issues arise when other people can hear or read the conversations, and may require special attention with PwD to prevent exploitation, specifically of people with severe cognitive impairments. Users less experienced with technology may not feel secure setting up a device that listens to them, since speech may contain sensitive information.

Koebel et al. (2022) points out that some PwD might be embarrassed by their condition, and may be more willing to ask and accept help from an anonymous, machine-like device than from a human. A structured, somewhat predictable conversation produced by chatbots based on decision tree models can support patients with cognitive impairments, as structure and repetition can make them feel secure.

For people in middle and late stages of dementia, the largest set of technologies are those that increase safety, such as fall detectors, motion-sensitive lights, sensors that measure room temperature and alarm when it gets too hot or too cold, and stove or smoke detectors. At this stage of dementia, active use of safety technology tends to shift to the caregiver, while the PwD often becomes a less active user (Stara et al., 2021b). When it comes to the late stage of dementia, caregivers may have to use the chatbot in a monitored environment for safety reasons, such as nursing homes or daycares due to the fact that dramatic fluctuations in mood and behavior can often occur, and that it is therefore not predictable how individuals will react to what may be experienced as an unknown virtual assistant (Stara et al., 2021a).

Research frameworks

The use of research frameworks is essential to guide the development and evaluation of mental health chatbots. Several research frameworks can guide the development and evaluation of MHCs for dementia care, treatment and follow-up. User-centered design, human-computer interaction models, and measuring technology acceptance can be used to ensure that chatbots are designed to meet the needs of PwD and their caregivers, are user-friendly and are acceptable and effective in supporting their care.

All included publications generally dealt with research questions about whether chatbots can be technology that PwD and their caregivers can use in dementia care, and/or about which design features can facilitate or complicate the use of the chatbots. Both qualitative and quantitative methodology were applied to answer these questions focusing on meanings and understanding of experiences of PwD and their caregivers. All the users in the studies had given informed consent to participate in sessions and observations, and any experimental environments were always under the responsibility of researchers or caregivers. Overall, the publications came to the general assumption that using chatbots is suitable for PwD.

Only two studies were conducted in home environments (Stara et al., 2021a; Stara et al., 2021b), while the rest were conducted in public or institutional settings, and three studies used a sample size above 30 (De Arriba-Pérez et al., 2022; Stara et al., 2021a; Stara et al., 2021b).

Limitations

This theme refers to the identified shortcomings, constraints, or boundaries related to MHCs for PwD and their caregivers. Limitations are important to consider when

interpreting the results of studies examining UX of MHCs for dementia care, and are mentioned in 11 (92%) of the publications.

Several limitations were identified across the publications in this ScR. One of the limitations is the "White coat" effect, which can occur in hospitals or institutional environments when participants alter their behavior or responses because they are aware that they are being observed or part of a study. This can result in skewed results and may not accurately represent the users true experience with the chatbot in a natural setting. A related effect is the "Halo" effect, where participants may respond more positively to the chatbot due to its novelty or perceived benefits. This effect can inflate the perceived effectiveness of the chatbot and lead to overestimation of its impact on the users well-being.

Another limitation is the general use of small sample sizes over a short period of time or a few sessions only, which can reduce the generalizability of the findings. Only three publications included in this ScR had a minimum of 30 participants (De Arriba-Pérez et al., 2022; Stara et al., 2021a; Stara et al., 2021b).

Yet another limitation is the moral and ethical problems that arise when using chatbots to support PwD, particularly in cases where there is potential for harm or deception. For instance locking PwD in the house, and/or observing them using cameras to keep them safe (De Jong et al., 2018), or doubts whether it is respectful to allow PwD to be taken care of by chatbots instead of humans (Koebel et al., 2022; Stara et al., 2021b).

Lack of customization in the chatbots is also a limitation as individual preferences and needs may not be adequately addressed, for instance to specific demographic groups (Koebel et al., 2022), or to different forms and stages of dementia which comes with its own special signs and symptoms where people react and respond differently even within the same diagnosis (De Jong et al., 2018).

Additionally, chatbots may come off as unnatural (Koebel et al., 2022), leading to low levels of acceptance by some users. This can be deteriorated when the chatbot does not respond adequately or produces irrelevant answers (Carós et al., 2020; Stara et al., 2021b), which can decrease its usefulness for some users. Chatbot may also have poor speech with monotonous tone and no stop for punctuation (Stara et al., 2021b).

PwD may also require assistance to handle the chatbot (Carós et al., 2020; De Arriba-Pérez et al., 2022; Stara et al., 2021b), which can impact the usability and effectiveness of the technology. Discrepancies between observations and reported results were identified in some studies (Stara et al., 2021b; Wagnier et al., 2018), suggesting that UX may not always be accurately reflected in survey responses or other forms of data collection. Furthermore, individuals with severe symptoms or late-stage dementia may be excluded from studies (Stara et al., 2021b), limiting our understanding of their experiences with chatbots.

Psychological mechanisms can be complex, and it is important to understand what motivates each individual to use the chatbot and how this motivation affects their experiences. E.g. humanizing digital software can lead to affection or attachment feelings, and reward systems can be addictive if used carelessly (Koebel et al., 2022).

Automatic speech recognition may not always accurately understand user inputs, which can limit the adaptability of the chatbot. Also unintended conversations may be initiated by the chatbot due to speech directed to someone besides the chatbot being picked up (Koebel et al., 2022; Stara et al., 2021b), which can lead to confusion or frustration for users.

DISCUSSION

Summary of evidence

The results of this ScR highlights the importance of considering application areas, attractiveness, usefulness, adaptability, and safety when designing and evaluating MHCs for PwD and their caregivers. Research frameworks are critical in guiding the development and evaluation of chatbots, and limitations should be acknowledged to inform future research efforts.

This ScR identified 12 publications about UX of PwD and their caregivers interacting with MHCs regarding dementia care, treatment and follow-up published between 2018-2022. An overview of the purposes and key findings of each of the included publications are put together and shown in Appendix B. Several studies suggest that chatbots can provide valuable assistance to both dementia caregivers and PwD living alone, and could act as a companion since a significant proportion of people over the age of 75 do not have daily social interactions (Müller et al., 2022). However, there are limitations to the appropriateness, consistency and specificity of chatbot content.

"Elisabot", presented by Carós et al. (2020), was found to generate questions and feedback well formulated grammatically, but not always appropriate in content, tending to produce non-specific responses and losing consistency in its comments. Nonetheless, elderly people with cognitive impairments found the 30-minute reminiscence therapy sessions with the chatbot very pleasant and challenging (Carós et al., 2020). Participants interacting with the chatbot "LOUISE" found the instructions easy to follow (Wargnier et al., 2020). Stara et al. (2021a) and Stara et al. (2021b) found chatbot "Anne" to be useful to help PwD to continue living independently at home with specific adjustments, potentially impacting their

quality of life and to their caregivers. They also found that technology-based interventions in general require personalized features and patient-centered care pathways to be effective.

One study reported that an entertainment chatbot has strong potential for long-term user-friendly therapeutic monitoring of PwD, with a preliminary detection accuracy of cognitive impairment close to 90% (De Arriba-Pérez et al., 2022). Another study obtained dementia detection accuracy of 90.9% for chatbot-led conversations (Mirheidari et al., 2019). Another study found that chatbots could be desirable for PwD if message framing is right. Message framing appears to be of utmost importance, not only to prevent chatbots from belittling or patronizing the users, but to reduce anxiety, motivate, encourage and reward them (Koebel et al., 2022).

Nevertheless, it is essential to remember that chatbots are not a substitute for human interaction and care. They should be used as an integral part of health care alongside traditional care approaches. Many PwD and their relatives may have problems understanding the use of digital aids, which can lead to a reduced ability to accept the benefits of implementing the use of digital aids. Therefore, it is necessary to ensure that chatbots are properly designed, and tested with input from PwD and their caregivers, to ensure that they are perceived as effective and meet their needs.

Limitations of the ScR process

The process of conducting this ScR has some limitations. In order to carry out this ScR and to reach internal resources and network areas from the outside, the searches had to be made connected to NTNU's network, which has limited access to databases due to national negotiations in addition to the NTNU library's own access restrictions.

The literature recommends that librarians carry out the final search in order for it to be as accurate and comprehensive as possible, which was actually the plan in the first place. Unfortunately, meeting appointments regarding this were cancelled by the librarian twice, and due to the fact that we did not have enough time to wait for yet another meeting, the associated student group were compelled to carry out the search on our own.

The searches were conducted in English, so it is possible that there may be found a few more reports in other languages as well. Eligibility criteria were defied to include a couple of publications due to some very insightful and valuable discussions and viewpoints, which applies to a focus group (De Jong et al., 2018) and a poster (De Jong et al., 2019), based on their thorough work in the development process of ECA "Anne". Also, MCI was initially an exclusion criterion, but some of the studies have carried out tests on both PwD and MCI, or only MCI, even though the chatbots are intended for PwD.

Methodological guidance provided by JBI for conducting ScR recommends that at least two reviewers should perform data extraction on the selected publications (Peters et al., 2020). Due to the fact that this is a vast amount of work in relation to the timeframe we have at our disposal for the bachelor's thesis, the supervisor decided that it was okay if data extraction was performed by two reviewers on 20% of the selected publications.

Conclusions

The use of MHCs for dementia care, treatment, and follow-up has gained increasing attention in recent years. This ScR focused on exploring the UX of PwD and their caregivers interacting with these chatbots, and identified seven themes that were relevant to this topic; Application areas, Attractiveness, Usefulness, Adaptability, Safety, Research frameworks, and Limitations..

Application areas were found to include features such as reminders, emotional support, cognitive stimulation, and informational assistance with intent to enhance the quality of life for PwD and their caregivers. Attractiveness was an important aspect, with desirability, valuableness, personalization, and acceptance of the chatbot being essential for user engagement. Usefulness was determined by the quality of information and outputs provided by the chatbot, and it was important that these were relevant to the needs of the users and their level of comfort. Adaptability was also identified as a crucial factor, with the chatbot needing to be responsive to changes in effectiveness and efficiency. Safety concerns the user's personal security and perceived control over the interaction with the chatbot, whether it is experienced as safe and predictable, but has very limited coverage in the publications included in this ScR. This may be related to the fact that the chatbots are still in an early phase, under development, and have not yet been properly implemented as an aid tool on a general basis in dementia care. There is also very little coverage of satisfaction and accessibility, possibly for the same reason.

Research frameworks were found to play a crucial role in the development and evaluation of MHCs for dementia care, treatment, and follow-up, with user-centered design and usability testing being essential components. However, several limitations were also identified, such as small sample sizes, moral and ethical problems, lack of customization, and the complexity of psychological mechanisms, among others. These limitations highlighted the need for continued research in this area, and the importance of user-centered design in the development of MHCs for dementia care, treatment, and follow-up.

Potential implications

The potential implications of the findings of this ScR are significant for the development and implementation of MHCs for PwD and their caregivers. Findings suggest that chatbots can contribute as valuable tools providing personalized support and information, and can be adaptable to the changing needs of users. This can improve the quality of care provided, and help reducing the burden on caregivers.

Another potential implication is that chatbots can be used as a complementary tool to traditional forms of mental health care by providing additional support to users and help bridge the gap between appointments with healthcare personnel.

Limitations of current chatbot technology must be taken into account. Chatbots may not be suitable for all users, particularly those with severe symptoms of dementia or those having difficulty using technology. There may also be ethical concerns around the use of chatbots in dementia care, such as issues around privacy and confidentiality.

Recommendations for future research and application of chatbots

Based on the findings of this ScR, following recommendations for future research and application of chatbots for dementia care can be suggested:

(1) *Increase customization* of chatbots to meet the specific needs of PwD and their caregivers. This can be done by integrating the users preferences, interests, and abilities in the chatbots design and conversation.

(2) *Improve natural language processing* of chatbots to better understand the users responses, including those with severe symptoms and late-stage dementia. This can be done by incorporating more advanced technologies such as machine learning and artificial intelligence.

(3) *Conduct longitudinal studies* to assess the long-term effects of using chatbots on PwD and their caregivers. These studies can also help evaluating the sustainability of the technology and the impact of its continued use.

(4) *Foster user-centered design* approach in the development of chatbots, by involving PwD and their caregivers in the design process, and taking into account their feedback and suggestions.

(5) *Ensure ethical considerations* are taken into account in the development and deployment of chatbots for dementia care. This includes ensuring privacy, security, and informed consent of users, as well as addressing any biases in technology design and deployment.

(6) *Collaboration among stakeholders*, including researchers, healthcare professionals, industry, and regulatory and supervisory authorities, to ensure that chatbots are developed and deployed in an effective, safe, and ethical manner.

(7) *Addressing challenges* such as small sample sizes, discrepancies between reported and observed results, and complex psychological mechanisms in the development and evaluation of chatbots for dementia care.

In terms of future needs, it is important to note that the studies reviewed in this ScR have largely focused on developed countries, and there is a need for further research to be conducted in rural areas and developing countries.

Additionally, there is a need for research to explore how to detect early symptoms of dementia in order to potentially predict the onset of the disease and begin prevention and treatment as early as possible. This could involve developing and testing new screening tools or biomarkers that can detect early signs of cognitive decline.

Finally, there is a need to investigate the potential use of chatbots for making a valid and reliable diagnosis of dementia. This could involve developing and testing chatbots that can accurately assess cognitive function and provide recommendations for further evaluation and treatment.

Summary

This ScR has explored the user experiences of PwD and their caregivers interacting with MHCs for dementia care, treatment and follow-up as reported in the existing literature. Seven themes relevant to this topic were identified and elaborated; Application areas, Attractiveness, Usefulness, Adaptability, Safety, Research frameworks, and Limitations. The chatbots were found to potentially be a useful tool in dementia care for PwD and their caregivers, and could act as everyday companions, as many PwD lack daily social interactions. However, several limitations must be addressed to optimize efficacy, safety, and acceptance. Further research needs to increase customization, improve NLP, conduct longitudinal studies, foster user-centered design, ensure ethical considerations, stakeholders must have collaboration amongst one another, address challenges and limitations of chatbots to better meet the needs and preferences of individual users. In addition, moral and ethical considerations must be taken to ensure that chatbots are developed and implemented in an appropriate and responsible manner.

Overall, future research in these areas could have important implications for improving the early detection and management of dementia, particularly in underdeveloped and rural populations. By implementing these recommendations, future research and application of chatbots for dementia care can be optimized, thereby leading to improved quality of life for PwD and their caregivers.

Table 4

Summary

Existing knowledge on the topic:

- Both the size and the proportion of elderly people in the population are increasing globally because the population worldwide is living longer today than before (“population ageing”), hence more and more people may be at risk of developing dementia due to age.
 - At the same time, the WHO estimates an increase in the lack of health personnel, and hence a lack of mental health care worldwide which calls for the need for appropriate treatment concepts to compensate for this shortage.
 - Chatbots are being developed for various purposes, and are increasingly being used in mental health to meet this shortage.
 - Chatbots with capabilities for natural language understanding and engaging in social dialogue with users have improved in recent years, which involves understanding the user's intentions, emotions and social context, and responding appropriately using verbal and non-verbal cues. This enables researchers and companies to develop chatbots that can be used in treatment.
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Knowledge added through this ScR:

- An overview of reported user experiences and expert opinions on chatbots for dementia care.
 - Identification of relevant themes and research aspects to be considered to improve chatbots for dementia care.
 - Recommendations for future research, application, and implementation of chatbots.
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APPENDIX

Appendix A:

List of publications included in the thesis (N = 12)

ID	Author(s)	Year	Publication title	Type	Link
1	Carós, M., Garolera, M., Radeva, P. & Giro-i-Nieto, X.	2020	Automatic Reminiscence Therapy for Dementia.	Proceeding	Carós et al.
2	De Arriba-Pérez, F., García-Méndez, S., González-Castaño, F. J. & Costa-Montenegro, E.	2022	Automatic detection of cognitive impairment in elderly people using an entertainment chatbot with Natural Language Processing capabilities.	Article	De Arriba-Pérez et al.
3	De Jong, M., Stara, V., Von Döllen, V., Bolliger, D., Heerink, M. & Evers, V.	2018	Users requirements in the design of a virtual agent for patients with dementia and their caregivers.	Proceeding	De Jong et al.
4	De Jong, M., Hetinga, M., Stara, V., Evers, V. & Li, J.	2019	Eldertainment or functional necessity? How virtual agents affect the home lives of people with dementia using the quality of life (QOL-AD) scale.	Proceeding	De Jong et al.
5	Koebel, K., Lacayo, M., Murali, M., Tarnanas, I. & Çöltekin, A.	2022	Expert Insights for Designing Conversational User Interfaces as Virtual Assistants and Companions for Older Adults with Cognitive Impairments.	Proceeding	Koebel et al.
6	Mirheidari, B., Blackburn, D., Walker, T., Reuber, M. & Christensen, H.	2019	Dementia detection using automatic analysis of conversations.	Article	Mirheidari et al.
7	Müller, C., Paluch, R. & Hasanat, A. A.	2022	Care: A chatbot for dementia care.	Proceeding	Müller et al.

ID	Author(s)	Year	Publication title	Type	Link
8	Stara, V., Vera, B., Bolliger, D., Paolini, S., de Jong, M., Felici, E., Koenderink, S., Rossi, L., Von Doellen, V. & di Rosa, M.	2021	Toward the Integration of Technology-Based Interventions in the Care Pathway for People with Dementia: A Cross-National Study.	Article	Stara et al.
9	Stara, V., Vera, B., Bolliger, D., Rossi, L., Felici, E., Di Rosa, M., de Jong, M., & Paolini, S.	2021	Usability and Acceptance of the Embodied Conversational Agent Anne by People With Dementia and Their Caregivers: Exploratory Study in Home Environment Settings.	Preprint	Stara et al.
10	Ujiro, T., Tanaka, H., Adachi, H., Kazui, H., Ikeda, M., Kudo, T. & Nakamura, S.	2018	Detection of Dementia from Responses to Atypical Questions Asked by Embodied Conversational Agents.	Proceeding	Ujiro et al.
11	Wargnier, P., Benveniste, S., Jouvelot, P. & Rigaud A.-S.	2018	Usability assessment of interaction management support in LOUISE, an ECA-based user interface for elders with cognitive impairment.	Article	Wargnier et al.
12	Xin, T. L., Arshad, A. & bin Abdul Salam, Z. A.	2021	AlzBot- Mobile App Chatbot for Alzheimer's Patient to be Active with Their Minds.	Proceeding	Xin et al.

Appendix B:

Purposes and Key findings of the included publications (N = 12)

ID	Publication	Purposes	Key findings
1	Carós et al. (2020)	Present how reminiscence therapy can be automated by using deep learning, deployed to smartphones and laptops, making the therapy more accessible to every person affected by dementia.	Chatbot "Elisabot" generates questions and feedback well formulated grammatically, but not always appropriate content. It tends to produce non-specific responses and to lose consistency in its comments with respect to what it has said before. The overall usability evaluation shows that by users with MCI found the session very enjoyable and challenging.
2	De Arriba-Pérez et al. (2022)	Present an intelligent conversational system for entertaining elderly people with news of their interest that monitors cognitive impairment transparently.	The entertainment chatbot has strong potential for long-term user-friendly therapeutic monitoring of elderly people, with a preliminary detection accuracy of cognitive impairment close to 90%.
3	De Jong et al. (2018)	Understanding the needs and desires of the system in development thus manage to build a usable and effective system for supporting end-users (PwD and cognitive impairment), as well as unburden their informal and professional caregivers, by implementing the virtual agent "Anne" with three main features (agenda, news and video calling) in their daily lives.	Chatbot "Anne" can be useful to help people with dementia to continue living independently at home given specific adjustments. It may have an impact on the Quality of Life of both the users and (by proxy) their caregivers but its relevance needs to be explored in more detail within the forthcoming field trials.
4	De Jong et al. (2019)	Assess how a virtual agent affects the quality of life (QOL) of PwD and their caregivers using semi-structured interviews and the Quality of Life Scale (QOL-AD).	Propose an approach to evaluate assistive technology for elderly people with dementia by conducting a preliminary proof-of-concept study to test whether perceptions of a virtual agent, actual use of the agent and participants' quality of life are related, and whether a virtual agent improves quality of life.

ID	Publication	Aims	Key findings
5	Koebel et al. (2022)	Examine the benefits and shortcoming of conversational user interfaces (CUIs) for older adults, including those with mild cognitive impairment, and dementia-family diseases.	CUIs can be desirable for people with cognitive impairments given that they might allow bypassing social anxieties (feeling embarrassed about the condition), if message framing is right. Message framing appears to be of utmost importance not only to prevent a CUI from belittling or patronizing the users; but to reduce anxiety, motivate, encourage and reward them. While personalized and sophisticated systems can increase benefits in monitoring and managing the disease, even simple text based solutions, if message framing is right, offer important benefits and should be exploited.
6	Mirheidari et al. (2019)	Present and analyze an automatic classification system using an intelligent virtual agent for dementia detection.	Classification accuracies of 90.0% for the neurology-led and 90.9% for the intelligent virtual agent (IVA)-led conversations were obtained.
7	Müller et al. (2022)	Developing a chatbot that acts as a communication medium between caregivers and dementia patients, and conducting an interview to explore further improvement areas of the chatbot.	Chatbots can provide valuable assistance to older people since they live alone. It could act as a companion since nearly half of people over the age of seventy-five do not speak to anyone daily.
8	Stara et al. (2021a)	Identify which socio-demographic characteristics are independently associated with the use of the embodied conversational agent among subjects with dementia. Uncover patient cluster profiles based on these characteristics. Discuss technology-based interventions challenges.	Chatbot “Anne” was considered as easy-to-use and quickly learnable. The telemetry report detected different activity rankings in the three sites: at the beginning of the 4 weeks, users faced an exploratory period, trying out the many features and not knowing how to handle the device very well. Then, users’ actions become more efficient and purposeful.

ID	Publication	Aims	Key findings
9	Stara et al. (2021b)	This study aims to evaluate the usability and acceptance of the ECA Anne by older adults living with dementia. The study is also designed to assess the ability of target users to utilize the system independently and receive valuable information from it.	Participants evaluated the agent as easy-to-use and quickly learnable. They felt confident while using the system and expressed the willingness to use it frequently. Moreover, 21/55 of the patients perceived the virtual agent as a friend and assistant who they could feel close to and who would remind them of important things. Conclusions: Technology-based interventions require a significant effort, such as personalized features and patient-centered care pathways, to be effective.
10	Ujiro et al. (2018)	Propose a new approach to detect dementia using embodied conversational agents and an atypical question set that addresses several degrees of memory.	The results showed a 0.95 detection performance in the area under the curve of the receiver operating characteristic (AUROC). This result demonstrates that our system using atypical questions can detect dementia.
11	Wargnier et al. (2018)	Assess whether the interaction management framework of the LOUISE (Lovely User Interface for Servicing Elders) ECA has the potential to overcome the user interface constraints linked to cognitive impairment.	Most of our participants were able to interact with the ECA, succeeded in completing the proposed tasks and enjoyed our design. CONCLUSION: The field usability evaluation of LOUISE's interaction management framework suggests that this suite of interaction techniques can be effective in enabling interfaces for users with MCI or AD.
12	Xin et al. (2021)	Proposes a mobile application named AlzBot with the implementation of Chatbot to create an assistive toolkit application for both Alzheimer's patients and caregivers.	Findings indicate that the proposed system has the potential to meet the expectation of Alzheimer's patients and their caregivers to enhance their quality of life.

