RITA: A privacy-aware toileting assistance designed for people with dementia. ⋆

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Abstract. Dementia is one of the leading causes of disability and dependence among older people, currently affecting more than 55 million people and estimated to increase to 139 million by 2050. A growing number of technologies are being developed to assist people with dementia in their daily lives, but assistance with toileting remains a neglected area. In this work, we present RITA, a system to automatically guide people with mild dementia in the toilet. The system detects activities that the user performs and compares them to a predefined model that maps out the correct toilet procedure. If problems are detected, such as wandering around the toilet or sitting on the bowl for longer than a certain time, instructions are given on what to do next. As only depth images are used, the privacy of the users is guaranteed at all times, a crucial factor in such an intimate context as toilet-going.
For an automated assistance system to be effective, the adequate design of its interaction with the user is essential. For this reason, our design is not only based on the available technological solutions, but also on the conclusions derived from focus groups with healthcare professionals. We report these findings with the aim of contributing to reducing the information gap in interaction design for people with dementia.

Keywords: AAL · Dementia · Privacy-aware technology.

1 Introduction

Dementia is defined by the WHO[3] as a syndrome in which there is a deterioration in cognitive functioning beyond what might be expected from normal ageing.

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[3] World Health Organization `https://www.who.int/news-room/fact-sheets/detail/dementia` (accessed September 25, 2021)

In recent years, the international community has recognised the urgent need for action on dementia [15] and the Global action plan on the public health response to dementia 2017-2025 [16] includes among its key actions the development of support and services for dementia caregivers as well as the promotion of research and innovative technologies as a way to significantly improve the lives of people with dementia, their families and caregivers.

The severity of dementia progresses from the mildest stage, when the person's functionality is just beginning to be affected, to the most severe stage, when the person becomes completely dependent on others in order to complete activities of daily living (ADL)[4], which makes it one of the major causes of disability and dependence among older people globally [15].

With the aim of promoting the independence of people with dementia by supporting ADL, we present RITA (Respect for Intimacy in Toilet Assistance), which, by targeting users with mild cognitive impairment, is intended to provide step-by-step guidance to the person using the toilet in such a way that they do not need any assistance from a second person.

Applications to support people with dementia in the usage of toilet could benefit both caregivers and patients themselves [3]. However, assistance in the toilet seems to have been overlooked in the development of assistive technologies, which may be due to the high privacy requirements in this intimate context. RITA addresses these high privacy requirements through the use of a 3D sensor and edge computing, which eliminates the need to transmit images, ensuring that user privacy is respected at all times.

Moreover, given that dementia affects individuals differently [3,4], identifying the optimal approach to design interactions with people with dementia is a non-trivial task and there is currently not enough information to determine which is the best option. As this is a key determinant of the overall effectiveness of the system, considerable effort has been made to assess the range of interaction possibilities and our findings on this topic are also presented in this paper.

2 Related Work

An increasing number of technologies are being developed to support the autonomy of the older population. Yet, despite toileting being the third main ADL with which older people have difficulty [5], very little progress has been made in this area compared to other assistance applications.

An exception is, for example [1], which describes a public smart toilet developed for the older and disabled population. This is a continuation of work done at [13] and [18], to develop a modular toileting system for older adults.

In terms of the technologies designed for people with dementia, the systematic review presented in [4] provides an overview and emphasises the need to employ user-centred designs to successfully develop assistive technologies for this range of users. However, there is not much information available on how to

[4] National Institute on Aging's ADEAR Center https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis (accessed September 18, 2021)

design interaction with users with dementia and most of the studies on this topic are limited to providing general design guidelines without addressing specific aspects of design choices. An example is [17], where the authors present a series of recommendations for the design of smart homes for people with dementia, focusing on user interface aspects.

Lumetzberger et al. [12] developed a vision-based solution to assist users with cognitive impairment in the toilet. An avatar and simple visual and textual instructions are the proposed forms of interaction, but the adequacy of the selected interaction methods for people with dementia is not specifically addressed.

In general terms, many of the studies (e.g. [11, 6, 8]) place particular emphasis on the importance of designing a system that can be tailored to the individual in order to ensure the effectiveness of the indications. Smith et al. [19] and Fried et al. [6] mention the effectiveness of using multi-modal inputs for dementia patients and conclude that communication strategies should be based on multiple modalities to build on the patient's strengths.

Mihailidis et al. [14] test the performance of a system to assist people with severe dementia during hand-washing through verbal prompting, but no comparison with other prompting modes is provided. In fact, they note that more research should be done on the types of interactions and the effectiveness of prompts for people with dementia, suggesting the incorporation of video-based prompting strategies.

Of particular relevance is the work done in [10], where the authors compared verbal and audio-visual prompts to guide patients with moderate to severe cognitive impairment in the task of hand-washing. The results reveal little differences between the efficiency achieved with the two modes of automated assistance, with audio-visual assistance resulting in statistically fewer caregiver interventions. However, the authors conclude that the efficacy depends on many factors, such as the physical environment or the nature of prompts as well as their speed and timing. Therefore, further research is needed, possibly including other modalities in the comparison too.

The study conducted in [8], as part of the ACT@HOME project, presents a qualitative evaluation of an intelligent virtual assistant to assist Alzheimer's sufferers during hand-washing. The authors provide guidelines for the design of prompting methods and, in general, the design of virtual assistants for people with cognitive impairment. Despite the relevance of this study to our application, the results are limited to qualitative interviews with people with dementia and their caregivers about the virtual agent's physical appearance and acceptance, without delving into alternative modalities of prompting.

Virtual agents as personal assistants were also proposed in [20] framed in the Living Well project[5], which seeks to adapt a virtual ICT assistant for users with dementia or other age-related cognitive problems.

[5] Living Well with Anne. `https://livingwellwithanne.eu/` (accessed September 18, 2021)

Lighting signals are used in the PETAL project[6], aimed to develop a platform for personalising remote assistance for adults with mild cognitive impairment (MCI) to support their spatio-temporal orientation. However, no concrete data is provided to validate the hypothesis that communication using light signals is effective for patients with MCI, nor is this interaction modality compared with alternative solutions.

Only the works described in [8, 10, 14] provide a comparison between modalities or a validation of the effectiveness of the modalities investigated. Thus, when it comes to making specific design choices, not enough information is available for selecting the most appropriate interaction modality for people with dementia. This work aims at reducing this information gap as well as using these findings to provide a privacy-aware solution than can successfully guide people with dementia in the toilet.

3 Interaction with people with dementia: methodology and results

The effectiveness of an automatic assistance system critically depends on how it interacts with the user. Dementia causes communication difficulties, even for skilled caregivers[7]. So, it is clear that the interaction strategies need to be carefully designed to successfully convey the messages issued by automatic systems. In the lack of well-established methods, this work has devoted special attention to this aspect. It takes into consideration not only available technological solutions, but also the knowledge and recommendations from experienced carers as the most valuable input to define effective communication strategies.

3.1 Methodology

As a first step, we conduct a thorough review of possible solutions. This, in addition to saving resources, is particularly important when the users are people with dementia, as exposing users to early-stage devices as faulty prototypes can lead to anxiety and future rejection [17]. Orpwood et al. [17] advocate involving users in the design process, but propose collaborating in the first instance with caregivers and then, when relatively mature prototypes become available, conducting specific tests with the patients themselves.

Apart from ethical issues, caregivers seem to be the best placed to estimate the needs of dementia patients, to provide an overview of specific challenges and to assess the effectiveness of possible solutions [17]. For this reason, two focus group sessions are held with care home professionals.

[6] PETAL - PErsonalizable assisTive Ambient monitoring and Lighting. `http://www.aal-petal.eu/` (accessed September 18, 2021)

3.2 Communication in dementia

Communication difficulties tend to become more pronounced as the disease progresses[7]. However, dementia affects each person very differently, meaning that in addition to the stage of the disease, symptoms may vary depending on other factors, such as the specific type of dementia, the impact of the disease or the person's personality before becoming ill[3,4].

Due to the heterogeneity of the particular abilities and constantly changing needs of people with dementia, studies such as [6, 22] claim that communication strategies should be adapted to the specific needs and abilities of each person, evolving throughout the course of the disease. Moreover, consideration should also be given to the patient's socioeconomic status when opting for a specific communication strategy [22]. For example, in the case of considering text as a prompting modality, it should be borne in mind that written communication will be more effective for a person with a higher education level, than for someone who had difficulties in reading even before their dementia.

Multi-modal approaches can be effective ways to bridge the difficulty imposed by the inter-variability of dementia patients when communication cannot be tailored to each specific patient [6, 8, 19]. The use of multiple modalities provides more channels for the delivery of the message, giving more opportunities for the message to be received effectively by the target person. Finally, the challenge of the multi-modal approach lies in selecting complementary modalities with the highest cost-benefit ratio.

3.3 Review of possible solutions

The following is a brief description of the possible interaction solutions:

- **Verbal prompts.** Verbal guidance consists of using spoken language to give instructions to the user. Factors that play an important role in the effectiveness of messages in this modality may include, but are not limited to, tone of voice, speed of speech, choice of vocabulary, sentence structure, or whether the voice is familiar to the user.
- **Text.** Textual messages are displayed on a screen for the user to read.
- **Audiovisual prompts.** The use of audio-visual technologies falls, by definition, within multi-modal approaches, as it uses images or videos as a visual support and, generally, verbal language to transmit the information using the sense of hearing.
- **Agents.** A special sub-type of audio-visual approaches is involving the use of virtual or real agents. Virtual agents refer to embodied entities displayed on a screen designed in a way that encourages natural interaction with the user, while real agents involve the recording of a real person.
- **Light- or sound-based solutions.** Lights or audio sources are placed next to the objects involved in the toileting process, which will be switched on and off to guide the patient's attention as he or she moves through the process, offering a less intrusive form of guidance.

[7] Alzheimer's Association. `https://www.alz.org/` (accessed April 26, 2021)

3.4 Focus groups

To complement the information extracted from the literature review, two focus groups are organised with health professionals from a nursing home.

Participants Focus groups are conducted with health professionals of a specialised facility for residents with Alzheimer's and other types of dementia in Zaragoza (Spain). Two sessions are held with two different groups of healthcare providers (n=4 and n=9, respectively), with a total of 13 participants:

- Group 1: Higher level health professionals, including a psychologist, a nurse, an occupational therapist and a physiotherapist.
- Group 2: Professional caregivers composed of 9 nursing assistants.

All participants were female, aged between 23 and 58 years (mean: 40, standard deviation: 11.5) and had different lengths of work experience (minimum: less than 1 year, maximum: 20 years, mean: 7.4, standard deviation: 6).

Procedure Each focus group session lasted about 1 hour and 15 minutes and started with an explanation of the research project. Participants were told that the sessions would be voice-recorded and they agreed by signing a consent form.

The focus group guide was structured in two parts: the first part included a brief description of the proposed technology and the possible interaction modalities and questions on the interaction design while the second part was dedicated to perceived usefulness and barriers such as privacy and trust issues. Figure 1 presents three of the videos shown as example to the participants. The methodology used for the preparation of the sessions is described in [2] and [9].

Focus groups results The results presented here are a brief summary of a qualitative content analysis from the audio recordings and the notes collected during the focus group sessions. Conclusions about the interaction design and perceived usefulness and barriers are discussed.

Fig. 1. Samples of the videos presented to the participants. Left: Virtual avatar showing the action to perform. This option was preferred by all the participants in Group 1. Centre: Real person showing the action to perform. Right: Caregiver addressing the patient. The latter two were the options supported by participants in Group 2.

Interaction design

- **Separate systems for patients with mild and with moderate dementia**. Participants from both groups highlighted the need to create two different systems for users with mild and moderate dementia, as there is a significant difference in the symptomatology of these patients. Consequently, our target group has been reduced to people with mild dementia.
- **Overall preferred modalities: video and verbal messages.** In general, the combination of video and verbal messages was preferred over these modalities used separately. In addition, the use of text was perceived to be distracting rather than supportive if used in combination with these modalities. Participants of both groups concurred that a familiar voice would play a crucial role in the effectiveness of the instructions and that using the voice of a caregiver from the care facility where the system will be deployed is the best option. In line with this, video instructions were undoubtedly preferred to be recorded in the familiar physical setting too, such as the very same bathroom that patients are using. And if synthetic imagery is preferred, the design of facility's bathrooms should be reproduced. There was no consensus on which would be more effective: having the agent perform the action or only addressing the user. As for the appearance of the agent, participants in Group 1 opted for a virtual agent with a realistic appearance, while those in Group 2 preferred a real person (see Figure 1).
  Both groups discouraged the use of sounds, as they may frighten users, and lights were only considered useful for people with moderate dementia.
- **Structure of verbal messages: clear and short**. Both groups agreed that verbal messages should be clear and as short as possible. However, there were different opinions regarding the appropriate level of imperiousness of the prompts. Group 1 (higher level health professionals) indicated that instructions should always be imperative to convey clearly the message. Conversely, all the participants in Group 2 (professional caregivers) pointed out that although imperative instructions are sometimes necessary, their usual preferred way of proceeding is to first kindly ask to perform a certain action. Two participants pointed out that when residents are asked in a polite way, using a kind tone, "they even listen more".
- **Initiate interaction only after a problem is detected** for people with mild dementia. Participants of both groups expressed that, in the case of mild dementia, the system should delay interaction with the patient until a problem is detected, otherwise it could be upsetting or frightening to patients. For patients with moderate dementia, conversely, interaction should be initiated as soon as the patient enters the room.

Perceived usefulness and barriers Participants of both groups have positively evaluated the proposed system, stating that "it can be a great alleviation for patients as well as caregivers' work". Increasing patient's autonomy and thus reinforcing their self-esteem and sense of dignity was named among the main benefits, especially for people with mild dementia in need for support. Caregivers pointed out that this technology could greatly lighten their workload (Caregiver: "The most time-consuming task is accompanying them (the patients) to the toilet"), which would also be reflected in the reduction of their stress level. Furthermore, participants of both groups expressed their special interest and usefulness of the system's ability to detect falls.

As for barriers, both groups said that a period of adaptation would be necessary, but they were also confident that the residents would eventually accept the system. Higher level professionals also commented that caregivers might be initially reluctant, as the implementation process might be perceived as additional work. However, this claim was not supported by the caregivers themselves, who indicated the system could be a positive relief, although many residents would still need to be supervised. Practical aspects were mentioned, such as the use of diapers, which would prevent the system from being accessible to all users.

Regarding privacy issues, it is worth noting that no such concerns were raised by the participants themselves and that, only after specifically drawing their attention to the potential threats, they voiced some possible issues. Most of the participants were not concerned about being filmed, 8 out of 13 clearly stated that they would not mind it "at all". Two of the participants in Group 1 stated that they did not consider depth images as "images", "videos" or "recordings", as people cannot be identified and the images are not saved, thus it is not a threat to privacy. In contrast, all participants gave a categorical negative response when asked about the feasibility of using RGB instead of depth images. Caregivers were not concerned about appearing in such images either, even if a fall of a patient was captured while they were supervising them, stating that such falls are often inevitable even in their presence. However, when one participant expressed a worry that such images could be exploited by relatives as evidence against them (if the images were saved) in the case of a serious accident, several participants echoed this concern. Another participant noted that the use of "fuzzy images" could lead to different interpretations of their actions. Despite health professionals' general openness towards the suggested system, they also noted that patients relatives might be quite sensitive about privacy concerns. They strongly emphasised the importance of using the right language when explaining the technology as the use of terms such as "recording" or "video" could lead to misunderstanding and rejection of the system from the patients' families.

4 Implementation of the system

RITA has been implemented as a prototype, including both hardware and software components.

4.1 Overview of the system

Figure 2 is a block diagram of RITA. First, a modified version of the cogvisAI sensor[8] processes the depth image and publishes an MQTT message with the

[8] cogvis. `https://cogvis.ai/cogvis-en/` (accessed September 18, 2021)

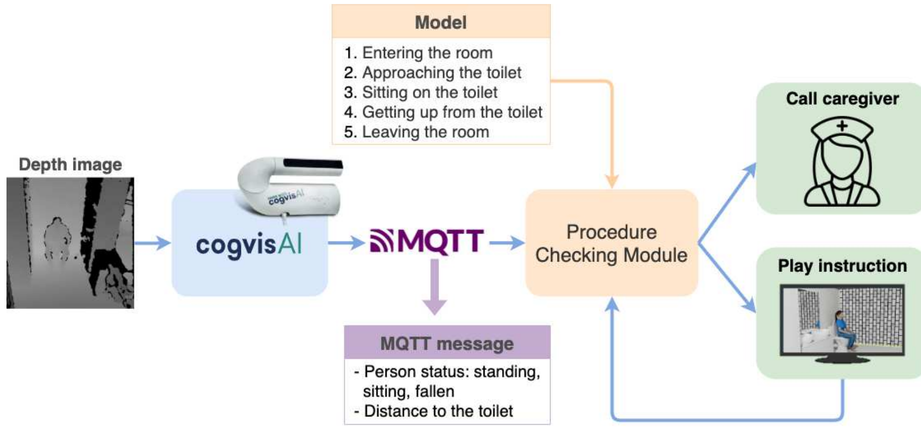

Fig. 2. Block diagram of RITA.

following information: status of the person (standing, sitting or fallen) and distance of the person from the toilet. The Procedure Checking Module then verifies whether the person's action conforms to the predefined model of the toilet procedure and, if not, it plays a message with the corresponding instruction. The instruction is repeated up to 3 times, with a time interval between repetitions, and in case the corresponding action is not completed after these 3 repetitions, a call is sent to the caregiver and a message informing that a caregiver is arriving to help is played. In the event of a fall, the system acts in the same way: an alert is sent to the caregiver and a reassuring message is displayed to the user.

4.2 Procedure Checking Module

Based on the inputs from the cogvisAI sensor, the model for the Procedure Checking Module features the following actions: entering the room, approaching the toilet, sitting on the toilet, getting up from the toilet and leaving the room.

The Procedure Checking Module determines what action the user is currently performing and waits for the user to perform the next action within a specified time. If the user does not perform the action, RITA plays the message giving the instruction. For development purposes, the time thresholds have been set heuristically and should be investigated further in the future. Furthermore, for the user's performance to be considered correct, the actions listed in the model must be performed in a specific order and any deviation from this sequence would cause the system to initiate interaction with the user.

The Procedure Checking Module identifies the current action of the person following a rule-based logic that takes as input the last message received from the cogvisAI sensor and previous actions identified by the module. For instance, for the action to be set as "approaching the toilet", the conditions to be met are: distance from the toilet below a distance threshold, not sitting on the toilet, and the previous action being "entering the room".

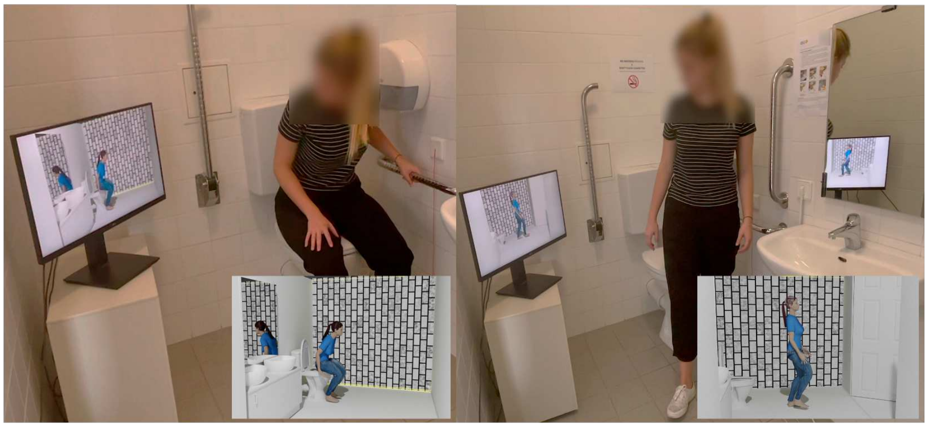

Fig. 3. Photos of the demonstration of the system. Left: “Stand up” action. Right: “Leave the room” action.

4.3 Interaction module

The conclusions drawn from the focus group sessions helped to narrow down the design options and, together with some insights gained from literature surveys, largely determined the design of interaction procedures. We decided to select people with mild dementia as target users and adopt a multi-modal approach to overcome the challenge posed by the inter-variability of communication impairments in people with dementia. The modalities selected are a video showing an avatar performing the action and an audio recording giving the instruction verbally, and no text was included in the visual support. Figure 3 shows photos taken during the demonstration of the system in the lab. The design decisions can be summarised as follows:

- **Audio messages recorded by a caregiver.** In addition to being a voice familiar to the residents as recommended by [17] and the participants of the focus groups, this allows the vocabulary and local accent to be matched to improve the effectiveness of the instruction as well as to harness the experience of caregivers in communicating with people with dementia.
- **Verbal messages: short, clear and polite**. Given that, as stated in [17], assistive technologies should be designed to emulate the behaviour of the caregiver, we followed the guidelines on communication strategies for health professionals [9] [7] to design verbal messages as clear and brief as possible. In addition, instructions start with the word “please” to reduce the level of imperiousness as recommended by [8] and by the Group 2 participants.
- **Virtual agent with a realistic appearance.** A virtual agent was selected over a real agent, as respondents in Group 1 stated that a real agent would

[9] National Health Service (NHS) - UK. `https://www.nhs.uk/conditions/dementia/communication-and-dementia/` (accessed April 27, 2021)

not have a positive impact on the effectiveness of the modality, but instead could cause discomfort to users. As for the appearance of the agent, we opted for realistic appearance and avoided a cartoon-like design, as it is also proposed, for example, in [21].

– **Interaction only after a problem has been detected** in order to minimise the risk that the system will be perceived as unduly intrusive by users, as recommended by participants of the focus groups.

4.4 Prototype implementation

For the prototype, an MQTT broker has been installed on a Raspberry PI where both the cogvisAI sensor and the computer in charge of the Procedure Checking Module are connected. In this way, the cogvisAI sensor publishes messages in topics to which the computer subscribes. The monitor and speakers used to play the instructions are wired to this computer. A wireless router acting as a mobile Wi-Fi access point ensures that all devices have Internet connection.

5 Conclusions

RITA has been implemented as a prototype to guide people with mild dementia in the toilet. Preliminary tests in the lab confirm RITA's ability to detect actions performed by the user and to identify whether he/she is following the correct sequence and, if not, issuing suitable instructions to the user or to a caregiver.

Since interaction is a critical factor for the effectiveness of an automatic assistant, significant effort has been put into determining the best communication strategy. To this end, focus groups were conducted with healthcare professionals from a care home specialising in dementia. Findings from these sessions are presented, as they have been crucial for the design process and they may be of value to future researchers too.

Furthermore, although the focus group sample is insufficient to draw statistical conclusions, participants in both groups positively rated the potential of RITA to increase patient independence and self-esteem, and to reduce workload for caregivers. These preliminary results also suggest the feasibility of using depth images to protect personal privacy and ensure greater user acceptance.

The directions in which RITA is planned to be further developed include the incorporation of the detection of hand-washing actions, the implementation of an action acknowledgment message when the user performs the action after being guided by the system and the definition and evaluation of test cases. The latter may include seeking additional feedback from healthcare professionals as part of the collaborative design process, conducting simplified testing in controlled environments, and investigating end-user reactions to the prototype.

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