Digital Resources Aiding Opportunities for Affiliation and Practical Reasoning Among People with Dementia: A Scoping Review

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Abstract. Persons with dementia face several challenges in daily life and the consequences of the disease can be a threat to live a dignified life. Martha Nussbaum has developed the concept of dignified life for people with dementia and suggests the capability approach focusing on what people are able to do and to be in certain agreed-upon areas. Particularly, affiliation and practical reasoning are crucial to preserve a dignified life. For people with dementia the consequences of the disease may affect their opportunities to achieve these vital human capabilities. Digital resources have been shown to have potential to support people in their everyday life and provide them with the means necessary to participate in all aspects of life. In this study, our purpose is to describe digital resources aimed at supporting opportunities for affiliation and practical reasoning among people with dementia. Specifically, we wanted to give an overview of the existing digital resources used to support affiliation and practical reasoning and how such resources affect opportunities for people with dementia. A framework for scoping reviews was used and literature searches were conducted in PubMed and Scopus. The results, by providing a deep analysis of digital resources for affiliation and practical reasoning, highlight the need for a clearer direction towards the very core of vital aspects in a dignified life. Hence, there is a need for a framework that can guide attention towards crucial aspects for supporting a dignified life when developing and evaluating digital resources.

Keywords: Digital resources · Dementia · Affiliation · Practical reasoning · Social interaction · Decision making · Independence

1 Introduction

1.1 Dementia: Needs and Challenges

Dementia is known to cause both disability and dependence among older people. It impairs cognitive functioning and impacts memory, thinking, orientation, and learning

L. Mucchi et al. (Eds.): BODYNETS 2019, LNICST 297, pp. 301–314, 2019.
https://doi.org/10.1007/978-3-030-34833-5_23

ability [1], causing challenges in the daily living activities. Both people who live with dementia and their families need to face with multiple challenges to cope with the illness, as well as to live their everyday lives despite changes that the illness causes [2, 3].

For persons who lives with dementia Kitwood [4] stated the need for a subjective insight on what it is actually like to live with dementia. The advantages of this insight and understanding come when considering each person's experiences as unique. Persons who lives with dementia have described comfort, attachment, and inclusion as phenomena of importance to feel involved in everyday living. Nevertheless, they often have worries regarding loss of life as familiar, loss of abilities and anxiety of becoming a burden to others. Losses of familiarity in daily living is a phenomenon closely linked to dignity [5]. For persons with dementia, the support of a dignified life has been shown to be a challenging task; still the importance of a dignified life is crucial for quality care despite context. Living with dementia dignity as phenomenon can be understood as threatened in a twofold manner, both by the illness itself, and from external views and perceptions of what dementia means [6].

Dementia does not singularly imply disability and dependence; it has additionally been shown to constitute a threat to living a dignified life for the persons affected. The reduced cognitive ability caused by the illness affects the individuals own ability to preserve dignity and live a dignified human life [7]. It is therefore crucial that all support is planned and provided with an outset aiming to sensitively guiding the persons living with dementia towards vital human capabilities of importance to live a dignified life [8]. Livingston et al. [9] described how close relatives caring for people with dementia experience a huge responsibility of hard decision-making during the entire course of the disease. Further, the main troubling areas of decision-making involved areas such as accessing dementia related health and social services, and to be prepared with a plan for the person with dementia if the close relatives became unable to adequately support the person. These two areas imply uncertainty in the everyday lives of close relatives who care for a person with dementia.

For people living with dementia Cohen-Mansfield et al. [10] have shown that the most common and also unmet needs among people with dementia concern aspects such as boredom/sensory deprivation, loneliness and lack of social interaction. Social stimulation and meaningful activities were shown to promote quality of life among people with dementia. Martin and Younger [11] highlighted the importance of empowering persons who live with dementia and showed that it was crucial to be given choices around aspects of everyday life. The health of close relatives when caring for a person with dementia is to be seen as strongly related to how the needs of the person with dementia are being met and the assurance of preserving the dignity of the person with dementia is of crucial importance in everyday living [9].

1.2 Human Dignity in the Context of People with Dementia: Nussbaum's Approach

Human dignity can be understood in a variety of ways; for example, Nordenfelt [12] stated that all human beings are equal by virtue of their humanity. Nussbaum [13] provides an outlook of dignity that focuses on what a dignified life should include. To

live a dignified life, Martha Nussbaum [13] suggests a capability approach that focuses on what people are able to do and to be in certain agreed-upon areas that are thought to be central to the quality of the human life. Nussbaum suggests that a dignified human life comprises ten human capabilities: life, bodily health, bodily integrity, senses, imagination, and thought, emotions, practical reasoning, affiliation, other species, play, and control over one's environment. Even though Nussbaum emphasizes that all capabilities are important, the pursuit of affiliation and practical reasoning is crucial since they permeate all other capabilities. Affiliation includes opportunities to live with and for others, to recognize and show concern for other human people, and to engage in various forms of social interaction. It also entails to be treated as a dignified being whose worth is equal to that of others. Practical reasoning concerns opportunities of being able to form a conception of the good and to engage in critical reflection about the planning of one's life. However, for people living with dementia the consequences of the disease may affect their opportunities to engage in social interactions [14] and achieve the human capability of affiliation. There might also be challenging for them to participate in the planning of their lives and attain the human capability of practical reasoning [7]. A dignified life for individuals with dementia requires adapted and sufficient support that targets these vital human capabilities.

1.3 Digital Resources Supporting People with Dementia

Digital resources are today used in several ways with the goal of supporting the daily life of people with dementia leading them to become more independent and to participate in all aspects of life [15]. Additionally, digital resources have been described as useful ways to discover, communicate and give meaningful feedback on situations and conditions with relevance for the person who lives with dementia, families and carers. Martínez-Alcalá et al. [16] showed that digital resources could be used to strengthen the quality of life among people with dementia as well as their close relatives. When it comes to the everyday dependency, that is common in persons who live with dementia, the use of digital resources can provide attention towards improving the well-being of the person and also to decrease stress among families. Using technological resources for people with dementia has previously mainly focused on safety and monitoring, and has now evolved to include empowering the person with dementia and promoting independence through the completion of daily physical and psychosocial activities [17]. The most frequently adopted digital resources are tele-assistance, information systems and internet, while geolocation and robotics were less commonly used as support in everyday living related to dementia. Digital resources have the potential to support the individuals to maintain their capabilities and hence, preserve dignity. Sharkey [18] discussed the need for an ethical approach on studies in the area of digitalization and older people, and highlighted that the capability approach of Nussbaum [13] has some advantages over other accounts of dignity, but that further research is needed.

2 Aim

This paper aims to describe digital resources that support opportunities for affiliation and practical reasoning among people with dementia. Specifically, we provide an overview of the kind of existing digital resources used to support affiliation and practical reasoning and how such resources affect the opportunities for persons with dementia.

3 Methodology

In this study, we used a framework described by Arksey and O'Malley [19] concerning scoping reviews. With this framework, we could apply a broader approach and include studies regardless of study design, such as research articles, and reviews, as well as grey literature. Since we focused on gaining an in-depth and broad view concerning the aim of the study, we undertook an iterative process to ensure that the literature was covered in a comprehensive manner. To undertake the scoping we worked in five stages built on reflexivity. In the first stage, we formulated one research question with a wide approach to enable a breadth coverage of the topic. After achieving a sense of volume and general scope of the field we decided on the parameters related to the term "digital resources", as well as what could be included in the terms "affiliation" and "practical reasoning", to let these parameters guide our literature search. For example, social, communication, and engagement were deemed as appropriate parameters for searches concerning affiliation, while decision, empower, and independence were used for searches concerning practical reasoning. The inclusion criterion was papers written in English between the years of 2014–2019.

The second and third stage involved identifying and selecting relevant studies, which in this study implied searching for literature in the electronic databases PubMed and Scopus. To enhance the comprehensiveness in data collection, we also performed a manual search in reference lists. The selection of relevant studies was performed in several steps, starting with reading the title of the studies, followed by reading the abstract. If the article seemed to fit the scope of this study after these initial steps, or if the relevance of an article was unclear from the abstract, the full article was read. After reading the materials in full 38 papers (30 focusing on affiliation, and 17 papers focusing on practical reasoning), were selected for final inclusion. Meaning that some papers were included in both domains.

In the fourth stage, a narrative review of the articles was undertaken, applying a broad view on extraction of textual units from the included articles. This approach allowed to include information (e.g. the description of a system utilized for a digital resource) in order to contextualize and make the outcome understandable. We recorded information concerning author(s), year of publication, study location, type of digital utilized resource(s), important results related to the parameters set for affiliation, and practical reasoning. Together, these data formed the basis of the analysis. The extracted data were then sorted into domains based on the type of digital resource described in the article. At the last stage, we collated and summarized the results in order to provide a narrative account of the existing literature. The results are reported as a running text

for affiliation and practical reasoning, respectively, and are divided into domains for presenting the digital resources.

4 Results

4.1 Characteristics of Included Studies

The 38 included papers (30 focusing on affiliation, and 17 papers included for practical reasoning) mostly took part in Western countries.

4.2 Digital Resources for Affiliation

Robotics

Robotic Animals. One study described the usage of pet-robots [20], and three studies focused on the Paro robotic seal [21–23]. Paro is a socially responsive robot with moving parts. It makes authentic baby seal sounds and recognizes voices. Paro had a clear positive impact on social interactions and connections. Pet-robots are suggested to stimulate persons with dementia's interaction with the robot, as well as with other people. However, people might lose interest due to the limited behavioral repertoire of the robot [20].

Robotic Telepresence System. A review by Blackman et al. [24] outlined a robotic telepresence system that remotely connects carers to individuals and their homes. The impact was not presented. Moyle et al. [25] deployed the Giraffe telepresence robot, which provides opportunities for families to 'virtually' visit people with dementia by videoconferencing. The Giraffe can be moved by the user and driven to chosen places in the environment. The Giraffe was viewed as having the potential to decrease social isolation and increase connection by enabling persons with dementia, families and friends to "visit" each other.

Assistive and Social Robots. Wang et al. [26] utilized a custom-designed robot to provide stepwise prompting and complete activities at home. A trained tele-operator remotely controlled movements, speech, and prompting functions. The robot was viewed as having the potential to improve interactions and relationships between the person with dementia and families. Chu et al. [27] studied social robots designed specifically for emotional and intentional communication and interaction purposes. The robots had baby-face-like appearances and features such as face and emotion change recognition, voice vocalization and emotive expressions, singing, and dancing. Social interaction increased with the robots. Similarly, in [28] a social robot with human attributes, such as baby-face-like appearance, human voices, facial expressions, gestures, and body movements was used. The robot affected engagement in general, and specifically verbal engagement with others was observed. However, it was not clear if the robot helped persons to make more friends. In [29] a robot that could move autonomously within predefined areas was deployed. It addressed by-passers asking if they liked to interact with it via voice output. Interested persons could then click through some information about the robot and the research project on the screen, or had

the information read out aloud. Even though people were interested in the robot, it was viewed as never being able to replace humans.

Multimedia Digital Tools for Reminiscence. The review by Holthe et al. [30] outlined a tablet with photos, music, and video clips used for reminiscence. The tablet increased the interaction between carers and persons with dementia. A tablet with a reminiscence conversation aid was also utilized in a study by Purves et al. [31], which provided a strong sense of shared history within a group when discussing something that all participants had been a part of, or by having different perspectives on a shared topic. In [32] a digital photo diary was used. It automatically took photographs and annotated them with geolocations using global positioning systems diary using a wearable camera. The digital photo diary created a shared connection between the persons with dementia and their partner having shared memories to discuss. Subramaniam and Woods [33] utilized multimedia digital life storybooks, which were experienced as encouraging communication and interaction between the persons with dementia and their families, as well as with carers. Samuelsson and Ekström [34] and Davis and Shenk [35] studied a multimedia digital tool in which personalized and generic material were created using videos and other visual stimuli. The tablets supported finding things to talk about. In [36] online reminiscence tools, which allowed the storing of photos and music and enabled connection with family and friends, were described. The impact of these tools was not outlined. Another multimedia digital tool for reminiscence was studied by Garlinghouse et al. [37]: a 3D printing to create small-scale models that individuals with dementia could recognize and relate to their personal past was investigated. The models influenced the person with dementia to talk to family members about both old and new topics and encouraged carers to interact more with the person with dementia.

Smart Home Environment. In [38] a smart home environment, in which a person's location could be detected, and lost objects could be located, is outlined. Development of this environment included technologies enabling the possibility to identify person's activities, such as watching TV, and preparing a meal. The impact of this smart home environment was not described.

Touchscreen Technologies/Apps/Social Media. Ekström et al. [39] utilized a touchscreen tablet with a communication application with individually designed pages consisting of for example personal pictures and films with accompanying speech. The number of communicative initiatives made by the person with dementia was not affected, but this system facilitated topics to talk about. In [24] a care management system was developed. The impact of this system was not described. Cutler et al. [40] conducted technology sessions using a range of software, games, and apps for the Apple iPads, Nintendo Wii, and Nintendo DS. Digital gaming promoted social interaction among persons with dementia, as well as the development of group cohesion.

Four studies [30, 41–43] described the usage of tablets for leisure activities, to assist in daily living, and social contact. The tablets were used to carry out a range of different activities, such as playing music, games, art and drawing, use of Skype, emailing, and playing videos. The tablets supported social connections between residents and provided opportunities to interact with a wider community than without this technology,

for example to stay in touch with families and friends by using Skype for remote contact [41, 43]. The tablets also changed the way family members spent time together, with improvement in their relationships and the possibility of bringing people from different generations closer together by providing shared activities [42, 43]. The activities carried out with the tablet facilitate conversational topics [41, 43], and supported communication for the person with dementia [41]. In addition, the balance in conversations became more equal when using the tablet, making the person with dementia initiate significantly more interactions [42]. The tablets strengthened carers' interpersonal connection with persons with dementia by getting to know them better [42, 43]. Djabelkhir et al. [44] deployed a tablet with a cognitive engagement program, which facilitated creation of social ties between the persons participating. The usage of tablets for simple video chat with relatives and the possibility to join interest-based groups was described in the study by Nauha et al. [45]. The tablet was considered useful and provided opportunities for persons with dementia to communicate with their family. In [46] a videophone mock-up with a touch screen provided the possibility to receive a call and make a call to a person on the contact list. The videophone was perceived as useful and easy to use after understanding the basic functions. Lazar et al. [47] deployed a commercially available computer system with touch screen that provided activities, such as video calling, emailing, and Facebook, games, videos, and music. The system promoted interaction and communication between the person with dementia, families and carers. In [36] distance communication via mobile phone or Internet applications was described as common means for social interaction and networking. Social media and the internet were also described as ways to share experiences, engage with others, and receive support.

4.3 Digital Resources for Practical Reasoning

Smart Environment. Braley et al. [48] utilized smart home auto-prompting to increase the functional independence of people with dementia. A smart home testbed equipped with sensors, cameras, and a prompting system was used. The impact of this technology related to practical reasoning was not described. In [49] smart homes with pattern-analysis were described, such as electronic calendars, registering water taps, gas and water sensors and mobile phones. These technologies were emphasized as supportive, especially in tasks that require learning and decision-making, facilitating independence. Another smart home technology, which focused on secure communication between different sensors for localization and presence identification, was described in [38]. The system included a user interface designed to provide the persons with dementia with support to promote their independence. Impact of the system was not described.

Audio/Visual Prompts/Reminders. Burleson et al. [50] investigated a dressing prototype to guide the person with dementia through dressing processes to promote independence. The impact of the prototype related to practical reasoning was not described. [51] and [52] outlined different audio/visual prompts to support people with dementia in daily activities (e.g. audio/visual prompts applied to everyday activities

and prompts to promote activity performance). In sum, the impact of these prompts was positive, with fewer interactions needed from carers, higher correct activity performance, and better completion of activities. In similarity, reviews by Holthe et al. [30] and Siegel and Dorner [49] described a range of assistive technologies for cognitive aid to support the person with dementia to perform daily activities by, for example, providing step-wise audio prompts. This kind of technologies may promote independence and autonomy by reminding persons with dementia about the steps in a given task, and hence, making them recapture the performance. van der Cammen et al. [53] described augmented reality glasses to guide the person with dementia in daily routine activities. The impact of these glasses was not described. In [54] sensors were utilized to provide individualized prerecorded voice reminders if the person with dementia had not carried out activities at certain times. The sensors supported the person with dementia, provided a sense of security and independence and allowed to establish daily routines and create the life they wanted. Still, some sensors were deemed as reducing the sense of being in control by being told what to do, and technological problems were considered as a threat to be independent. Reminders were also described in [49] and outlined that reminders to support the persons to perform daily activities may enable them to act more independently. Fleming and Sum [51] described technologies to aid memory and increase independence, such as night-and-day calendar, remote day planner, pre programmable telephone, a picture gramophone, and medicine reminder. Holthe et al. [55] conducted a study focusing on a range of technological devices to support people with young onset dementia, e.g. object locators, visual and verbal reminders, remote digital calendar, and memory clock. Technology that promoted independence and freedom was deemed important.

Every Day Assistive Technologies. Every day assistive technologies were described in [30, 55] and comprised, for example, a simple remote control to TV, mobile phones [55], computers, coffee maker, microwave ovens, cash machines, and flat-iron [30]. Technologies that supported meaningful and safe activities, especially when the person with dementia was alone, were considered important.

Positioning System/GPS. GPS was outlined in [45, 52, 55] either as part of mobile devices or in bracelets. The GPS device enabled the person with dementia to go out alone and take independent walks. In [53] GPS tracking to provide outdoor guidance was described, and Magnusson et al. [56] studied the usage of mobile phones with emergency response, GPS and geofencing. Independence related to outdoor activities increased, with the person with dementia being able to take walks by himself or herself.

Decision-Making Support. [57] outlined an interactive web tool aiding shared decision-making for people with dementia. The web tool had a chat function that facilitate communication among users, a step-by-step guide for decision-making, and a function that supports the users to give their individual opinions based on their own situation. This technology was deemed important by persons with dementia. It enabled them to do the things they wanted without asking for permission or support from others.

Touchscreen Technologies/Games. In a study by Swan et al. [43], touchscreen tablets with applications were deployed to provide individualized activities to the

person with dementia. For example, music, sensory stimulation, email, games, joining the local library, searching information, and writing life stories were some of the utilized applications. The impact related to practical reasoning was not outlined. Tablets were also used in a study by Evans et al. [41] to carry out different activities, such as playing music, videos and games, and using Skype. This facilitated opportunities for persons with dementia to share their thoughts with others on their own terms. In [40] technology sessions with software, games, and apps for the Nintendo DS, Nintendo Wii, and Apple iPad were performed with people with dementia. The games promoted independence for the persons with dementia, as it enabled them to explore games, and equipment independently in absence of carers.

5 Discussion and Concluding Remarks

The objective of this study was to describe digital resources aimed at supporting opportunities for affiliation and practical reasoning among people with dementia. Specifically, we wanted to provide an overview of the typology of existing digital resources adopted and their impact in supporting affiliation and practical reasoning for people with dementia. The achieved results on affiliation showed that social stimulation and interaction were encouraged by digital resources. For example, digital resources affected carers to spend more time with the person living with dementia due to finding topics to talk about and sharing experiences. This social interaction was said to strengthen the relationship between staff members and the person with dementia. Social interaction is important to strengthen and support a dignified life for people who live with dementia; still there is a risk of missing out on creating deep and meaningful relations that are a core in the concept of affiliation. Affiliation as concept refers not only to relating to others in general, instead it is important to grasp the very notion of the concept as being able to live with and towards others, and to be able to show and express concern for others [13]. The results show that some studies on digital resources supported the maintenance of relations to close relatives, which can be understood as supporting meaningful relationships, and hence, promoting affiliation.

Moreover, the existing research related to practical reasoning is mainly focused on phenomena such as security, independence and empowerment of the person who lives with dementia. Whilst research tends to focus on independence there is very sparse research on what supports the person with dementia to actually exercise the ability to be involved in daily matters that concerns decision making in one's own life. Very few studies focused on digital resources that supported the person with dementia to make decisions to be able to do the things they wanted and live a life in line with their wishes and desires. To be involved in decision making and to critically reflect when planning one's own life are the core of practical reasoning [7, 13].

Therefore, this study highlights the need for a framework that can guide attention towards key aspects to support a dignified life when developing and evaluating digital resources. To ensure a dignified life for the person who lives with dementia the capability of affiliation and practical reasoning needs to be supported [7, 13]. This means that the person needs support that creates opportunities to live with and for others, to recognize and show concern for other human people, and to engage in

various forms of social interaction and opportunities to form a conception of the good and to engage in critical reflection concerning the own life.

The existing research tends to miss out on essential aspects of what a dignified life ought to contain if it is to be called dignified. For example, it is evident that social interaction and independence are important areas that the development of digital resources strive to support. Still, it is not clear what actually is regarded as a meaningful social interaction or independence and how it relates to core values in a dignified life. The support towards leading a dignified life despite living with dementia is well known as crucial for a society that aims to create equal opportunities for all, despite decline in functions and cognitive ability [58]. Nussbaum's approach on human capabilities could offer future development of digital resources guidance by directing the attention towards vital aspects important to support to preserve a dignified life for people with dementia. The capability approach could also be of benefit when considering the evaluation of digital resources aiming to support the lives of people with dementia.

Taking into account the previous considerations, our suggestion is that future research on digital resources should focus on developing resources that can aid and nourish the capabilities of affiliation and practical reasoning. By using the capability approach as a foundation, future research on digital resources could more specifically target a dignified life for persons who live with dementia. Practical reasoning and affiliation are to be seen as crucial when it comes to ensuring a dignified life, and according to Nussbaum [13] these two human capabilities permeates all other human capabilities.

Upcoming 5G technologies can furtherly improve the possibility to help people with dementia. Features like ultra-low latency and anytime anywhere real-time ultra-high definition video can lead to the development of new applications/services to help people with dementia to be more autonomous. Moreover, the accurate positioning that 5G technologies can provide, even without GPS, can provide additional location-based services and alerts that help carers to even better monitor people with dementia.

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