



What Do Nurses and Carers in Portugal Wish and Need from a Digital Intelligent Assistant for Nursing Applications

Natália Machado¹ , Carina Dantas¹ , Ana Filipa Leandro¹  ,
Diana Guardado¹ , Thomas Münzer² , Nicole Helfenberger² ,
Georgios Vafeiadis³, Konstantinos Manolios³, and Claudiu Amza³

¹ Innovation Department, Cáritas Diocesana de Coimbra, R. Dom Francisco de Almeida 14,
3030-382 Coimbra, Portugal

analeandro@caritascoimbra.pt

² Geriatriche Klinik St. Gallen, Rorschacherstr. 94, 9000 St. Gallen, Switzerland

³ Bluepoint Consulting Srl, Barajul Arges Street, Nr. 11, 014121 Bucharest, Romania

Abstract. Cognitive disorders (CD) are challenges in healthcare and present a looming threat to the financial and social systems of most countries. There are nearly 10 million new dementia cases every year and this has a physical and psychological impact on their nurses and carers. To soften this burden, the DIANA Project (AAL Programme and FCT) is developing a solution composed of smart 3D sensors, an open management platform, and a mobile application to fulfil several functionalities such as: monitoring patient safety 24/7 (e.g., unusual behaviour, falls), support activities of daily living (e.g., toileting) and observe health trends of patients (e.g., fluid intake, changed behavioural patterns). To better understand the secondary end-users' needs and preferences regarding a solution of this kind, we applied a user-centred approach, to gather information from a questionnaire to retrieve the initial requirements of this solution. This outcome was combined with a literature review on the state-of-the-art projects in this field and the care for patients living with CD. As a result, the responses from 54 Portuguese nurses and carers were analysed regarding the establishment of a first set of functional requirements to the DIANA project, as well as the definition of use cases and personas to study. The results show that the three most important advantages of DIANA in Portugal would be assistance in nursing care, social interaction, and falls/mobility detection.

Keywords: Artificial intelligence · Cognitive disorders · Nurses · Carers

1 Introduction

In 2020, over 50 million people globally were living with cognitive disorders (CD). This number is expected to double every 20 years, reaching 75 million in 2030 and 152 million in 2050 [1]. In 2018, the combined EU28+ non-EU countries had 9,780,678

people living with CD with an estimated rise to 18,846,286 in 2050 [2]. The main cause for this increase is demographic change. As people live longer, chronic diseases become more prevalent, along with a trend of lifestyles and behaviours that favour them, since ageing is not a *sine qua non* condition to CD. The frequency of dementia rises exponentially with advancing age. It duplicates with every 6.3 year increment in age, from 3.9 per 1000 person-years at age 60–64 to 104.8 per 1000 person-years at age 90 and over. In Europe the peak frequency is among people aged 80–89 years [3].

In 2015, the estimated worldwide cost of CD was US\$ 818 billion [4], being one of the toughest financial challenges in healthcare. A high proportion of patients with CD eventually requires placement in a long-term care facility such as a nursing home, assisted living facility or group home. At the same time, their care is very demanding for nurses and formal carers, leading to an increase in these professionals' burnout. For this reason, it is of utmost importance to develop solutions that can support nurses and related carers in their daily working routines.

Considering this background, the digital intelligent assistant for nursing applications (DIANA), a project co-funded by the Active & Assisted Living Programme (AAL), thought of an innovative solution to assist nurses and carers in their daily lives and helping the care of persons with CD. The solution aims to alleviate medical staff of routine tasks which could be managed by an AI-powered digital assistant, e.g., monitoring the safety of patients 24/7, control walks during the night, react to alarms from existing sensors, support in activities of daily living (ADL) or observe health trends of patients and recording of such data for later assessment by clinical experts.

However, to better adapt to the medical staff routine, the integration, effectivity, and usability of these functionalities need to meet the real needs and expectations of the end-users. For this reason, nurses and formal carers were involved since the beginning of the project in the requirements collection.

This manuscript describes the methodology and the results of the users' requirements compilation.

2 Methods

DIANA builds on a user-centred approach, focussing on users and their needs in each phase of the design process [5]. This approach goes beyond consultation by building and deepening equal collaboration between citizens affected by, or attempting to, resolve a particular challenge.

Three essential phases of this study were a) a literature review, that provided a theoretical background and benchmarked some of the best practices and results of previous AAL and H2020 projects; b) a literature review about the care and special treatment of patients with cognitive disorders and c) an online questionnaire, which collected information from both nurses and carers (secondary end-users)¹ [6], including samples from Portugal and Switzerland, the other end-user organization country in the project. In this manuscript, the main objective is to present the view from the Portuguese consultation.

It is important to emphasize that, although the focus of the project is the improvement of the quality of life of patients with CD, their involvement in this phase of requirements

¹ Link to online questionnaire: <https://redcap.link/51uki44z>.

collection was not necessary. Nurses and carers have the main role in this project, therefore they were the first to be consulted. By collecting their opinions about the care of people with CD and the use of technology, the project collects an overview of what can be implemented through the solution.

The literature review was composed by the benchmarking of the best practices and results of previous AAL and H2020 projects in the same field of the DIANA project (intelligent digital systems in care; ambient assistance living; systems to people with mind impairment) and a review about the care and special treatment of patients with cognitive impairment, as well as statistical information about the use of technology in the daily work of nursing homes and hospitals in Portugal.

To complement these findings, an online questionnaire was used to learn more about the carers' and nurses' perception and needs to use new technologies in their work environment. The information was collected through 54 questionnaires completed by both carers and nurses.

We used a set of different approaches to achieve the targeted number of respondents. Firstly, a meeting with the Centro Region delegation of the Order of Nurses [7] was held, that engaged the organisation in the dissemination of the questionnaire, supporting *Cáritas Diocesana de Coimbra* (CDC) to reach potential respondents. Also, several invitations were sent to the regional delegations of the Order of Nurses all over the country. Besides this, the questionnaire was disseminated by sending it to a mailing list of stakeholders, and a broader engagement was reached through social media, local newspapers, and specific home care centres. In this last area, the direct engagement of the professionals in the units of CDC was also relevant to reach the established goal. Finally, although this consultation took place during the pandemic period, it was possible to overcome the initial goal for Portugal ($n = 54$).

The questionnaire was developed in REDCAP [8] and thus the answers were automatically saved and grouped, which allowed to avoid manual errors in data handling and to analyse the results in a simple and agile manner. Besides the research team, also the respondents benefited from this questionnaire, as it ensured the absolute anonymization of the answers, which was also an objective at this phase of the study.

With the results achieved, the medical, technical, and social requirements were laid down in the description of 4 personas (a fictional character in the user-centred design created to represent a user type that might use a site, brand, or product similarly).

The outcomes of these three different phases will be explored and detailed in the following sections.

3 Results

3.1 Literature Review: Benchmarking of State-of-the-Art Projects in DIANA Field

The benchmarking was designed to present true state-of-the-art of projects in the same field as DIANA. It is practically impossible to survey all the solutions that are currently on the market, given the immense number of programs and investment. Nevertheless, an overview in the AAL and H2020 programs lead the consortium to perceive some

good practices that should be integrated into DIANA. With this research, it was possible to understand what should be avoided and what needs to be implemented, in terms of system design and approach.

The Roadmap project [9] observed that people are increasingly having access to technology that allows the use of app-based activity monitors. However, concerns around data security limit the use of the technology available on smartphones and tablets, as does a lack of confidence or willingness to use this technology. The project described an important factor, that people affected by CD are vulnerable and have difficulties to communicate effectively, making it increasingly difficult to know what their priorities and preferences are. Thus, nurses and carers' opinions are prioritized at this stage of development in the DIANA project.

Guidelines retrieved from ICT4Life [10] report that primary end-users are very concerned about sensors and the camera, but after testing it, generally, accept them well. During the pilot tests, the project verified that the voice commands were very well accepted by patients and that the evolution and recommendations of the system for patients were very well accepted by physicians and physiotherapists. Finally, they concluded that the communication tools between health professionals, carers, and other professionals and between patients and health professionals are the key point for integrated care platforms: this aspect has been underlined by all end-users; it has an economic impact because, according to users' opinions, it reduces personal visits to the doctors and emergency interaction.

The Toilet4me [11] started reflections both technologically and ethically for the development of smart toilets. Some guidelines have already been developed regarding data protection: Restricting access to data based on a "need to know" basis; providing users with unique login data with individual access levels; using encryption when sharing the data, developing a "clean policy," meaning not to leave personal data to unauthorized people and ensuring that all archived data is encrypted.

These conclusions will be considered during the development of the DIANA solution.

3.2 Literature Review About the Care and Special Treatment of Patients with Cognitive Disorders

Care for patients with cognitive disorders includes support in basic Activities of daily living (ADL). The health workers must do these routine tasks while encouraging the function and independence of patients for as long as possible [12], thus, promoting patient's safety, reducing their anxiety and restlessness, upgrading communication and in parallel educating the family carers. Bathing/hygiene, dressing and grooming, impaired physical mobility, wandering and risk for injury are some of the areas to which assistance from nurses and carers is needed and addressed in nursing care plans.

Risk of Falls

Inpatient fall prevention has been an individual area of concern for nursing for almost 50 years. At the international level, studies show that 30% of people over the age of 65 suffer at least one fall per year. According to the World Health Organisation (WHO), falls are the second leading cause of accidental or unintentional injury deaths worldwide and older adults suffer the greatest number of fatal falls [13].

Toileting Behaviour Analysis

Competent toileting is a critical life skill necessary for independent living, and not being able to use it adequately is a significant barrier for the quality of life of individuals with CD. Independent toileting can improve an individual's quality of life through improved hygiene and improved self-confidence, as well as reduced stigma and reduced physical discomforts. The use of technology could facilitate some tasks. For someone who regularly wets themselves, it may be helpful to develop a timetable that offers a reminder to go to the toilet. For example, real-time notifications on user's smartphone can also be useful for the person to remember to use the toilet or to check if their pad needs changing.

This information will also be considered during the development of DIANA.

3.3 Questionnaires – Requirements Collection

Demographics and Working Conditions

From the 54 respondents, most had working experience of ≤ 5 years or 6–10 years. The majority worked in a hospital or long-term care setting. The respondents were aged between 31 and 40 years and 78% were women. The questionnaires were broadly disseminated, so we can argue that the gender imbalance among respondents reflects the scenery in social and health care in Portugal for carers and nurses. The number of persons with CD they care for was mentioned as < 25 per workspace in most of the cases and the respondents spend between less than one hour and more than 6 h together with these persons. Needs for assistive/non-acute medical devices were discovered in most cases during regular care and either the physician or family-members were informed about it. Such products arrive within less than one week.

The respondents described their residents/patients as persons who have difficulties to go to the toilet in more than 90% of the time, that also have difficulties finding the room or their way in a room. More than 83% estimate that their patients have gaps in several aspects of the correct toileting sequence [14].

The most challenging tasks when providing care for persons with dementia in Portugal was to help with mobility, eating and toilet visits.

Use of Technology - Experience and Requirements

As for new technologies, 82% of the respondents agreed or strongly agreed that they would find them simple to learn. In contrast, half of the professionals did not think their cared persons would accept DIANA or were neutral. Nevertheless, the vast majority (80%) believed that digital assistance is an important asset for the care of old persons in the future. In addition, 72% felt that their company/institution would support such technologies. The most important areas mentioned were cognitive training and security, while only 26% mentioned autonomy (e.g., using the toilet) as a goal for AAL-technology and 23% did not feel well due to data safety issues. Positive thoughts on any device were mentioned if it reminded the person to wash the hands, to detect falls and had additional intelligent features, such as light control, monitoring of unwanted movement and call for help. 65% of the participants thought that an avatar or an acoustic clue is helpful to demonstrate correct use of a toilet. Also, the use of optical guidance was deemed helpful in 76% of the health care professionals.

Use of Technology – Available Devices

As for currently available devices, the respondents had some experiences with falls sensors, intelligent toilets, and highest experience with light sensors (24%). Roughly, 30% use tablets for nursing documentation. The nurses/carers spend about 10 min per day in the management of residents/patient personal data, between 10 min and one hour per day to implement information and tasks induced by physicians, including delivery for medication, while the time spent for individual nurse care planning is largely fluctuating.

New Systems and DIANA Solution Perception

As for potential new systems, the respondents ranked patient/resident privacy protection the highest, while there were heterogeneous responses related to cables, wires, installation, mobility, and cleaning.

The three most important advantages of DIANA in Portugal would thus be assistance in nursing care, social interaction, and falls/mobility detection. Nurses and carers see the potential of DIANA in the areas of wellbeing, medication management and the monitoring of mobility. Most of the nurses/carers would also be willing to share experiences with such systems and the most frequently used resources to collect information about DIANA would be articles, conferences, and social media.

4 Discussion and Conclusion

For fall risks, the literature review revealed that it is necessary to address extrinsic and intrinsic fall risk factors to optimize patient safety. This is done mainly by the medical or nursing staff. However, the DIANA solution can support this task, by providing additional security monitoring safety of patients 24/7, e.g., bed-exits, falls, wandering, etc. If nurses and carers receive this critical information, they can be able to prevent falls in time and act accordingly. Furthermore, they can adjust the system to their patient's needs, while maintaining privacy.

Regarding toilet issues, the DIANA project has thought of an innovative solution that can foster primary end-users' autonomy all the while helping the carers and nurses' work and saving time by not having to provide toilet assistance. The use of 3D sensors in a toilet allows for private sphere protecting action by using behaviour recognition algorithms already available but trained for other application areas. The algorithms are specifically trained to recognize movement sequences during toilet visits. After training the algorithms to detect relevant actions, they are combined into a complex activity model. The solution is to have an avatar to inform the patient if he/she missed some of the steps. Through this non-intrusive way, the user can autonomously use the toilet and the carer/nurse does not need to intrude privacy.

Regarding what has been gathered from the replies to the questionnaire, the respondents believe that they can use and work with AAL solutions such as DIANA. They already know several digital technologies in their field and most of them have at least some experiences using them. The care of patients is challenging - eating and toileting - the latter being the most challenging one. Secondary end-users think DIANA should be reliable, easy to install, wireless and easy to transport. Data on patients and or nurses should be safe since this is of concern.

Based on these findings and outcomes, the first set of functional requirements that the DIANA system must provide for was developed. The DIANA solution requirements extracted from this study reinforces that the prospects and needs of secondary end-users (nurses and carers) must be considered since the beginning of the project, especially in solutions that will have a direct impact in their work routine. Further information and requirements will be developed along with the project's timeframe, especially during pilot tests.

Acknowledgements. This work is supported by the Diana project, funded by AAL (Active Assisted Living – ICT for Ageing, 2017) and in Portugal by Fundação para a Ciência e a Tecnologia.

References

1. Alzheimer's Disease International. <https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/>. Accessed 28 Apr 2021
2. Alzheimer Europe: Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe. Alzheimer Europe, Luxembourg (2019)
3. Alzheimer's Disease International, World Alzheimer Report 2015, The Global Impact of Dementia, an analysis of prevalence, incidence, cost and trends. Accessed 02 Aug 2021
4. An Alzheimer's Disease International. <https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/>. Accessed 28 Apr 2021
5. Interaction Design Foundation Homepage. <https://www.interaction-design.org/literature/top-ics/user-centered-design>. Accessed 28 Apr 2021
6. AAL. <http://www.aal-europe.eu/ageing-well-universe/i-am-a-user-2/>. Accessed 28 Apr 2021
7. Ordem dos Enfermeiros da Região Centro. <https://www.ordemenfermeiros.pt/centro/>. Accessed 28 Apr 2021
8. REDcap. <https://www.project-redcap.org/>. Accessed 28 Apr 2021
9. CORDIS EU. <https://cordis.europa.eu/project/id/116020>. Accessed 28 Apr 2021
10. ICT4life. <https://www.ict4life.com/>. Accessed 28 Apr 2021
11. Toilet4me. <http://www.toilet4me-project.eu/>. Accessed 28 Apr 2021
12. Nurseslabs. <https://nurseslabs.com/alzheimers-disease-nursing-care-plans/6/>. Accessed 28 Apr 2021
13. WHO. <https://www.who.int/news-room/fact-sheets/detail/falls>. Accessed 28 Apr 2021
14. DIANA. <http://www.aal-europe.eu/projects/diana/>. Accessed 28 Apr 2021