eCare Tool for Person-Centred Care of People with Dementia in Nursing Homes

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Abstract—**Electronic tools have the potential to support healthcare staff in providing more person-centred care to persons living with dementia in residential nursing homes. The paper describes work in progress to develop an eCare tool that provides relevant information to caregivers about the needs of persons living with dementia and appropriate actions related to behavioural and psychological symptoms of dementia. The eCare tool, an eHealth technology to be integrated in electronic care records kept in nursing homes, is particularly relevant in the context of 'nurse team applications'. Increased person-centred care is linked to increase in job satisfaction and personal competence among nursing staff, resulting in lower turnover figures in nursing homes.**

Keywords-eCare tool; person-centred care; dementia; life stories; behavioural and psychological symptoms of dementia.

I. INTRODUCTION

The World Health Organization (WHO) estimates that 50 million people were living with dementia worldwide in 2015. The total number of Persons Living With Dementia (PLWD) is projected to increase to 80 million in 2030 and to triple to 152 million in 2050 [1]. Dementia affects cognitive functions, often followed by Behavioural and Psychological Symptoms of Dementia (BPSD), such as physical and verbal aggression, wandering, calling out; agitation and anxiety, hallucinations; depression and apathy [2]. Currently, there is no curative treatment available.

Dementia progressively inhibits the affected person's ability to communicate and satisfy basic human needs. PLWD often express or manifest their unmet needs through socially inappropriate or unusual behaviour including the above symptoms [3], which may lead to negative feelings in professional caregivers and other nursing home residents [4]. When caregivers focus on the physical needs, this can come at the expense of the psychosocial needs of this person. This incorporates an actual risk that nursing care tends to be more task oriented, objectifying and even depersonalizing. Some caregivers believe that progression to severe dementia leads to the gradual loss of personhood until there is nothing left of the person. It poses a real threat that the life of this PLWD is perceived to be meaningless, thus the role of the caregiver loses meaning too [5].

Already 20 years ago Kitwood introduced the conceptual model of Person-Centred Care (PCC) based on the idea that the personhood of PLWD is not lost, but is concealed [6]. Whether the psychological needs of PLWD are met and if personhood is maintained or strengthened, is largely determined by caregiver behaviour and environment [7][8].

Recent systematic reviews demonstrate the effectiveness of non-pharmacological interventions of PCC to reduce BPSD [9]-[12]. Reminiscence therapy (reliving experiences from the past by talking about recognizable photos, objects, etc.) [13]-[16], music therapy [17]-[19] and the use of biographic information of the PLWD during communication or care activities [20][21] are successful interventions that reduce BPSD.

PCC also positively effects the professional caregivers' personal accomplishment and job satisfaction [22]: e.g., reminiscence improves caregivers' communication with residents and increases their knowledge of the resident's background significantly [15][16], music therapy enhances caregiving techniques [18], while life story work enables healthcare staff "to see the person behind the patient" and empowers them to engage in "genuine participatory practices" [23][24]. There is also strong evidence that professional caregivers benefit from learning and skill development in PCC interventions and communication in order to sustain the effects of those interventions to apply person-centred care into practice [9][25].

Lastly, the above positive effects influence the perception of quality of care provided by the nursing home: the person-centred care staff feels more satisfied and competent to perform their job while the PLWD and their relatives feel more satisfied with the care received [25].

We are currently exploring the feasibility of an electronic tool that guides healthcare staff to integrate person-centred care in the daily care of persons living with dementia in residential nursing homes. The results of the feasibility study are expected to feed into a two-year implementation study.

Section II describes the objectives, study design and the work performed so far. Section III presents the preliminary findings, while Section IV elaborates on the work in progress for the development of the (e) learning and training modules and the eCare tool into the existing care records. Section V holds the conclusion and future work.

II. STUDY CHARACTERISTICS

A. Objective

Our study aims to develop and validate a practical electronic tool that enables healthcare providers to integrate person-centred care in the daily practice. The current study funding supports the preparatory work to test the feasibility of the tool, to identify the interventions preferred by healthcare staff to provide PCC to persons living with dementia and to outline the functional specifications of the eCare tool that facilitates PCC in nursing homes.

B. Study design

We conducted a literature review on the effectiveness of non-pharmacological interventions and person-centred care for PLWD. We held two focus group discussions with professional caregivers working in residential nursing homes to identify which PCC interventions they prioritize to be integrated in the eCare tool. They were also asked to express the desired functional requirements of the eCare tool in terms of content and technology, and how it can be integrated in existing healthcare records. We conducted interviews to explore the market of software applications for PLWD and their caregivers. We assessed the economic and societal relevance of electronic tools for PCC interventions.

III. PRELIMINARY FINDINGS

A. Preliminary lessons learnt

Ongoing research about integration of PCC in the daily care of PLWD and our study results so far have given us insights into:

- the PCC interventions considered by caregivers as being the most relevant to address the (unmet) needs of PLWD, in particular life stories, reminiscence and music;
- the need for staff training in person-centred care and supportive actions to address and prevent BPSD;
- the preference/need to integrate the eCare tool in the existing electronic care records used in nursing homes.

B. Development of an eCare tool supporting PCC of PLWD

The focus groups with potential end users (i.e., professional caregivers of PLWD in nursing homes) discussed primarily the most effective interventions to guarantee PCC of PLWD, and the preferred PCC interventions to be integrated in the electronic care records. Coding and analysis of the focus group discussions in NVivo revealed that nursing staff prefers to incorporate two main instruments into the eCare tool: (1) 'know the person living with dementia' and (2) incidents related to BPSD. As mentioned above professional caregivers identify reminiscence therapy or use of life stories as effective interventions to get to know the caretaker better, but often they don't hold all relevant personal or biographic

information at hand: the focus group participants clearly expressed interest in having this information readily available, for use in daily care or when observing BPSD.

Figure 1 reflects how these two elements would be included in the eCare tool whereby the tool on the one hand provides information to get to know the PLWD better and on the other hand hints to address and prevent agitation and other BPSD.
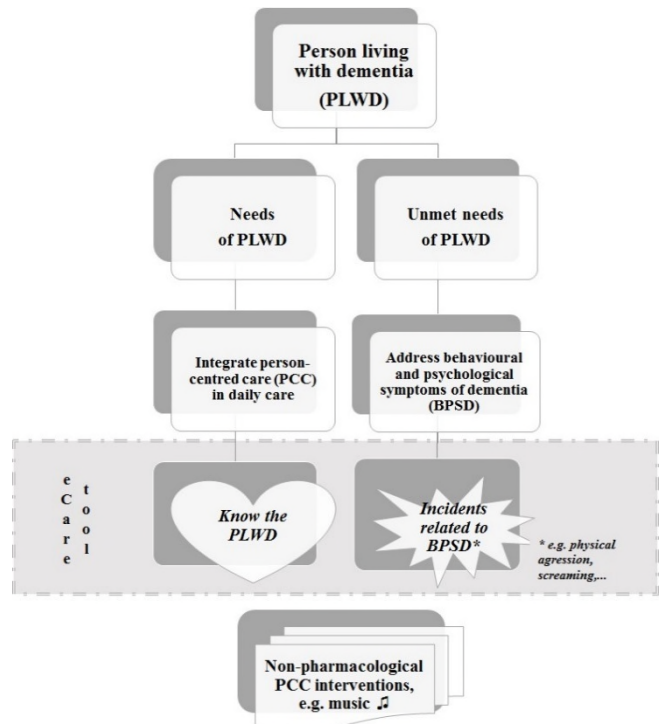

Figure 1. Elements to be integrated in the eCare tool.

1) Know the PLWD:

Nursing staff gives considerable importance to knowing the 'needs' of the person taking care of. → The eCare tool should allow to 'know the PLWD' through life story material and additional information received from the PLWD, their relatives and the nursing staff.

2) Incidents:

Nursing staff acknowledges the challenges to address BPSD in the most effective way. → The eCare tool should allow to register incidents related to BPSD, to analyse the incident and to suggest supportive and preventive actions.

IV. WORK IN PROGRESS

With the lessons learnt so far, we have prepared a study design to develop, test and evaluate the eCare tool. We will do this together with the end users, i.e., professional caregivers of PLWD in nursing home settings in Flanders. We are currently awaiting approval of study funding by the Flemish Agency for Innovation & Entrepreneurship and hope to start the study in September 2018.

A. Design of the eCare tool

In developing the eCare tool, we will follow the standard agile development cycle as depicted in Figure 2.
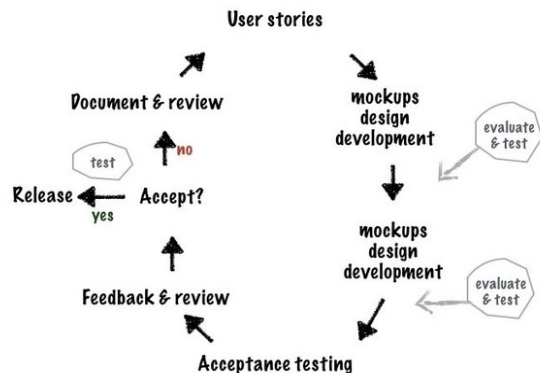

Figure 2.   Agile development.

Before development can start, the requirements have to be analysed and described. Each requirement is split up in a number of user stories. A user story is an informal, natural language description of one or more features of a software system. User stories are often written from the perspective of an end user or user of a system. Each user story contains one well defined feature as in: *As a user I want to add an incident concerning this person*.

After this analysis and description phase, agile development is used to implement the software [26]. Agile is an iterative process. In each iteration, a prototype of the eCare tool is developed and tested. When a prototype is demo-ready, the end user can try it and give feedback, both at the level of the specifications and the user interface.

Agile uses test-driven development, meaning that testing is an essential part of the process [27]. Testing is performed at three levels. Each user story is tested in isolation (Unit Testing). After a set of units belonging to a specific subpart of the application has been finished, the subpart as a whole is tested (Integration Testing). When the total application is ready for testing, tests can be performed at that level (System Testing). We will also perform usability testing with the end users. This type of testing results in useful information about how easy it is to work with the software, and how good it looks. The eCare tool can be used a stand-alone mobile application but is supposed to be further integrated in the electronic care records used in nursing homes.
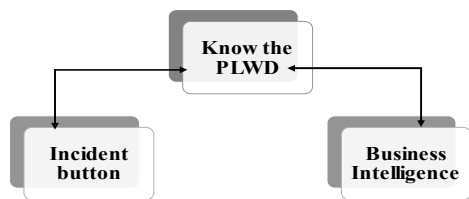

Figure 3.   Application structure woth three modules.

We will focus on 3 software modules (Figure 3):

- Know the PLWD Module. For each PLWD, facts of life (incl. personal interests, needs and preferences) will be collected through intake interviews in the nursing homes and elements provided by the PLWD, their family and formal and informal caregivers. Both word processing software and database systems can be used for this purpose. Using Information Retrieval technology, relevant information is extracted from these texts. A feedback loop ensures the dynamically-evolving nature of the personal information and records the response of the person with dementia to certain interventions. This module is the central data repository for the other modules.

- Incident Button Module. A caregiver can use this module to register incidents related to BPSD. The eCare tool asks targeted questions to report BPSD, which can be answered quickly via a drop-down list of pre-selected options. A requirements analysis of BPSD follows by: 1) objectively describing the BPSD (based on pre-defined categories); excluding possible medical causes such as pain, urinary tract infection, constipation...; examining the context of behavioural change; 2) discussing and analysing the case at the next team meeting; 3) drawing up an action plan in team with focus on person-centred care and approach (first choice is a non-pharmacological intervention, followed by medical treatment if needed).

- Business Intelligence (BI) Module. Historical data regarding the incidents can be consulted by the head nurse or by other management staff, both about a specific individual and at the level of a unit. Appropriate visualizations help to analyse and understand the trends. Notifications are stored in the database in a structured way. This makes it possible to map out the historical course of a resident's BPSD over time. 'Drill down' techniques allow the user to request more details about the incidents themselves.

B. Design of the learning and training modules

The implementation of the eCare tool requires training in the correct use of PCC interventions and the eCare tool itself by the end users (i.e., professional caregivers of PLWD in nursing homes). Currently, we are testing a training programme with practical workshops on (1) how to address and prevent BPSD (e.g., physical aggression, screaming, etc.) and (2) how to integrate PCC in the daily practice through PCC interventions, i.e., reminiscence therapy, the use of music and the use of biographic information of the PLWD during communication or care activities. We are investigating the possibilities to provide the training programme in e-learning modules.

Once the eCare tool is ready to be integrated in the current (electronic) care records an additional training

programme will be developed to train the end users on how to use the new applications/software modules.

V. CONCLUSION AND FUTURE WORK

The eCare tool is eHealth technology to be integrated in electronic care records kept in nursing homes and provides support to their healthcare staff for a person-centred approach of persons living with dementia. Increased quality of care and person-centred care are linked to increase in job satisfaction and personal competence among nursing staff, resulting in lower turnover figures in nursing homes.

The project team is currently conducting further discussions with IT experts and focus group discussions with healthcare providers and health managers about the functional requirements of the eCare tool. Future work depends on approval of study funding for two more years.

ETHICAL CONSIDERATIONS

Ethical approval will be requested from the Ethics Committee of the Antwerp University Hospital if application for further funding for development is successful.

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