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Quality of Life Tools to Inform Co-design in the Development of Assistive Technologies for People with Dementia and their Carers

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Abstract. A number of tools exist to measure quality of life (QoL) for people with dementia (PwD). A selection of existing measures are summarised, obtained from an online literature survey, comprising of scales administered either by healthcare professionals with the PwD (self-report) and/or their carers (proxy report) or from observation. It is suggested that a combination of such tools with user satisfaction questionnaires may provide a way to approach the problem of evaluating Assistive Technology (AT) solutions or inform co-design of technological solutions with PwD and their carers.

Keywords: Assistive Technologies, Telecare, Ambient Assisted Living, User experience, Dementia, Quality of Life measures, Health Technology Assessment

1 Introduction

A major goal of designers during preliminary phases of development of new technology products is to investigate user expectations, needs and desires, in recognition of the distance between mental model(s) of designers and those of users. In particular this distance needs to be reduced when the designed product is an Assistive Technologies (AT) for people with dementia (PwD), in order prevent non-use or abandonment [1]. In the field of interaction design there is a long tradition of user involvement in early design stages which and such methods are being applied to technology support for PwD and carers [2]. One approach to eliciting user needs is to investigate dimensions of quality-of-life (QoL)[3],[4], [5].

As Peterson et al. have noted [6], tools in use are mainly derived from the constructs of Lawton. There are two main ways to determine QoL of patients with dementia: i) Questionnaires and interviews (self-report by the PwD and/or proxy-report by the carer) and ii) direct observation of behaviours assumed to be related to QoL. The selection of the most appropriate tool will depend on the setting (home or care institution), the severity of dementia and the nature of the technology being considered. The advantage of using disease specific tools in pre-design and post–use phases are: i) to understand which are the needs and aspirations of PwD on the basis of reported or observable aspects of their daily life, ii) an indirect measure of the potential impact of ATs in their life, based on the improvement in their QoL that the technology could provide.

2 Quality of Life (QoL) tools

In the following section, in Table 1, a summary of tools to measure QoL for PwD are presented. The search was performed on Google Scholar with free text search terms: {dementia}AND{quality-of-life, QoL, scales} for English language papers (including reviews) published in the last 20 years. The tools selected were those intended to be administered by healthcare professionals with the PwD (self-report) and/or their carers (proxy report) or from observation. Papers solely about staging were excluded.

Table 1. QoL tools for people with dementia

Name	Description
Cornell-Brown Scale for Quality of Life in Dementia (CBS)[7]	Clinician rated scale administered jointly with the PwD and carer using 19 bipolar items (-2,+2) in a semi-structured interview format, to provide a single score (-38,+38). High QoL is indicated by the presence of positive affect, physical and psychological satisfactions, self-esteem and the relative absence of negative affect and experience. Adapted from the Cornell Scale for Depression in Dementia. Can be used for mild, moderate and severe dementia although for severe the validity and reliability may be affected by lack of patient self-observations.
Dementia Quality of Life Instrument (DQoL)[8]	Administered to PwD with mild to moderate dementia. 5-point visual scale used to present multiple choice questions. Each point on the scale is associated with a verbal description. 29-item scale to measures 5 domains of QoL: Positive Affect (6 items), Negative Affect (11 items), Feelings of Belonging (3 items), Self-esteem (4 items), and Sense of Aesthetics (5 items) plus one global item (Overall, how would rate your quality of life?). Subscale scores are not summed.
Quality of Life-Alzheimer's Disease (QoL-AD)[9]	Questionnaire of 13 items designed to provide seperate PwD and carer reports of the patient’s QoL with a 4 point rating (1 = poor, 4 = excellent). Measures domains of physical condition, mood, memory, functional abilities, interpersonal relationships, ability to participate in meaningful activities, financial situation, and global assessments of self-as-a-whole and QoL-as-a-whole. Response options are 4-point multiple choice options (1 = poor, 4 = excellent). Overall score range (13, 52). Composite scores that combine reports from patients and caregivers are weighted to favour patient self-reporting. Can be used for mild, moderate and severe dementia
Quality of Life Assessment Schedule (QOLAS)[10]	Interview and rating scale where PwD and carers (may include care home staff) are interviewed separately to identify 2 QoL issues for each of 5 domains: Physical, Psychological, Social/family, Usual activities, and Cognitive functioning. PwD and carers rate each issue they have identified 6-point scale (0 = no problem, 5 = it could not be worse). Overall score range (0,50) with higher score for poorer QoL.
DEMQOL[11]	Health professional administered questionnaires to assess health related quality of life for PwD and/or carer as proxy. There are two versions: 28-item DEMQOL for people with mild/moderate dementia and 31 item DEMQOL-proxy for carers of people with mild/moderate dementia or with severe dementia. 4 point scale.

OPQOL-35[12]	35-item questionnaire. Not a dementia-specific tool but can be applicable to people with mild to moderate dementia. 5 point scale.
Alzheimer Disease Related Quality of Life (ADRQL)[13]	Binary (Agree, Disagree) questions administered to the carer as proxy to the PwD in a structured interview format. The ADRQL evaluates 5 QoL domains: social interaction, awareness of self, feelings and mood, enjoyment of activities, response to surroundings. There are two versions of ADRQL , the original composed of 47 items and a revised version with 40 items, the majority of items in both versions measuring actions and observable behaviours. Each item has a specific numerical score provided in the ADRQL manual.
Quality of Life in Late-Stage Dementia (QUALID)[14]	Carer (proxy report) instrument that measures 11 observable behaviours of PwD over 7 days, indicating activity and emotional states, administered by nursing home personnel. 5-point Likert scale. Designed for quick administration (5 minutes).
Dementia Care Mapping (DMC)[15]	Structured observational tool for assessing PwD well-being in residential care who are unable to provide their own report. Health professional administered. Covers all stages of dementia (mild, middle or severe). Well-being and activities are recorded every 5 minutes over a period of 6 hours. 24 activity categories and indicators of social withdrawal are measured in terms of ill-being/well-being (-5, +5).

3 Conclusions

Although a number of valid and consistent QoL scales are in use there is presently no one tool to directly assess the impact of AT for dementia in terms of QoL improvement [6]. Consequently there is a lack of a standard approach to formative evaluation and user-centred design of new AT for PwD and their carers. However, some tools exist to evaluate user satisfaction and usability after a use of an AT prototype e.g., Psychosocial Impact of Assistive Devices Scale (PIADS)[16], Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST)[17] which may be used in formative evaluation. For people with mild or moderate dementia a combination of QoL tools with satisfaction questionnaires may provide a solution which therefore warrants further investigation e.g. to determine which tools to combine. There is unmet need of a tool for severe dementia related to AT evaluation with respect to QoL, although the proxy version of PIADS may be applicable.

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