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Human Factors for Dementia: Evidence-based Design

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Abstract. Designing care environments for people living with dementia is a complex challenge as the key stakeholder may have difficulty communicating their capabilities, limitations and preferences. This paper describes the use of evidence-based design personas in a multi-disciplinary team with architects and chartered human factors specialists. Four individual personas (Alison, Barry, Christine and David) and a couple persona (Chris and Sally) were used to bring the voices of the people living with different stages of dementia to the design process. Their changing/fluctuating symptoms were communicated in two formats (wheel and matrix) within an inclusive design process to adapt a Victorian semi-detached house. The demonstrator house presents evidence-based design, adaptation and support solutions to support people living with dementia to age well at home.

Keywords: dementia, human factors/ergonomics, care, environment

1 Introduction

Dementia is an increasing global issue, with a worldwide estimate of 46 million people living with dementia and expected to rise to around 131.5 million people by 2050 [1]. The diverse symptoms of dementia (cognitive, perceptual, functional and communicative changes) contribute to the challenge of designing appropriate and supportive care environments [2,3]. A well-designed care environment can improve quality of life and enable those with dementia to maintain some level of independence [4-6], but a poorly designed care environment can have negative consequences for quality of life and wellbeing [5].

'A person's home is not just the place where they live, but also a place of work for home care workers' [7]. Home care aims to satisfy peoples' health and social needs in their homes by *'providing appropriate and high-quality home-based healthcare and social services, by formal and informal care-givers, with the use of technology when appropriate, within a balanced and affordable continuum of care'* [8]. However, the home setting presents challenges for the more established (acute) caregiver-patient interactions and requires adaptation of policies, protocols and routines [9].

People living with dementia (PWDem) may find it difficult to communicate their design needs due to cognitive difficulties which are a core feature of dementia. To address this challenge, a human factors/ergonomics (HFE; [10]) inclusive design approach was taken to develop dynamic personas for PWDem (changing/fluctuating limitations and capabilities)

2 Design Personas

Personas have more commonly been used in fields, such as marketing and software design [11]. It was suggested that this concept could be used in dementia design to communicate the needs, symptoms, limitations and abilities of PWDem, and could be enhanced by an evidence-based approach. Design personas can be used to represent the needs of archetypal PWDem to provide designers (architects) with access to information which would be particularly useful for people in middle to later stages, where communication abilities deteriorate further.

A systematic literature review established the framework for a scoping study to explore activities of daily living (ADLs) and instrumental ADLs (iADLs) for PWDem [2]. The results suggested that eating, toileting, social interaction and physical activity were the most important activities which needed to be considered in the design of dementia care environments. The first version of the personas was based around design needs associated with eating and toileting; social interaction was promoted through supporting communal dining. Physical activity was supported by enabling independent mobilisation to the toilet. The subsequent versions were reviewed and revised iteratively in a series of focus groups and interviews with architects, care support workers, and care home developers. This included the addition of clinical assessment scores for the Mini Mental State Exam (MMSE; [12]), the Montreal Cognitive Assessment (MoCA; [13]), the Addenbrooke's Clinical Examination III (ACE-III; [14]) and the Abbreviated Mental Test (AMT; [15]). Icons were also added to illustrate content such as eyesight or hearing problems, and requiring assistance with activities of daily living, for ease of reference.

The final personas describe four stages of living with dementia as Alison, Barry, Christine and David [16]. They are available in two formats; firstly, as a dynamic wheel to indicate a good, average or bad day (Figure 1) with green representing a good day, amber an average day and red a bad day. Secondly, as a matrix (Figures 2) to show symptoms, care needs and design needs across good, average and bad days for each persona without having to scroll through the persona wheel.

Barry (second stage of living with dementia) is a 74 year old retired postman. He has been diagnosed with dementia and is currently still living in his own home. He has difficulty with word finding, planning and organising and has a small risk of falls (physical changes). On an average day he sometimes forgets recent events (including personal information about himself) and may need support for numerical tasks. On a bad day he may have communication difficulties and be confused, particularly in new environments (navigation information processing). These cognitive and physical symptoms and care needs are linked as a 'good day' in the next level, Christine (Figure 2).

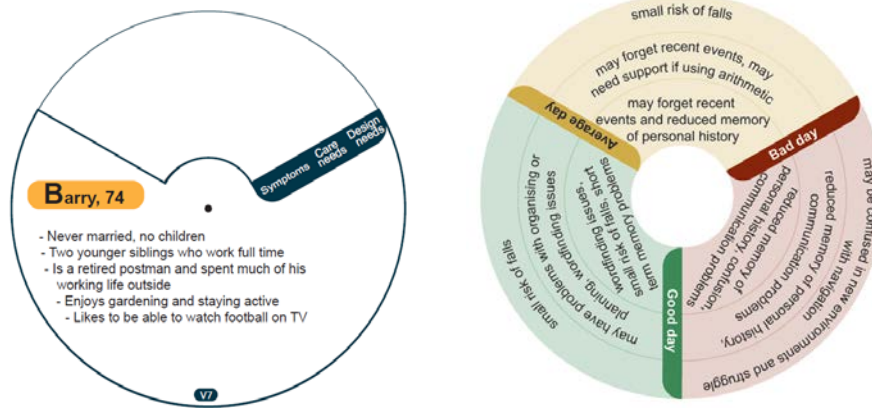


Fig. 1. Persona Barry as a dynamic wheel

Christine (third stage of living with dementia) includes a generic ‘ageing’ characteristic of hearing loss since the age of 70 years (she is described at 82 years). She uses bilateral hearing aids which may present dementia-related challenges for her in remembering to wear them and for usability with physical dexterity in their operation and maintenance (for example battery changes). As she is a talented musician, this hearing challenge can contribute to frustration with her changing capabilities and limitations.

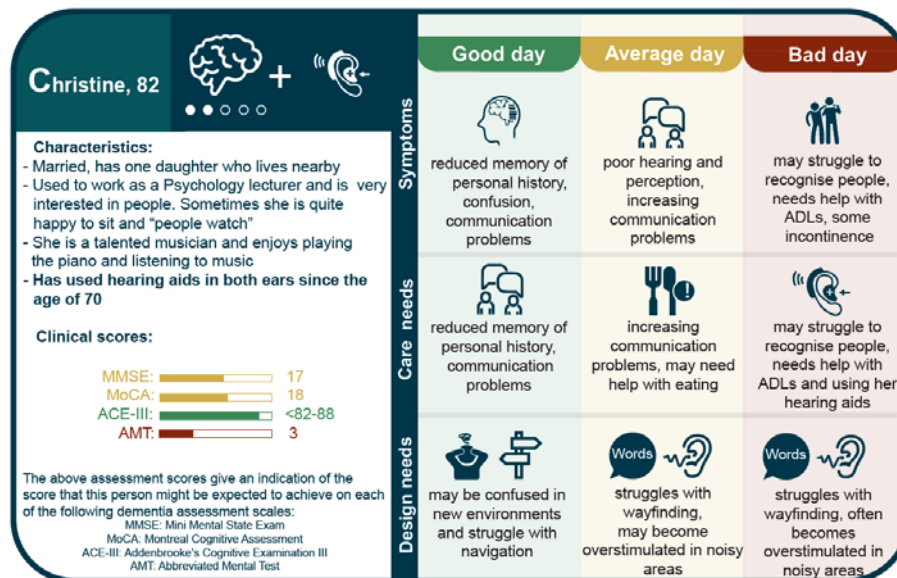


Fig. 2. Persona Christine as a matrix (more detailed information about Chris)

The final iteration was the development of a persona representing a couple to reflect the needs of a home care environment. This uses the same format as the individual personas, but has an inner wheel to represent the needs of Chris (PWDem. Figure 3), and his wife (carer), Sally. Chris has the same characteristics as Christine (third stage of living with dementia). They have been married for over 50 years but Sally is starting to find it harder to care for Chris as his dementia progresses. If their ‘bad’ days coincide, Chris may struggle to recognise people, exhibit sundowning syndrome [17] and become frustrated (lash out physically). Sally needs considerable help and may awake all night to care for him.

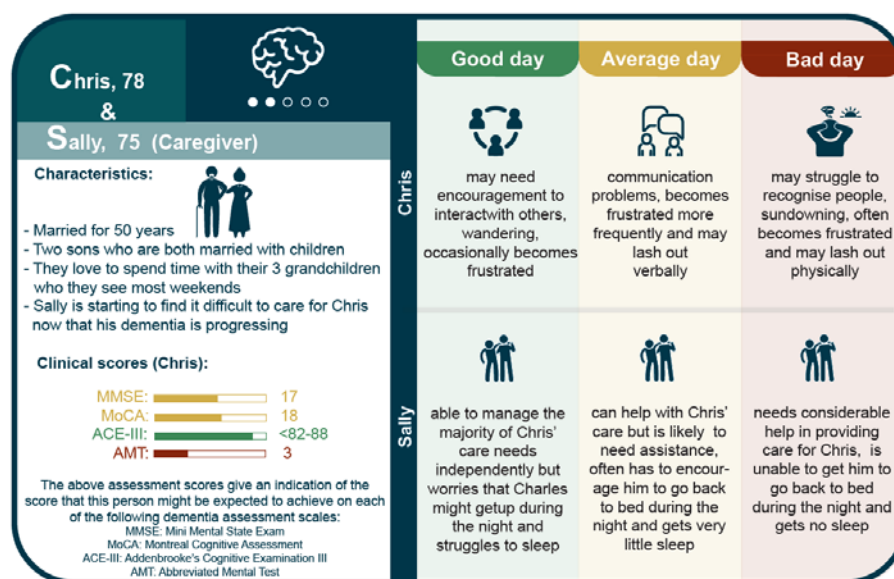


Fig. 3. Chris and Sally (couple persona)

The final personas were evaluated and validated in a third study by discussing the personas with professional caregivers (care managers, nurses and care assistants). The participants responded that the personas were a useful representation of PWDem; they ‘recognised’ needs and symptoms displayed by their residents and could identify features of the care home that might cause difficulties for the personas (as experienced by their residents). Overall, the personas were confirmed as a useful design communication tool, with applications in both care home design and care delivery.

3 Chris and Sally’s House

Providing care and treatment at home presents challenges for PWDem whether care is delivered from one or multiple organisation(s) or within different models of home care. These may include the hospital in the home, patient-centred medical home, home first policies and aging-in-place. Hignett, Edmunds-Otter & Keen [18] summa-

rised the state of science for physical interactions (context for design) with the results grouped as environment (health policy, physical and social), artefacts (equipment and technology), tasks (procedures and work schedules) and care recipient/provider. This included permanent and temporary building design and access, communication and lone working, provision of equipment and consumables, and clinical tasks. The care tasks were categorised as basic care, including personal hygiene, mobilisation, nutrition and social company, and advanced care, including medication administration, tube feeding, and operating home care technology (e.g. ventilator, electric wheelchair). There was research evidence identifying risks associated with awkward working positions, social environment issues (additional tasks and distractions), abuse and violence, inadequate team (peer) support, problems with workload planning, needle stick injuries and physical workload (moving and handling).

This research has been taken forward as part of a project with the Building Research Establishment (BRE; <https://www.bre.co.uk/>). A demonstrator house (Figure 4) is being developed through evidence-based design to present adaptation and support solutions that enable people living with dementia to age well at home and maintain independence.



Fig. 4. Victorian semi-detached house, with side view

Dementia design guidelines have been critically appraised [6,19-25] and found to be mostly based on professional consensus and stakeholder opinions rather than robust research evidence. The personas address this gap by integrating a systematic literature review with empirical qualitative and quantitative data from stakeholders (scoping study, focus groups, interviews, and care home observations).

The Victorian house (re)design plans were reviewed and discussed by the multi-disciplinary team using the personas to explore usability within a theoretical framework of inclusive design [26]. The final layout has key features of dementia friendly toilets downstairs and upstairs, and a through-floor lift (rather than a stair lift) to achieve end of life care in the first floor bedroom with an adjacent kitchenette (for

overnight support/respice carers). A ceiling track hoist is included to support moving and handling activities during full (end-of-life) care for David.

The research evidence incorporated within the personas includes the use of colour as a navigation aid (and cue) [5,27-29]. For example, Namazi & Johnson [29] found that PWDem achieved better success with navigation tasks in environments using primary colours, improved contrast and concrete nomenclature (rather than abstract) with supporting diagrams, and indirect cues from signage placement.

4 Conclusion

Chris and Sally's house gives an example of how university-based research can be taken from empirical data through to real life application. The multi-disciplinary team has benefited by incorporating human factors expertise as a 'linking discipline' between clinical and safety science and design to produce an inclusive design. We hope that this offers both an exemplar for housing adaptation and also potential for incorporation into future building regulations to support ageing well at home.

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6 References

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