Developing personas for use in the design of dementia care environments

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Abstract:
Context: Dementia has a high global prevalence, and the number of people with dementia (PWDem) worldwide is expected to rise in coming years. The various symptoms associated with dementia can cause difficulties for PWDem when engaging with activities of daily living (ADLs) as the disease progresses. However, designing a care environment which enables PWDem to successfully engage with ADLs is not a simple task, in part because PWDem may find it difficult to communicate their needs to a design team. For this reason, design personas which aimed to represent PWDem at different stages of the disease were created as a means of communicating these needs to designers. This paper describes an evaluation study on these personas.
Objectives: To consult design stakeholders and obtain feedback on the use of the personas in the process of designing a dementia care home.
Methodology: Interviews and focus groups were used to obtain feedback on the personas.
Main results: Participants suggested several improvements for the personas. These included (1) diagrams (images and symbols) rather than text, (2) focusing less on specific design guidance, and (3) including a wider range of symptoms and needs.
Conclusion: The wide range of suggested changes from the participants indicated both engagement with, and potential for, the initial personas. The personas have been revised and will be tested in care homes to explore how far they accurately represent the needs of PWDem both with caregivers and PWDem.

Keywords: personas, dementia, human factors, care home, design

1. Introduction

Designing dementia care homes is challenging, not least due to the complex nature of dementia. Symptoms which affect cognition, functional abilities, behaviour and perceptual abilities mean that a poorly designed care environment can have negative consequences for quality of life and wellbeing (Day, Carreon, & Stump, 2000). Conversely, a well-designed care environment can improve quality of life and promote independence (Cioffi, Fleming, Wilkes, et al., 2007; Day, Carreon, & Stump, 2000; Fleming & Purandare, 2010).

Due to some of the cognitive difficulties such as communication problems which are commonly present in dementia, it is not always possible for people with dementia (PWDem) to explicitly state what they need from a care environment. This poses a problem when designing dementia care homes. One way in which this could be overcome may be through the use of design personas which represent the needs of archetypal PWDem. These could provide stakeholders with access to the information that they require, avoiding the need to rely on PWDem being able to communicate their needs to them. This could be particularly useful for representing the needs of people in the middle to later stages of the condition, where communication abilities deteriorate further.

2. State of the art

Currently no existing design personas have been identified which focus specifically on PWDem or dementia care home design. Preliminary personas (Figure 1a) were developed after a scoping study which looked at the activities of daily living (ADLs) that may be relevant to PWDem (Jais, Hignett, Habell, et al., 2016).

3. Objectives and Methods

This study aimed to evaluate the initial set of personas by seeking feedback from potential users (design stakeholders). The study assessed whether the proposed format and content were appropriate for use in the design of dementia care environments, and explored how they might be further developed. Potential users of the personas were consulted with the intention of identifying where the personas might best fit within the design process and ensuring that the personas would meet their needs.

3.1 Methods

Participants were recruited from the scoping study. Interview schedules and focus group protocols were designed to cover two main topics, the content of the personas and the format of the personas. These were written in a semi-structured style to allow participants the freedom to contribute other ideas or comments that may not have been covered otherwise. Audio recordings were made of the interviews and focus groups. Two recordings were made during each session to avoid losing all audio data in the event of technological problems. Interviews were carried out over Skype. After each session, a contact summary sheet was completed to note points of particular interest, and anything that might have been missed out that would need to be discussed during the next session. An ethical checklist was filed for the study in accordance with Loughborough University's ethical procedures.

3.2 Interview procedure

Participants were sent copies of the information sheet, consent form and personas before the interview; this provided the opportunity to ask questions about the research and give informed consent. Sending this information to participants before the interview also meant that they had time to familiarise themselves with the personas before the session. Two researchers were present for all interviews. Participants were called over Skype. Once the call had connected, participants were asked to confirm that they were happy to take part in the study. Audio recording was started once they had given verbal consent. Participants were then briefed on the session content, and were given an overview of the aims of the personas. They were asked if they had any initial thoughts or comments on the personas before proceeding with the interview. The researchers and participants discussed specific aspects of the personas, such as the content and layout. Participants were asked about each section of the personas, e.g. social information and clinical condition. Once participants had no further points to make, the researchers summarised what had been said and asked if there were any other questions or comments. Participants were thanked for their time, and reminded to email the researchers if they had any further questions or comments about the research. At this stage, each researcher completed a contact summary sheet detailing anything that was particularly interesting as well as extra points to bring up in future interviews or focus groups.

3.3 Focus group procedure

The focus group session was held in London as this was mutually convenient for participants and researchers. Although four participants initially agreed to take part, one participant was unable to make the session and was interviewed via Skype instead. Another did not attend, meaning that two participants attended the focus group. Participants were given information sheets and consent forms to read and complete. After consenting to take part in the study, each participant was given a copy of the personas to read through before the session began. Participants were encouraged to make notes on the personas if they found this helpful. Once participants were familiar with the personas, the audio recordings commenced and the session began. Each persona was examined in turn, and participants were asked about content and format in line with the focus group protocol. After all four personas had been covered and when participants had no further comments, the researchers summarised the main points made during the discussion and the session was brought to a close. Each researcher then completed a contact summary sheet as with the interviews.

3.4 Participants

The 6 participants included:

- P1 (architect) and P2 (architect, wife has dementia) interviewed together over Skype;
- P3 (care home developer) and P4 (care worker) interviewed separately over Skype
- P5 (head of dementia innovation) and P6 (architect) attended the focus group together.

4. Results & Discussion

Data were coded and analysed in NVivo10.

4.1 Personas

A number of suggestions were made to develop the personas. Participants suggested that the social background section could be expanded, with a wider range of social backgrounds, to highlight that anybody can develop dementia. Including some information about the person's family, as well as their likes and dislikes, was thought to be beneficial in providing some context for the personas and giving the design team a clearer idea of the range of people who might use a dementia care home. The importance of incorporating such things as preferred leisure activities was stressed. This supports the findings of a recent scoping study (Jais, Hignett, Habell et al., 2016) which suggested that activities other than those which are typically classed as ADLs are also important for PWDem.

It was felt that the inclusion of too many clinical details may not be helpful to a design team, as care homes are designed for a range of people rather than for specific individuals. It was suggested that instead describing a range of symptoms may be more useful, perhaps by outlining typical symptoms that PWDem might experience on a bad day, an average day or a good day. Including a short description of typical symptoms in each persona was deemed to provide enough information without going into too much detail. Similarly, including a range of different ages in the personas was thought to be useful.

Some suggestions for the layout of the personas were also made. Whereas version 1, which was presented to participants during the study, was largely text based, it was recommended that the second version should be more visual in appearance:

"*Maybe a way to do it is to have the person in the middle and then, sort of have circles radiating out"* – P5; head of dementia innovation.

It was noted that users of the personas may gain more from using something presented as a diagram rather than something which is solely text based, particularly those on the design team whose work is likely to be more visual in nature. A visual method of presenting the personas was therefore explored during the development of version 2 to ensure that the personas would facilitate communication between all stakeholders including both the design team and PWDem.

One participant highlighted that it is becoming more common for couples to move into care homes together and that therefore it may be useful to have a persona which represents a couple. As well as this, it was suggested that having a persona which represented family carers may also benefit the design team in that it would highlight what this group may need from a care home.

Participants also discussed where the personas could fit into the design process. It was suggested that they could be used as a discussion tool during the development of a design brief, as they could help all parties to identify the requirements of the proposed care home. This suggests that personas would likely be most useful in the pre-design phase of the design process (Taylor, 2016). As well as this, stakeholders could discuss the needs of the intended users and how they were similar to or different from those described in the personas.

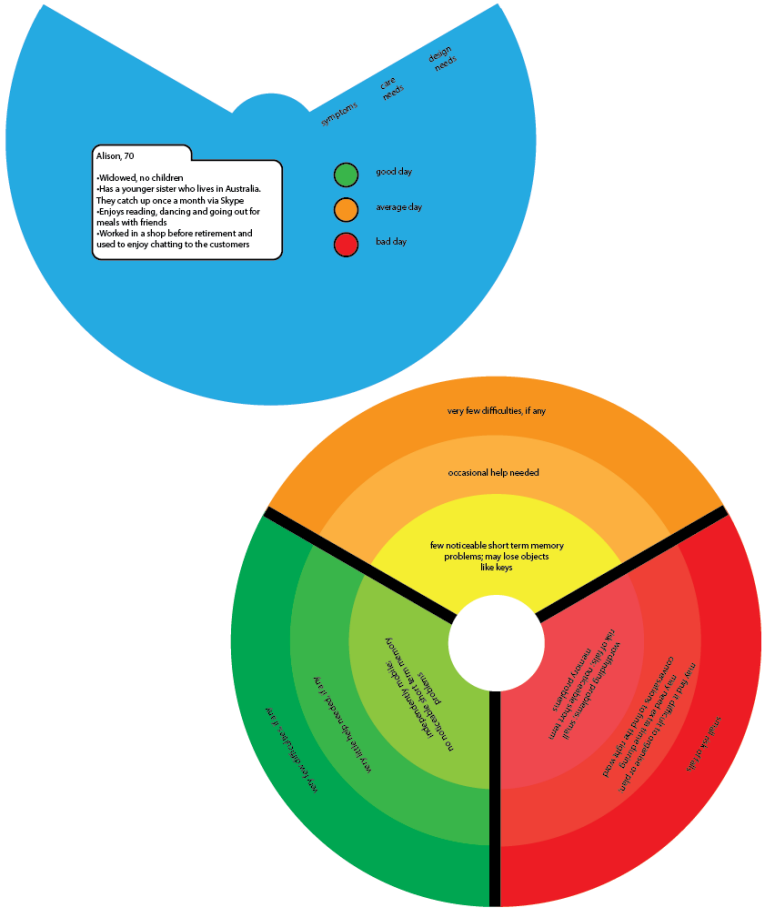
Including detailed design guidance was not thought to be particularly useful as it was noted that those working on the design of a dementia care home would likely already possess this knowledge. If this were not the case, this information is already well covered by existing design guidelines, including space standards and building regulations.

4.2 Other findings

Various other topics were raised, broadly including the symptoms of dementia, the stakeholders

Alison	Female
Social information	Widowed
Age	70
Job (current/past)	Retired shop worker
Clinical condition	Early stage dementia (Alzheimer's Disease)
Current situation	Planning for long term care and possible future move to care home as disease progresses
Physical abilities	Independently mobile, small risk of falls
Cognitive abilities	Short term memory problems, struggles to learn new skills, sometimes forgets what she has just read
Perceptual abilities	May struggle to distinguish between different objects where there is little contrast
Communication	Sometimes has difficulties in finding the right word
Built environment issues	• Alison may find it difficult to locate the bathroom, so it is important that bathrooms are clearly visible. Signage on walls, doors and floors could help with this. Signs should use contrasting colours, relevant images and large, clear text[1]. • Alison also faces difficulties inside the bathroom. Contrasting toilet seats can help to reduce her risk of falls[2], and fixtures such as dual lever taps which are both familiar and easy to use may enable her to engage with activities related to toileting such as handwashing[3]. • Signage could also assist Alison in finding the dining room. To help Alison to remember where she is and why she is there, the dining room should resemble a typical "homelike" dining room as far as possible[4]. To prevent falls and injuries, furniture such as tables and chairs should contrast well with the floor and walls[2].

[1] Signs with large clear text, high contrast colours and relevant images can help to promote bathroom finding when placed on walls or floors (1).
[2] Reduced contrast sensitivity has been shown to be one of the most important visual risk factors for falls (2). Coloured toilet seats which contrast with the toilet bowl can help to enhance visual abilities within the bathroom and may help to prevent falls. Similarly, using contrast between the walls, floors and furniture in dining areas may help to prevent falls occurring here.
[3] Familiar fixtures may help to avoid confusion and enable people with dementia to complete tasks such as handwashing more independently (3).
[4] Environments which would have looked familiar to a person with dementia during their early adulthood can help to counteract the difficulties which they experience as a result of dementia (4).



Figures 1a & 1b: Examples of personas from version 1 (left; 1a) and version 2 (right; 1b)

involved in the design of a dementia care home, design considerations, the design brief, activities and care practices.

Participants noted that some symptoms such as perceptual issues are commonly attributed to dementia but in fact such symptoms could also arise as a result of general ageing. Different types of dementia were discussed, as were the different stages, and it was suggested that these factors contributed to some of the challenges when designing for groups of PWDem in that this group has diverse needs and abilities.

It was recognised that culture could present challenges for signage; as certain symbols or icons may be familiar to people from some cultural backgrounds but not others. The needs of various stakeholders, including the families of PWDem, the design team and other residents in the home who are not living with dementia were also considered.

Many different aspects of design were considered. The use of colour and contrast were generally thought to be an important factor in care home design, which supports previous literature on this topic (Day, Carreon, & Stump, 2000). However there were areas in which participants weren't sure of the relevance of colour:

"Although I would say, tongue in cheek, how the colour is relevant as you back towards the toilet seat, I don't know" – P1; architect

Cost was also explored, and it was noted that the financial implications of certain design features meant that compromises often had to be made between the design team and the client. Participants brought up design guidance and suggested that while dementia design guidelines were useful, Health Building Notes (e.g. Department of Health, 2015) were not always particularly useful as they were perceived to be outdated. Participants emphasised the importance of using familiarity in care home design and creating environments which looked homely, and the use of signage was thought to be important in helping PWDem with navigation. This supports the design guidance described in the literature on this topic (Day, Carreon, & Stump, 2000). It was suggested that using carpet throughout the care home could help to reduce high levels of noise which can be problematic for PWDem (Fleming & Purandare, 2010). Safety was also brought up, and it was noted that tasks such as trying to make a cup of tea or coffee could be potentially dangerous for people with advancing dementia:

"I've seen people put the actual teabag inside the kettle and sort of putting coffee in the kettle as well, sort of thinking they have to make a cup of tea that way" – P4; care support worker

The layout of the home was also mentioned, and the locations of bathrooms were thought to be particularly important in that they needed to be easily accessible and visible. This again supports previous research findings on this topic (Day, Carreon, & Stump, 2000).

Participants stressed the importance of putting together a good design brief:

"If you don't get the brief right, you won't get a good build. It's really important." – P6; architect

It was suggested that the personas could be useful here as they could promote discussion amongst different stakeholders.

While activities such as eating and toileting were considered to be important, participants also emphasised how crucial it is to enable residents to take part in their preferred leisure activities and complete everyday household chores to maintain a sense of normality. This again provided support for the findings of a recent scoping study in this area (Jais, Hignett, Habell, et al., 2016). Discussions on care practices also touched on this and it was acknowledged that person centred care was likely to be the most suitable approach to dementia care as it encouraged carers to treat residents as individuals.

5. Conclusion & perspectives

These data have been incorporated into the next stage of the persona development (Figure 1b). Whereas version 1 was more text based, version 2 is much more visual in nature. In version 2, the two elements fit together so that the bottom section can be rotated to reveal different sections under

the blue cover. The social information section (in the blue cover of version 2) has been expanded. Version 2 also covers a wider range of symptoms and needs by showing what the person's symptoms, care needs and design needs could be on a good day, an average day and a bad day. These are represented by different coloured sections in the bottom section, with green representing a good day, orange an average day and red a bad day. Version 2 of the personas focuses more on the specific issues experienced by PWDem rather than the ways in which these issues could be addressed through design as participants had indicated that they were, more often than not, already aware of the relevant regulations and guidance. It was also noted that if this were not the case, this information is readily available to the design team and that therefore it does not need to be included in the personas.

The results of this study showed that there were several ways in which the personas could be improved. These suggestions were taken into account and influenced version 2 (Figure 1b). As participants were able to identify a specific stage of the design process at which the personas would most likely be useful, it is intended that these will be used as a discussion tool for those involved in drawing up a design brief for a dementia care home. This will help to ensure that all parties are able to contribute to the design brief and fully discuss the needs of the future residents of a proposed care home, while considering how the design of the home will need to account for these needs. It should be noted however that the sample used in this study was small, meaning that these findings cannot be generalised to all designers or care workers. For this reason, the development of the personas will continue to be an ongoing process to ensure that more varied perspectives and viewpoints are also incorporated.

Once development of version 2 has been completed, the personas will be taken into care homes to evaluate current care home design for PWDem. Additionally, PWDem will be consulted to seek feedback and ensure that the personas accurately represent their needs. The personas will then be reviewed once again and revised accordingly, leading to a final version.

Acknowledgements

Thanks to the Design Star Doctoral Consortium for funding this PhD studentship.

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