Co-designing new resources to support better quality end of life care with people with dementia and family carers

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BACKGROUND

Over the last decade there has been considerable national effort to help people with dementia and their families 'live well' through a focus on earlier diagnosis and intervention (Alzheimer's Disease International, 2011; Department of Health, 2009). However with increasing numbers of older people dying with, or from, dementia (Public Health England, 2016), it is essential they receive good quality care throughout their illness including towards, and at, end of life (NICE, 2015). Research focused on improving dementia care should involve people living with the illness and their families, in addition to care professionals. Facilitating such engagement with people with severe dementia is challenging as people's memory and speech deteriorates (Alzheimer's Disease International, 2016); in addition their families may find talking about end of life issues upsetting. Notwithstanding it is particularly important for people with dementia to have the opportunity to talk about their wishes and beliefs about their future care whilst they are able to do so to enable their family and professional carers to confidently make decisions on their behalf when they are no longer able to do so themselves (Alzheimer's Society, 2017).

If such discussions, usually called advance care planning by professionals, are had, people with dementia and their families need to feel confident that their wishes and preferences will be acted upon; formally writing such discussions down, and sharing this information with health care professionals, may assist this (National Council for Palliative Care (NCPC), 2015). However research to date has shown that having such sensitive discussions with people with dementia about planning ahead for future care is difficult; health professionals struggle to find the right time whilst patients and families may be reluctant to write their wishes down in case they change their minds at a later date (Dickinson et al, 2013; Robinson et al, 2012). There thus appears to be a need for resources and/or tools to help initiate early discussions about future care planning in dementia not only for families living with the illness but for healthcare professionals as well (NHS England, 2017).

Supporting Excellence in End of life care in Dementia (SEED study)

Internationally research looking at improving end of life care in dementia is increasing but is still limited in the United Kingdom (Van der Steen, 2010). One of the largest studies to date, the Supporting Excellence in End of life care in Dementia programme (SEED, http://research.ncl.ac.uk/seed/) funded by the National Institute for Health Research, is exploring how best to enable both service providers and service commissioners (Amador et al, 2016; Lee et al, 2015) to deliver better quality, community-based care to people with dementia towards, and at, end of life. Findings from a very large qualitative study identified 7 key components which contributed to the provision of good quality end of life care in dementia (Bamford et al, 2017)(see figure 1):

Insert Fig 1 near here

Figure 1. The SEED intervention.

Using these findings, the SEED study developed a dementia nurse-led intervention which is currently being tested in primary care settings. However the data also suggested the need for a ‘care resources kit’, containing current and possibly new resources, and targeting the 7 key components, which would help the dementia nurse specialists deliver the intervention, work more effectively with patients and their families and improve the knowledge and skills of the patient’s usual healthcare team. This paper describes how the SEED team used a co-design approach, based on previous successful research (Macdonald et al, 2012; Robinson et al, 2009), to work with people with dementia, their families and professional carers, to develop a new resource to support discussing, making and documenting plans for future care, particularly towards and at end of life.

METHOD

Development of the new resource comprised two separate, but linked, pieces of work which progressed concurrently to inform the other:

i) Review and mapping of existing resources to assist people with dementia and their families and/or key carers discuss end of life. This also enabled us to identify possible gaps for developing new resources and a

ii) Co-design process to develop the new resource.

Mapping existing resources

Resources were initially identified using specific search criteria including end of life care and dementia and by targeting key websites, for example, Alzheimer's Society, Alzheimer's Association and the National Council of Palliative Care. Identified resources were reviewed and sifted by a small group from the research team with personal and professional experience of dementia care at end of life (EM, KD, ST, LR). Resources were initially grouped according to:

▪ Title and content
▪ Relevance to 1 or more of the SEED 7 key themes
▪ Content: general to end of life care or specifically targeting dementia
▪ Target audience (people with dementia, family carers; professional carers) and
▪ Country of origin.

Format and availability (e.g. downloadable; freely available; cost) were also considered with regard to how accessible resources would be to professionals and people with dementia and their families. Further exploration of resource content was then undertaken by the small group with a focus on quality to determine if the development of the resource was grounded in, or influenced by, research evidence.

A final review process then took place to select the most appropriate existing resources to include in the intervention. Selected resources were prioritised based on the following criteria:

- Dementia-specific
- Freely available
- UK-based
- Grounded in evidence

International resources for professionals were included if they were high quality and had a strong evidence base. International resources for people with dementia and their families were included if they were accurate, high quality and judged acceptable by lay members of the SEED team.

The 'final' list of resources demonstrated considerable variation in the quality and quantity available for the 7 different key components. A large number of detailed resources were found addressing component 1, *Timely planning discussions;* however these were either targeted at enhancing professional knowledge and skills or if patient/family focused, not presented in a simple accessible manner, to specifically encourage practical discussion between people with dementia and their carers. For the latter group, existing resources also tended to focus on a single area of care planning; there was nothing available which enabled people with dementia and their families to bring together all aspects of care planning documents/information in one place. Thus a specific area of development need for the co-design phase was identified.

A co-design approach: development of a prototype new resource

A co-design approach was seen as integral to ensure meaningful and useful resources were created to support planning end of life care for people with dementia and their families and to ensure the views of all stakeholders were equally represented. The concept of co-design *"enables a wide range of people to make a creative contribution in the formulation and solution of a problem. This approach goes beyond consultation by building and deepening equal collaboration between citizens affected by, or attempting to, resolve a particular challenge. A key tenet of co-design is that users, as 'experts' of their own experience, become central to the design process."* (Design Council, 2014; Design for Europe)

Involving all relevant stakeholder groups, people with dementia, family carers, paid carers, doctors, nurses, support workers and occupational therapists was an important aspect of our co-design approach. The co-design approach comprised two stages:

1) Development of an initial prototype for the new resource via internal project workshops with i) the multidisciplinary SEED team which included a patient and public involvement (PPI) representative (ST) and ii) the project's external PPI advisory group and
2) Refinement of the prototype through external workshops involving newly recruited participants from the key groups listed above.

Design-led researchers from the School of Design at The Glasgow School of Art (AM, SN), experienced in using co-design and stakeholder engagement for co-developing healthcare interventions, added to the more traditional dementia, palliative and nursing care specialists in the research team.

The initial prototype developed by the project team comprised a 'Care Plan Guide' (CPG) which brought together in one tool a wide variety of planning resources including:
1) lasting power of attorney (health & welfare; and property & financial);
2) advance statement;
3) advance decision to refuse treatment (including non-resuscitation);
4) making a will; and
5) funeral planning.

Feedback from the SEED PPI advisory group, suggested the need for a digital or web-based version. The design team thus developed a model of an app which could be used alongside the printed version for testing in the subsequent co-design workshops.

Co-design workshops: refining the prototype Care Plan Guide

One group of professionals (registered nurse and support workers) was recruited from a specially designed community complex with six supported households, which aims to create a family atmosphere for older people requiring full-time care, including those with dementia. This service was provided by a not-for-profit organization and was characterized by a stable senior management team and a large core workforce. This service had participated in the earlier qualitative work. Potential participants were identified through the service manager and invited to attend a co-design workshop.

Participants in the remaining two groups were invited to participate through the support of the project manager at Alzheimer Scotland for Dementia Circle groups, who acted as “gate-keeper” to identify potential participants and introduce the researcher to the groups. The researcher was invited to present the study to the Dementia Circle group members and provide information sheets and criteria for participation. This provided an opportunity for the group to meet the researcher and ask questions regarding the study. Later, group members informed the project manager about their wishes to take part of the study and a day and time was arranged for the researcher to return and conduct the workshops. The format for each co-design workshop was similar (see Figure 2).

Insert Fig 2 near here

Figure 2. The workshop set-up.

Specific questions discussed in the workshop included:

- The concept of the CPG
- Content
- Format
- Language
- Medium
- Design
- Title
- Other comments

A full-size mock-up of the print-based CPG was made available to participants to mark-up with their own suggested improvements. Participants could also try out the mocked-up app version. In the preparation of these mock-ups, guidelines were referred to for age- and dementia-appropriate design (Dementia Engagement and Empowerment Project, 2013a; b; Knowles, 2014). Participants were also each asked to complete a set of workbook questions to capture their individual comments on key aspects of the CPG (see Figure 2).

Ethical approval was granted by Glasgow School of Art (GSA) Research Ethics Committee and research approval from Alzheimer Scotland in February 2017.

FINDINGS

Three co-design workshops were held with 20 participants. Group 1 comprised 9 participants: 8 support workers and 1 registered nurse; Group 2 comprised 7 participants: 2 people with dementia, 3 family carers and 2 occupational therapists and Group 3 included 4 participants: 2 family carers and 2 people with dementia.

Overall, participants indicated that the CPG, as a general concept, would not only positively address the intended purpose of facilitating timely planning discussions between people with dementia and their families and carers but would also be helpful for many other individuals wishing to have these types of difficult timely planning discussions.

The CPG structure, with its overview, general introduction to each plan, detail and links to further information, with all information kept in a single place together with the record of progress and decisions against each plan were all seen as helpful. Suggested improvements, such as to the navigation, the way colour was used to differentiate different sections, font size, and arrangement and amount of text, were embodied in further iterations of the CPG (both paper and app versions) for subsequent workshops. The initial use of acronyms and formal legal language were regarded as unhelpful and later revised. Although some individuals were unable to use, or were not at ease in using, apps, preferring the printed version, tablet- or phone-based interaction was regarded by younger generations as convenient enabling direct links to further web-based resources. Suggestions included customising the format and text-size and use of voice-command features to enhance usage.

As the use of the CPG would involve all stakeholder groups in discussions at some point, its development required input from each group. Although there was an overlap of interests, each stakeholder group had particular interests typified in Figure 3. For example, people with dementia tended to be concerned more with the terminology used (to avoid unfamiliar jargon), legibility, layout and navigation within and between sections. Family carers were more typically concerned with alternative (to paper-based) formats such as websites and apps, to enable more interactive and engaging discussions and to enable access to further web-based resources. The concern of support workers and specialist nurses was typically more on how the resource could best help them to support family carers.

Insert Fig 3 near here

Figure 3. Focus of feedback from different stakeholder groups

DISCUSSION

Our project set out to involve all key stakeholders including people with dementia and their families in the co-design of potential tools/resources to support professionals to deliver better quality care in the challenging and sensitive area of end of life care. Our experience showed that the co-design process proved to be a positive experience for participants. The iterative evaluation, by the different stakeholder groups, of the paper- and app- based mock-ups, helped us identify early not only what was effective, but what was problematic, and how features could be improved.

The SEED CPG was conceived specifically to speak directly to people with dementia and their families. Thus it had to be accessible, user-friendly in design and language, and to incorporate age- and dementia-friendly design features. Interestingly, during the co-design stage, a number of resources aimed at this same audience and with the same general purpose were published, some from established organisations, but even with these ‘new’ resources, feedback from family carers identified persistent issues with their format and the language used.

In terms of developing new resources/technologies, the tendency has been for devices to be created *by* technologists *for* older people with little reference to the specific requirements of end users (Brittain et al, 2010). With respect to the involvement of people with dementia in co design and co-development approaches this has been very limited (Span et al, 2013; Topo, 2009), especially in the area of assistive technologies which have the potential to improve quality of life and sustain independence. However expectations are changing with the realisation that older people can continue to contribute even when compromised by illness and/or disability. In the case of dementia care, international consensus recently advocated user engagement at all stages of technology development as an extension of the principles of person centered care (Meiland et al, 2017).

Strengths and limitations section
Only people with dementia and carers who were willing to discuss end of life care participated in the co-design groups. The difficulties experienced with recruitment confirmed that many people with dementia and carers prefer not to engage with this topic. We cannot assume that their views are similar to those of people who participated in the co-design workshops.

The findings from the SEED programme corroborate the case for ‘rich’ stakeholder involvement in translational research processes through a co-design approach regardless of the nature of research. The next step in resource development will be to create a workable version of the CPG for ‘user’ testing in terms of acceptability and feasibility. Despite our concerns and anxiety around the research topic, people with dementia and their families were enthusiastic and welcomed and valued research addressing the sensitive and potentially distressing area of end of life and planning ahead for future care. Our model of stakeholder involvement has helped the SEED programme move the discourse from that of designing ‘for’ to that of designing ‘with’ (New Economics Foundation, 2014) its stakeholders in these very sensitive matters around end of life care.

The SEED project advisory group raised issues about 'generational' comfort or discomfort with particular technologies. However, evidence (Joddrell & Astell, 2016) suggests many more opportunities and potential for this interactive, intuitive, and customizable tablet-based technology for engaging and supporting these discussions with people with dementia than is yet evident in currently available apps for supporting decision-making for people with dementia and their families.

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References

Alzheimer's Disease International (2011) *World Alzheimer Report 2011. The benefits of early diagnosis and intervention.*London.

Alzheimer's Disease International (2016) *World Alzheimer Report 2016. Improving healthcare for people living with dementia: coverage, quality and costs now and in the future.*London: (ADI), A. s. D. I.

Alzheimer's Society (2017) *End of life care. Factsheet 531*, 2017. Available online: https://www.alzheimers.org.uk/download/downloads/id/2267/factsheet_end_of_life_care.pdf [Accessed.

Amador, S., Goodman, C., Robinson, L. & Sampson, E. (2016) UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey. *BMJ Supportive and Palliative Care*, Oct 14(bmjspcare-2016).

Bamford, C., Poole, M., Lee, R., McLellan, E., Exley, C. & Robinson, L. (2017) IMPROVING END-OF-LIFE CARE IN DEMENTIA: KEY AREAS FOR IMPROVEMENT. *Innovation in Aging*, 1(suppl_1), 266-266.

Brittain, K., Corner, L., Robinson, L. & Bond, J. (2010) Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health & Illness*, 32(2), 272-287.

Dementia Engagement and Empowerment Project (2013a) *Guide: Creating websites for people with dementia*, 2013a. Available online: http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Creating-websites.pdf [Accessed.

Dementia Engagement and Empowerment Project (2013b) *Writing dementia-friendly information*, 2013b. Available online: http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf [Accessed.

Department of Health (2009) *Living with Dementia: a national dementia strategy*, 2009. Available online: https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy [Accessed.

Design Council (2014) *Innovative codesign project reinvents the hospital waiting room*, 2014. Available online: http://www.designcouncil.org.uk/news-opinion/innovative-codesign-project-reinvents-hospital-waiting-room [Accessed.

Design for Europe *What is co-design?*Available online: http://designforeurope.eu/what-co-design [Accessed.

Dickinson, C., Bamford, C., Exley, C., Emmett, C., Hughes, J. & Robinson, L. (2013) Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *International Psychogeriatrics*, 25(12), 2011-2021.

Joddrell, P. & Astell, A. (2016) Studies involving people with dementia and touchscreen technology: A literature review. *JMIR Rehabilitation Assistive Technologies*, 3(2), e10.

Knowles, D. (2014) *Dementia Friendly Print*, 2014. Available online: http://www.solopress.com/blogprint-inspiration/dementia-friendly-print/ [Accessed.

Lee, R. P., Bamford, C., Exley, C. & Robinson, L. (2015) Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC palliative care*, 14(1), 32.

Macdonald, A., Teal, G., Bamford, C. & Moynihan, P. (2012) Hospitalfoodie: An Interprofessional Case Study of the Redesign of the Nutritional Management and Monitoring System for Vulnerable Older Hospital Patients. *Quality in Primary Care*, 20(3), 169-77.

Meiland, F., Innes, A., Mountain, G., Robinson, L., van der Roest, H., Garcia-Casal, J. A., Gove, D., Thyrian, J. R., Evans, S., Droes, R. M., Kelly, F., Kurz, A., Casey, D., Szczesniak, D., Dening, T., Craven, M. P., Span, M., Felzmann, H., Tsolaki, M. & Franco-Martin, M. (2017) Technologies to Support Community-Dwelling Persons With Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics. *JMIR Rehabil Assist Technol*, 4(1), e1.

National Council for Palliative Care (NCPC) (2015) *Dementia. Achieving a good death for people with dementia*, 2015. Available online: http://www.ncpc.org.uk/dementia [Accessed.

New Economics Foundation (2014) *Co-production: theory and practice [online]*, 2014. Available online: https://prezi.com/eitdkeaoly8t/co-production-theory-and-practice/ [Accessed.

NHS England (2017) *Dementia: Good care planning*, 2017. Available online: https://www.england.nhs.uk/wp-content/uploads/2017/02/dementia-good-care-planning.pdf [Accessed.

NICE (2015) *Care of dying adults in the last days of life*.London.

Public Health England (2016) *Dying with dementia*, 2016. Available online: http://www.yhpho.org.uk/resource/view.aspx?RID=237877 [Accessed.

Robinson, L., Brittain, K., Lindsay, S. & Olivier, P. (2009) Keeping in Touch Everyday (KITE project); developing assistive technologies for people with dementia and their carers to promote independence. *International Psychogeriatrics*, 21(3), 494-502.

Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J. & Exley, C. (2012) A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, ' a good idea in theory but… ' *Palliative Medicine*, 27(5), 401-408.

Span, M., Hettinga, M., Vernooij-Dassen, M., Eefsting, J. & Smits, C. (2013) Involving people with dementia in the development of supportive IT applications: A systematic review. *Ageing Research Reviews*, 12(2), 535-551.

Topo, P. (2009) Technology studies to meet the needs of people with dementia and their caregivers: A literature review. *Journal of Applied Gerontology*, 28(1), 5-37.

Van der Steen, J. (2010) Dying with dementia: What we know after more than a decade of research. *Journal of Alzheimer's Disease*, 22(1), 37-55.