

Comment

Mobile app: Living and dying well with dementia

Sarmishtha Bhattacharyya MBBS, MRCPsych, MA in Med Ethics and Law, Susan Mary Benbow MB ChB, FRCPsych PhD, Eve Collins RGN, RNT, BSc, PGCE, MSc, and Project Team

Digital technology is gaining wider use in health care. Here the authors consider whether a mobile application or app they have developed could help promote understanding of dementia, its impact on those affected and to focus formal and family carers on key issues in end of life care.

Dementia is a life limiting illness that affects around 35 million people worldwide¹ and 800 000 people in the UK alone. There is growing recognition that quality of care that people with dementia receive needs to improve.¹⁻⁴ The vision of 'Living well with dementia; A national dementia strategy'² is that people with dementia and their carers receive quality care across the course of the condition. Priorities include promoting personal control and choice as well as increasing understanding about the disease and its impact on life;⁴ and involving people with dementia and their carers in planning for end of life care.²

It is important for people with dementia and their families to understand the impact on end of life and to start planning. The Department of Health⁵ suggests that, for many, a good death would involve being treated as an individual, with [dignity and respect](#), without pain and other symptoms, in familiar surroundings and in the company of close family and friends. Too often people with dementia receive undignified treatment and end their lives in pain^{3,4} and partnerships between dementia care and palliative care are underdeveloped.⁶ Significant, co-ordinated and holistic support is needed to ensure that all people with dementia end their lives with dignity, free from pain and in the place of their choosing.^{3,4} The Alzheimer's Society³ recommends that good end of life care focuses on the quality of a person's life and death, not on the length of life. This supports the person to die naturally and with dignity, and covers all aspects of wellbeing: physical, psychological, social and spiritual.

Planning requires a skilled workforce who can recognise the early signs of dementia, provide appropriate care and communicate effectively with the individual, their family and other professionals.⁷ Much of the care for people with dementia is provided by health and social care assistants and / or family and friends,⁴ many of whom have minimal education and little or no access to further training. For paid and unpaid carers both time and resource are limited; hence there is a need for easily accessible education.

Evidence suggests that recent technological advances offer a means of enhancing the learning experience and improving performance in academic work and clinical practice.⁸ Mobile applications (apps) may enable educators to reach a broad spectrum of learners who are unable to access traditional educational initiatives. Few researchers have investigated the use of mobile technology for the education of health and social care workers, but Thompson *et al.*⁹ offer anecdotal evidence of its efficacy. The proliferating application of

information and communication technology to health service delivery suggests that the future health and social care workforce will increasingly employ mobile technology.

Development of the app

The 'Living and dying well with dementia' mobile app was devised by drawing on the expertise of a wide range of healthcare professionals and educationalists in collaboration with the Alzheimer's Society, the Gold Standards Framework and the End of Life Partnership (EOLP). The team aimed to develop an app as a free, accessible educational resource in order to promote understanding of dementia, its impact on those affected and to focus on key issues in end of life care.

A wealth of literature attests to the power of storytelling to evoke an emotional response and facilitate learning in the affective domain.¹⁰ The app draws on education's tradition of storytelling: users follow the journey of Jill as she ages, develops dementia and eventually dies. Her journey is supported by text-based theoretical content, with interactive exercises and reflective prompts to facilitate learning and encourage users to consider how the content applies to their caring role. Content is split into bite size chunks so that learners may engage with the resource for short periods of time where and when they have the opportunity to do so. The app can be used independently or integrated into other educational initiatives. Alternatively, educational facilitators can work with groups of learners and use the exercises as short activities within a formal educational setting.

Participants at a workshop held to evaluate and disseminate the app appreciated its usability and usefulness, and suggested ways of disseminating the app, especially through a media campaign and by putting up posters in GP surgeries. Carers particularly felt that it would be useful for informal carers for whom there was little education available. Using the app could enhance family preparedness of informal / family carers of PwD. The app was felt to be useful for formal carers in care home settings too, and it will be important to evaluate the impact and change in practice following use.

The app is freely available on iTunes and from the Google Play store, for both informal and formal carers, for ease of learning and its use is being evaluated.

Conclusion

Care workers and families provide much of the care for PwD but with limited time and resources they require easy access to education that will enhance their caring skills. The 'Living and dying well with dementia' app is a free accessible educational resource that promotes understanding of dementia and its impact on those affected by the condition and focuses on key issues in end of life care. Future research should evaluate whether the app is being used regularly for training, and its impact, eg the number and quality of advanced care planning documents in specific care settings.

Dr Bhattacharyya is Consultant in Old Age Psychiatry at Wrexham, Betsi Cadwaladr University Health Board. Dr Benbow is an old age psychiatrist and systemic therapist and Director of Older Mind Matters Ltd, and both are Visiting Professors at the University of Chester. Eve Collins is Acting Head of Department Social Work and Interprofessional Education, Faculty of Health and Social Care, University of Chester.

The project was funded by Health Education North West.

Declaration of interests

All three authors were involved in the project group and in developing the app.

References

1. Department of Health (DoH). *G8 Dementia summit: Global action against dementia – 11 December 2013*. London: DoH, 2013. www.gov.uk/government/publications/g8-dementia-summit-global-action-against-dementia/g8-dementia-summit-global-action-against-dementia-11-december-2013 (accessed June 2017).
2. Department of Health. *Living well with dementia; A national dementia strategy*. London: DoH, 2009. www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy (accessed June 2017).
3. Kane M. *My life until the end, Dying well with dementia*. London: Alzheimer's Society, 2012.
www.alzheimers.org.uk/downloads/file/1537/my_life_until_the_end_dying_well_with_dementia (accessed June 2017).
4. Alzheimer's Society. *Dementia 2012: A national challenge*. London: Alzheimer's Society, 2012.
www.alzheimers.org.uk/download/downloads/id/1389/alzheimers_society_dementia_2012_-_full_report.pdf (accessed June 2017).
5. Department of Health. *End of Life Care Strategy. Promoting high quality care for all adults at the end of life*. London: DoH, 2008.
[www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_lif_e_strategy.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf) (accessed June 2017).
6. National Council for Palliative Care (NCPC). *The Power of Partnership: Palliative care and dementia*. London: NPCP, 2009
7. Skills for Care and Skills for Health. *Common core skills for supporting people with dementia – A guide to training the social care and health workforce*. Leeds: Skills for Care and Skills for Health, 2011.
www.gov.uk/government/uploads/system/uploads/attachment_data/file/215562/dh_127587.pdf
8. Yoo IY, Lee YM. The effects of mobile applications in cardiopulmonary assessment education. *Nurse Educ Today* 2015;35(2):e19–23.
9. Thompson C, Maiden N, Nouri M, et al. Evoking emotion through stories in creative dementia care. In: Proceedings of the 8th Knowledge, Information and Creativity Support Systems Conference. 7–9 November, 2013; Krakow, Poland. 2013;635–46.
10. Alm CO, Sproat R. Perceptions of emotions in expressive storytelling. In: *INTERSPEECH-2005*, 533–6. www.isca-speech.org/archive/interspeech_2005/i05_0533.html (accessed June 2017).