

COMMENTARY

Massive Open Online Courses: enhancing caregiver education and support about dementia care towards and at end of life

MARIE POOLE, NUALA DAVIS, LOUISE ROBINSON

Newcastle University, Newcastle upon Tyne NE4 5PL, UK

Address correspondence to: Marie Poole, Institute of Health and Society, Newcastle University, Newcastle Biomedical Research Building, Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL, UK.

Tel: +44 (0)191 208 7215; Fax 0191 208 1101; Email : marie.poole@ncl.ac.uk

Abstract

As the ageing population grows globally, the need for informal care—usually provided by family and friends—will continue to increase. Numbers of people with dementia also continue to rise, and much of their care will be provided by relatives. As such, more people who may themselves be older, will take on such caring roles. Consequently, more carers are likely to have education and support needs. Amidst government recognition of the need to provide good quality, person-centred education and support to carers, there are tensions between the potential for such provision to be resource intensive and whether existing services have the capacity to meet the needs of carers. Massive Open Online Courses (MOOCs) are a resource with scope to meet some of these educational and support needs. MOOCs enable flexible learning, are often free, and can be accessed anywhere in the world. Providing supportive dementia care requires carers to have an understanding of the condition, assistance to cope with the responsibilities of caring, and recognition of the importance of their own health and wellbeing as well as the person they support. In response to the needs of family carers of people with advancing dementia identified through a 5 year programme of research, we developed a MOOC—dementia care: living well as dementia progresses. This is an accessible source of relevant and engaging information; which enables carers to learn about advancing dementia, consider their own needs and create an interactive global forum of peer support.

Keywords: *dementia, carers, Massive Open Online Course (MOOC), education, older people***Key points**

- Massive Open Online Courses (MOOCs) enable findings to be translated into an informative and practical resource, which has global reach. This may have particular relevance to lower middle income countries, where formal support may be particularly limited.
 - MOOCs can provide free, flexible learning and peer support for carers who may struggle to access or engage in more traditional learning and support due to caring commitments.
 - The success of dementia MOOCs challenges perceptions of appropriateness of online learning for older carers.
 - Promotion via primary and secondary care services may be a cost-effective way of meeting unmet educational and support needs of carers.
-

Introduction

Massive Open Online Courses (MOOCs) may be an effective way of providing free, accessible education and support opportunities for carers around the world. We describe how a MOOC developed for families of people with advancing dementia contributes to meeting carer needs.

Meeting unmet educational and support needs for carers continues to be a significant challenge in the UK [1], globally [2] and for carers of people with dementia [3]. Global estimates indicate that more than 80 billion hours of informal dementia care are provided each year, mostly by family members, with the biggest impact in lower middle income countries [4]. In the UK, a recent survey carried out by the Alzheimer's Society stated that many carers report difficulties obtaining help and support, with almost 40 percent of carers of people with dementia providing round-the-clock care, thus making it difficult to take time out from caring commitments to address their own needs [5]. There is recognition of the potential of MOOCs to improve dementia knowledge for carers globally [6], and MOOCs enable a flexible way of learning, which can fit around personal responsibilities. This is important for family carers of people with dementia, who face many difficulties attending courses and groups [7, 8] and may also have limited access to leisure pursuits and 'spare time' [9].

Carers of people with dementia are commonly older. In the UK, over one million carers are over 65; a fifth of carers are aged 50–64; and one in 10 people are over 85; with 11% of all carers providing care for people with dementia [10]. We considered the appropriateness of an online resource for older carers. Assumptions about the use of online resources by older people is challenged by the continued growth of internet use among older adults in the UK; with 83% of people aged 65–74 now using the internet, and use amongst people over 75 doubling to 47% since 2011 [11].

Current UK national guidance on dementia emphasises the necessity to support carers through opportunities to learn more about the condition, enhance their own wellbeing and the care of the person they support. Furthermore, training, education and support should be tailored to individual needs, available at a location carers can get to easily, and provided in a suitable format, including online [12].

MOOCs are recognised as a way of enhancing understanding of dementia and provide a way of engaging with practitioners, family carers and people experiencing the condition (Figure 1). One notable benefit is learners re-evaluating their perspectives and attitudes towards the condition and people living with dementia [13]. Evidence suggest a range of positive benefits and limited disadvantages of online forums to support the wellbeing of informal carers of people with dementia [14], and combining tailored information with interaction may meet the educational and support needs of carers of people with dementia well, with fewer financial costs [15].

Fundamental to MOOCs is online availability, there is often no charge to participate, and therefore can be accessed

globally. MOOCs are now a well-established way of learning, and continue to grow. They offer a variety of courses, with a range of formal and informal learning outcomes, and are designed for a broad audience beyond those who are often considered to be traditional learners [16]. However, although MOOCs may enable ready-access to information and support, courses may only be available intermittently, and are not necessarily instantly available for participation. MOOCs require active moderation and review, which must be supported by on-going resources and infrastructure. Universities and partner companies commonly work together to provide courses and promote their availability. There are thousands of courses available from over 70 current providers [17]. These include information for many long term and life-limiting conditions, but may not necessarily be specifically for family carers. There are also a small number of MOOCs focusing on broad, non-condition specific issues relating to carers aimed at professionals (Figure 1).

Our MOOC is hosted by Futurelearn, a digital education platform working in partnership with hundreds of Universities and specialist organisations globally. Futurelearn promote the importance of the social experience of learning and opportunities to engage with others to explore new ideas. This is facilitated by online participation using desktop, tablet and mobile devices [18]. Our MOOC reflects a social, learner-centred approach, encouraging participants to actively engage with the course and other learners; and supporting participants to self-pace, engage in self-assessment and peer support, leading to an empowering learning experience [19].

Dementia care: living well as dementia progresses: meeting dementia carer educational and support needs

We developed our MOOC, Dementia care: living well as dementia progresses (<https://www.futurelearn.com/courses/comfort-care>) based on research findings from the SEED project (Supporting Excellence in End of Life Care in Dementia)—a 5-year programme on improving end of life care in Dementia [20]. The research indicated particular unmet need around information about the progression of dementia and support for the person with dementia, and their relatives. Our aim was to help carers of people with advancing dementia to feel more prepared, confident and supported as the person living with dementia moves towards end of life.

Our objective was 2-fold—to provide accessible sources of relevant and engaging information to family carers; and to enable carers to create a space in which they could engage in peer support. We intended for this resource to act as an additional source of assistance for family carers with unmet support needs.

Central to the course was providing sensitive information about aspects of dementia progression identified as confusing, misunderstanding and distressing for families, by family

Featured MOOC	<i>Dementia Care: Living Well as Dementia Progresses</i> https://www.futurelearn.com/courses/comfort-care
Dementia MOOCs	<i>Dementia Care: Staying Connected and Living Well</i> Newcastle University <i>Understanding Dementia</i> University of Tasmania <i>Preventing Dementia</i> University of Tasmania <i>The Many Faces of Dementia</i> University College London <i>End-of-Life Care for People with Dementia</i> University of East Anglia <i>Dementia and the Arts: Sharing Practice, Developing Understanding and Enhancing Lives</i> University College London. <i>Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies</i> Johns Hopkins University
General care MOOCs	<i>Supporting People Living with Long-term Conditions</i> Kings College London <i>Improving Palliative Care in Care Homes for Older People</i> Lancaster University <i>Medicine Administration for Carers</i> University of East Anglia <i>Caring for Older People: a Partnership Model</i> Deakin University

Figure 1. Dementia and relevant caring MOOCs.

carers and healthcare professionals, from our research on improving end of life care.

Through a range of media including videos, articles, quizzes, images and discussion forums; family carers, health and social care professionals, and the research team shared key information with learners. This comprised: first-hand accounts of experiences of caring; practical hints and tips for managing change; explanation of changing needs; signposting to specific sources of support—including organisations and self-help via the internet; visual interactive steps and completed examples of future planning documents and blank templates. Using prompts and questions, we encouraged learners to interact with the course materials and each other via comments sections throughout.

In terms of developing knowledge and skills, our end of course surveys indicated that over 90% of learners reported acquiring new skills and knowledge and over two-thirds have applied this learning in their daily lives. Over three-quarters also report sharing what they have learned with others. This indicates that the information is viewed as informative and pragmatic for learners. This is backed up by many positive learner comments about the relevance of the course and, in particular, feeling empowered and equipped to face previously challenging areas of care such as advance care planning.

Participants commented on the importance of the peer support element of the MOOC, which is created by learners interacting with the course content and each other by posting comments on the learning steps. Learners from around the world came together to compare experiences, offer guidance, suggest solutions, signpost to sources of support, exchange hints and tips, provide encouragement and condolences; and empathise with each other.

Participants also remarked on the value of the ‘Safe space’ in which they could share their feelings relating to sensitive issues of dementia and end of life such as ‘anticipatory grief

and negative feelings about their caring role. This offers social interaction within a supportive global community, who have a shared goal to learn more about dementia progression and perhaps some common experiences. This mirrors some aspects of social media sites in terms of posting information to share with others; however, comments are influenced by the course content and close monitoring of learner comments ensures that inappropriate posts are managed by the course educators.

Although developed for family carers, a diverse range of learners have joined the course to find out more about advancing dementia, including doctors, nurses, specialist dementia support workers and care home staff. People with dementia have also joined to help them to prepare for future changes as the disease progresses.

We are part way through the second run of this course, and in this period, over 4,000 learners from 115 countries have joined the course to find out more about dementia progression. Our well-established sister MOOC, dementia care: staying connected and living well, which focuses on helping carers to manage challenges of dementia has also achieved significant global reach, with over 23,000 learners in over 150 countries. The availability of both courses overlap to optimise access opportunities to those in need of support. The understanding dementia MOOC by University of Tasmania has engaged over 120,000 participants globally. This uptake of dementia MOOCs indicates that there is a significant international need for information and support for carers of people with dementia, which can in some way be addressed by the provision of MOOCs.

The SEED Programme received ethical approval from the Newcastle & North Tyneside 1 Research Ethics Committee on 16 January 2017 (reference 16/NE/0356). Health Research Authority approval was granted on 18 January 2017. The SEED WS4 study was sponsored by

Northumbria Healthcare NHS Foundation Trust (reference IRAS 211291).

Declaration of Conflicts of Interest: None.

Funding: Supporting Excellence in End of life care in Dementia (SEED programme): RP-PG-0611-20005 was funded by the National Institute for Health Research (NIHR). The financial sponsors had no role in the design, execution, analysis and interpretation of data or writing of the study. Prof. Dame Louise Robinson is also in receipt of a NIHR Senior Investigator award.

References

1. Department of Health Social Care. Carers action plan 2018–2020: supporting carers today. 2018.
2. Carers E. Embracing the Critical Role of Caregivers Around the World. Germany: Darmstadt, 2017.
3. Alzheimer's Disease International. World Alzheimer Report 2016. Improving healthcare for people living with dementia: coverage, quality and costs now and in the future. London, 2016.
4. Alzheimer's Disease International and Karolinska Institutet. Global estimates of informal care. London, 2018.
5. Alzheimer's Society. Carers for people with dementia struggling in silence. 2018.
6. Eccleston C, Doherty K, Bindoff A, Robinson A, Vickers J, McNerney F. Building dementia knowledge globally through the understanding dementia Massive Open Online Course (MOOC). *NPJ Sci Learn* 2019; 4: 3.
7. Brodaty H, Thomson C, Thompson C, Fine M. Why caregivers of people with dementia and memory loss don't use services. *Int J Geriatr Psychiatry* 2005; 20: 537–46.
8. Robinson A, Elder J, Emden C, Lea E, Turner P, Vickers J. Information pathways into dementia care services: family carers have their say. *Dementia* 2009; 8: 17–37.
9. Innes A, Page SJ, Cutler C. Barriers to leisure participation for people with dementia and their carers: an exploratory analysis of carer and people with dementia's experiences. *Dementia* 2016; 15: 1643–65.
10. Carers Trust. Key facts about carers and the people they care for 2019. Available from: <https://carers.org/key-facts-about-carers-and-people-they-care>.
11. Office for National Statistics. Internet users, UK: 2019. 2019.
12. National Institute for Health and Care Excellence. Dementia - assessment, management and support for people living with dementia and their carers: NICE. 2018. Available from: <https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0792/consultation/html-content-3>.
13. Petronzi D, Hadi M. Exploring the factors associated with MOOC engagement, retention and the wider benefits for learners. *European Journal of Open, Distance and e-Learning* 2016; 19: 112–29.
14. McKechnie V, Barker C, Stott J. The effectiveness of an internet support forum for carers of people with dementia: a pre-post cohort study. *J Med Internet Res* 2014; 16: e68.
15. Boots LMM, De Vugt ME, Van Knippenberg RJM, Kempen G, Verhey FRJA. Systematic review of internet-based supportive interventions for caregivers of patients with dementia. *Int J Geriatr Psychiatry* 2014; 29: 331–44.
16. Ferguson R, Scanlon E, Harris L. Developing a strategic approach to MOOCs. 2016.
17. MOOC List. 2019. Available from: <https://www.mooc-list.com/about-frequently-asked-questions-faqs>.
18. Futurelearn. Learning on FutureLearn: an effective way to learn. 2019. Available from: <https://www.futurelearn.com/using-futurelearn/why-it-works>.
19. Guàrdia L, Maina M, Sangrà A. MOOC design principles. A pedagogical approach from the learner's perspective. *elearning papers* 2013; 33: 1–6.
20. Bamford C, Lee R, McLellan E *et al*. What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders. *BMC Geriatr* 2018; 18: 302.

Received 17 September 2019; editorial decision 2 October 2019