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Supporting people with young onset dementia and their families: An evaluation of a training course for care workers

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ABSTRACT

This article reports the findings of an evaluation of a training course for care workers who care for people with dementia in the community. Twenty-four care workers participated in the training which took place in London and Surrey, United Kingdom. The training had a significant positive impact on participants' confidence in understanding the experiences and social care needs of people with young onset dementia (YOD) and their families. Participants also perceived that the training would help them improve their working practice by furthering their understanding of practical approaches to supporting and caring for people with dementia in general. Additionally, participants reported many ways in which they perceived being able to specifically support and empower people with YOD. It was concluded that the short training course improved knowledge and confidence for care workers on dementia care, and specifically in understanding how to support people with YOD and their families. Dementia specific training should be considered by service managers as a way of potentially increasing care worker job satisfaction.

1. Background

Young onset dementia (YOD), also known as early onset dementia (Chemali et al., 2012; Greenwood and Smith, 2016; Johannessen and Möller, 2011), is diagnosed in people aged 65 years or younger (Rossor et al., 2011). The number of people with YOD is difficult to determine primarily because many people present late with their symptoms (Jeffries and Agrawal, 2009). However, in the United Kingdom (UK) it was estimated that 42,325 people had YOD in 2013, accounting for just over 5% of the total number of people living with the condition (Prince et al., 2013).

It is well known that caring for someone with dementia can be challenging (Brodaty et al., 2014; Ory et al., 2000; Svendsboe et al., 2016) and can affect the physical and mental health of carers (Pinquart and Sorensen, 2007; Schulz and Sherwood, 2009). However, there are specific difficulties for those caring for people with YOD. The evidence from a range of research studies suggests that family carers of people with YOD experience high levels of burden, stress, depression and psychosocial issues such as relationship problems, family conflict, employment and financial difficulties (van Vliet et al., 2010), which have a negative effect on their quality of life (Rosness et al., 2011). The long duration of caregiving coupled with the lack of specialist supportive services may also be a contributory factor to psychological distress reported by carers and families (Arai et al., 2007).

UK Government policy has attempted to address these concerns by improving workforce training. For example, it was identified that dementia training for health and social care workers should include information specific to YOD: "*Training should enable an understanding of the diversity in dementia, including younger people with dementia* …" (Department of Health [DH], 2009, p. 66). It is also recommended that health and social care workers adhere to seven common core principles for supporting people with dementia (DH, 2011). These include: promoting independence and encouraging activity; communicating sensitively to support meaningful interaction; recognising signs of distress; and ensuring family carers are valued, respected and supported.

Staff training is commonly seen as a way of improving the standard of care for people with dementia and their carers (Ballard et al., 2001; Kuske et al., 2007; Surr et al., 2016; Testad et al., 2016). Care staff's confidence in dealing with the behavioural and psychological symptoms of dementia (BPSD) has previously been

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shown to be low, for example evidence suggests only 29% of care staff feel confident in dealing with agitation or aggressive behaviour (Hughes et al., 2008). It was also reported in the same study that higher staff confidence in caring for people with dementia was associated with receiving dementia specific training. There is also evidence indicating that dementia care staff who receive ongoing training are more likely to report greater job satisfaction (Coogle et al., 2006; Sung et al., 2005; Zimmerman et al., 2005) and increased commitment to their role (Gurnik and Hollis-Sawyer, 2003).

The evidence described above suggests that the care provided to people with YOD could be enhanced by training care staff about YOD. Such training could potentially improve understanding of the similarities and differences between YOD and late onset dementia and also highlight the challenges for all stakeholders, including the person with YOD, their carers and those providing formal support.

This evaluation investigated a training course for care workers providing services to people with dementia. The training was delivered by a community interest organisation in the first half of 2015. The organisation provides training to health care workers who support people with dementia and their families (e.g. care workers; support workers and care home managers). The training course was structured to cover set topics and was delivered in the same way for each of the four training groups. The overall aim of the training was to improve participants' understanding of YOD and to help them provide enhanced support for people with YOD and their carers.

1.1. Evaluation aims

The aims of this evaluation were to:

1) Investigate the perceptions of the training on participants' confidence in working with people with YOD and their families.
2) Understand participants' perceptions of their learning and which aspects of the training were most important to facilitate understanding.

2. Methods

2.1. Setting

The course was provided at five sites in and around London. Five courses took place between January and April 2015, with four running over two full days (either back to back or two weeks apart) and one running on four half days, one week apart. Participants were care workers based in the Greater London area. Courses were held in care homes or community buildings (such as the conference hall of a church).

2.2. The training

Training consisted of PowerPoint presentations, group work and video clips. It was led by a primary trainer (responsible for overseeing and delivering the training course), a support trainer (whose aim was to support the people with YOD and carer co-trainers) and by several people with YOD and their carers (referred to as co-trainers). The family carers and people with YOD talked to the participants about their personal experiences associated with YOD. They also assisted the primary trainer in delivering aspects of the course, for example, in helping to facilitate group discussions. The training was framed around Tom Kitwood's theory of applying person centred care in supporting people with dementia (Kitwood, 1997).

Participants were recruited by the training provider organisation team through contacting local care agencies and asking if they would be willing to ask their staff to attend. Care workers were eligible to attend the training if they were currently providing care for older people in the community.

2.3. The questionnaires

No validated rating scales were identified by the research team which would have measured the outcomes we were investigating. Subsequently, we constructed our own questionnaires. A mixed methods approach (Creswell, 2013; Hesse-Biber and Burke Johnson, 2013) was utilised in developing two semi-structured questionnaires to determine whether the training aims had been achieved. The questionnaires were piloted on the first cohort of participants. Responses suggested that the face validity of the questionnaires was adequate for use in this population.

Questionnaire 1 had ten questions relating to confidence in working with people with dementia and these were Likert scales. For example, participants could choose from the following responses 'very confident, fairly confident, neither confident nor unconfident, unconfident or very unconfident'. Other questions were open-ended and allowed participants to respond in their own words. For example question 2b: "If you have worked with anyone with young onset dementia, please describe the main challenges you found working with this group in the space below". Questionnaire 2 also included questions relating to the aspects of the course the participants found most useful, what they would change about the course and whether they would recommend the course to others. The questionnaires were designed to be brief with minimum impact on course delivery and took approximately 10 min to complete.

Both questionnaires were anonymous and participants were asked to only use there initials or a pseudonym when completing them.

2.4. Data collection

A researcher external to the training provider organisation attended the beginning and end of each training course. The purpose of the evaluation was explained and what was required of participants was described. The importance giving their honest opinions was emphasised and they were encouraged to ask questions. It was also stressed to participants that: they were under no obligation to take part; their responses would be anonymised; they could withdraw at any time without explaining why and all data would be stored securely on a password protected University computer. Also, all participants were given an information sheet detailing the purpose of the evaluation and what their participation would involve. The information sheet included the researchers' contact details in case they had any questions at a later date. It was explained that the evaluation findings would be used for the development of one or more publications, but that no participants would be identifiable in these.

Questionnaire 1 was administered before the training began and included participants' demographic details, previous experience working with people with dementia, confidence in working with people with dementia, and perceived confidence specifically relating to working with people with YOD. Questionnaire 2 was administered at the end of the final training day and included many similar questions as questionnaire 1 in order to identify change. The course trainers also recorded group feedback at the end of two training sessions. The researchers were given this anonymised group feedback and this was also utilised in the qualitative data analysis. Consent was assumed on completion of the anonymous evaluation forms.