Title;- Delivering a dementia carers support programme – reflection by a dementia specialist nurse

Authors:

Lauren Daughtrey

Dementia Nurse Specialist Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust

Dr Michele Board*

Principal Academic Nursing Older People

Bournemouth University

*Corresponding author

Faculty of Health and Social Sciences

Bournemouth House

19 Christchurch Road

Bournemouth

Dorset

BH1 3LH

Tel: 01202 961786

Email: mboard@bournemouth.ac.uk

Abstract:

There are significant numbers of people in the UK caring for someone living with dementia. Providing support to carers is both socially and economically important to enable them to continue in their caring role and improve their experiences.

This article provides a dementia nurse specialist's reflection upon running a 6-week educational support group for carers of people living with dementia. It describes the development of the group, challenges faced and discusses considerations for the future including a need to ensure sustainability through collaborative working. It highlights the positive outcomes described by carers who attended the course.

Key words:

Dementia – carers – older people – support – reflective practice

INTRODUCTION

There are approximately 850,000 people living with dementia in the UK, this number is predicted to increase to one million by 2025 (Prince et al. 2014). Most live in the community however 1 in 4 hospital beds are occupied by those living with dementia (Lakey 2009). Dementia impacts on a person's life and that of those around them. 24.6 million people have a family member or close friend living with dementia in the UK (Office for National Statistics 2014) and 700,000 of these will be carers (Lewis et al. 2014). It is important for all healthcare professionals to appreciate the impact of dementia and how best to support those affected, including their families and carers. The National Institute for Health and Care Excellence (NICE) guidelines (NICE 2018) recommend different options for supporting carers including psychoeducational approaches.

One aim of carer support is to improve carers' resilience to ensure the sustainability of the care they are providing (Parkinson et al. 2016). When implementing support for carers it is essential that it is based on what carers want as individuals (Barnes et al. 2017). However, there are several inconsistencies in the literature around what is the best intervention. Carers are often 'experts by experience' and are well placed to support each other (NHS England 2014). However, it is known that some do not identify themselves as carers and see the duties they carry out to be a natural part of their relationship with the person they care for (Robinson 2019). As a result, these carers do not readily access help from services (Social Care Institute for Excellence 2018).

This article will reflect on a carer's information programme developed by a dementia nurse specialist working in an acute hospital setting, in 2019, **in response to an expressed need of carers visiting people living with dementia in hospital.** The purpose of the programme was to provide local carers peer support and education about dementia **as a quality improvement project. As such a project we considered the lessons learnt from this are worth sharing with those who might want to consider doing this.** Peer support is valued by carers as it offers them opportunities to share experiences and feel listened to (Smith et al. 2018). When provided in a group format this support has been shown to reduce carer burden (Dickinson et al. 2017). Delivering structured sessions with specific topics increases carers' motivation to attend especially when an educational component is focused on enriching carers' skills (Yeandle and Wigfield 2011).

Developing and running the programme

Advertising

The carers information programme was advertised on social media and in the local newspaper. Leaflets and posters were displayed in patient areas. The location, a **designated training room at the acute hospital,** was central and easy to reach by public transport. Car parking and attending the course were free to improve accessibility. The programme was run within a local NHS hospital over six weeks, which is considered to be the most effective length (Jensen et al. 2015). Some carers registered interest but then did not attend or only attended one or two sessions. A courtesy call to remind carers about the programme and give them a chance to withdraw their interest would allow places to be offered to others. When carers did not attend other carers were given the opportunity to join the course even having missed a few sessions.

Timing

Sessions took place on Thursday afternoons for one and a half hours. Afternoons were selected to take into consideration caring responsibilities such as assisting with personal care and sundowning which could impact carers ability to attend at other times. However, evening sessions may have been more suitable for carers in employment or have other commitments such as childcare (Carers UK 2011). Certain support groups, often provided by voluntary organisations, regularly allow for the person with dementia and their carer to attend together, offering social opportunities for both. Some carers voiced difficulties finding someone else to care for the person with dementia in their absence. This appears to be a recurring theme in the literature (van der Roest et al. 2009, Carers Trust 2015). One carer attended one session with their partner who was living with dementia as they could not access support for them. We were flexible in allowing them to attend together however it clearly changed the dynamics of the group and some carers were cautious in what they discussed for fear of upsetting the person with dementia. This demonstrates the importance of allowing carers time and a safe space away from the person they care for. Maintaining a consistent time was valued by carers to reduce confusion and allow them to plan. Consistency was also maintained by the facilitators. Sessions were always run by two dementia specialist nurses. Carers were able to form a relationship with both facilitators and other group members, building trust and rapport. Creating therapeutic relationships with the carers, focussing on their individual needs, improved their engagement, with dialogues becoming longer and more animated each session as the carers became objectively more relaxed in each other's company.

Content

The content of the programme focussed on psychoeducation with each week having a different topic, as shown in Table 1. The educational impact of the carers programme was aimed at improving understanding of dementia and coping strategies. Addressing the issue of behavioural changes was felt to be important as this can be particularly challenging (Van der Lee et al. 2017). However, education alone can be counterproductive if increased knowledge instead amplifies feelings of anxiety in carers (Milne et al. 2014). Some sessions were dominated by one or two carers often in response to them having experience in the chosen topic. This was at times hard to contain for fear of invalidating individuals' experiences however it was important to enable quieter members to contribute (Yeandle and Wigfield 2011). The opportunity for all to be able to participate was highlighted as an important positive aspect of the programme by attendees and evidenced in their feedback.

Table 1

Content of Sessions Each session will last an hour and a half on Thursdays 13.30-15.00	
Session 1	What is dementia?
Session 2	The Impact of Caring
Session 3	Planning for the Future
Session 4	Cognitive Stimulation Therapy

Session 5	Life Story Work
Session 6	Practical Advice: How to make your caring role a manageable and positive experience.

The group

A limit of fifteen was decided to allow for carers to have the opportunity to contribute to the sessions and we had fourteen carers attend. A smaller group would have allowed for more interaction, but a larger group could have been too impersonal.

The diversity of the carers' journeys and varying roles and responsibilities became a concern, with some caring for someone with advanced dementia whilst others were only recently diagnosed or in the early stages. Whilst several appreciated knowing more about the progression of dementia, some appeared to find this emotionally difficult. Carers of working age described difficulties with the demands of employment and financial concerns whilst older carers reported struggling more with the physical aspects of caring. Some lived with the person they cared for whilst others did not and found difficulty relating to each other. Conversely, carers appreciated sharing experiential knowledge and finding common ground. For example, two individuals with partners with early onset dementia reported a desire to stay in contact to continue to support each other. Although nationally most carers are male (Age UK 2015), less than half of the attendees were male. Support groups must appeal to older male carers as they are less likely than their female counterparts to access community services as many feel their needs are different and groups tend to be female dominated (Slack and Fraser 2014).

Carers of people living with dementia can experience a level of perceived stigma and social exclusion especially when coping with complex physical and behavioural changes (Werner et al. 2012). Attending a group where the participants are solely made up of carers of those with dementia can assist in breaking down the barriers of stigma (Greenwood et al. 2018). Although group support is beneficial, one to one support should not be overlooked as carers may have individual, at times sensitive, issues they want to discuss away from a group (Hannan et al. 2016).

Feedback from carers

At the end of the programme carers were asked to complete an evaluation form. Nine out of the fourteen carers returned their forms. Feedback was anonymous to encourage carers to express their honest thoughts. However, feedback was not collected from all carers therefore the impact their opinions may have had when evaluating the effects of the programme are unknown.

One of the aims of the programme was to offer carers peer support. The carers did value the opportunity to meet "people in a similar position" appreciating "knowing you're not alone" and that "everybody was so kind and helpful and understanding".

However, enabling more carers to access sessions after the groups had already started was unsettling for some. One carer who had attended from the start felt it disrupted the group dynamics. She wrote how it was "nice to have a small group" but "a little confusing when new members arrived halfway through the course". Another important aspect of the sessions was to help individuals build resilience and knowledge of dementia to help manage their day to day lives of caring for someone with dementia. Their feedback demonstrated that they found the content and discussions useful suggesting that they "understand so much more about how to deal with things" and were given "very practical ideas on how to help, all backed up with reasons and knowledge".

Others reported on the effectiveness of the psychoeducation provided through a ”much better understanding of dementia" and managing their caring role by feeling "inspired on how to do things as symptoms progress".

They appreciated feeling "comfortable in joining in" and that "all attendees had the chance to speak, share issues and ask for help". Some reported the programme was "very well facilitated" and "thought evoking".

Many also provided feedback regarding my colleague and I personally, which inspires confidence in delivering future programmes describing the facilitators as "lovely nurses, so compassionate, caring, friendly and kind", suggesting we were "exceptionally equipped with knowledge, compassion and humour".

Reflection of group facilitator

By reflecting on the value of the carers programme and placing it within the context of the literature the benefit for carers is evident. Duplication of services is confusing for carers therefore it is important to consider how the programme sits within local provisions. Targeting resources through partnership working across health and social care by those with shared interests improves services, however this can be difficult to achieve. Dickinson and Glasby (2010) discussed the need for collaboration to be long-term and how this can add value and enhance services previously delivered by one agency in isolation. Utilising already established networks with other specialists in dementia care across the locality provides a platform for considering how different organisations could potentially pool resources to maintain sustainability. This would combat some of the identified practical barriers carers experience when accessing support such as locality of services. Community services could offer the programme to a wider audience. They may have links to aid in the identification of carers in particular those harder to reach groups who may be in touch with other agencies. On reflection, acting in isolation on such a project reflects a lack of previous experience in this arena. Being aware of the barriers to future programmes has prompted consideration of changes which could be made. One of the most difficult barriers to overcome is the need for respite to allow carers time away from the person they care for to access support. Further contemplation of the feasibility of running a parallel session for the individuals living with dementia is required.

This initiative was set up in response to an expressed need by carers speaking to the dementia specialists within in acute hospital trust. They wanted to know more about dementia and have support to enable them to better care for their loved one. On reflection we could have adopted a more systematic approach to this quality improvement initiative, such as the Plan, Do, Study, Act (PDSA) cycles and the model for improvement (Langley et al 1996). This process would have enabled us to more formally identify what works in the programme, amend the programme and test changes and so on. However, resource availability at the time meant we could only run the course once. We then started discussing how we could deliver such a programme sharing the responsibilities across different Trusts in the area, when a more systematic research approach could be adopted. Sharing knowledge and expertise, working collaboratively with other dementia specialists and the local university could help deliver a more robust evaluation of support programmes for carers.

Although the provision of group psychoeducation is of benefit to carers, as shown in the carers evaluation of this programme, the evidence is not consistent on exactly when and where this is best offered and by whom (Hall and Skelton 2012, Bunn el al. 2015). This represents a complexity when addressing the question of whether the support programme is best placed to be ran within a general hospital setting. We know that carer wellbeing has an impact on hospital admissions and delayed discharges, with 20% of hospital admissions occurring due to carer breakdown (Conochie 2011, Health Innovation Network 2015). We know that admission to hospital

often has an impact on the person with dementia's functional abilities, behavioural and psychological well-being (Alzheimer's Society 2016). A lack of information and ongoing support post diagnosis can lead to carers feeling unable to understand and adjust to these behavioural psychological and physical changes in the person with dementia (Van der Lee et al. 2017). Therefore, investing in support and services for carers should be viewed as an effective use of resources for an acute trust.

Carers are often 'experts by experience' and therefore are well placed to provide support to each other (NHS England 2014). Some carers appreciate knowing that sessions have a topic and a purpose influencing their motivation to attend (Yeandle and Wigfield 2011).

Research shows that peer support is valued by carers as it offers them opportunities to share experiences and feel listened to (Keyes et al. 2014, Smith et al. 2018). When provided in a group format this support has been shown to reduce carer burden (Chien et al. 2011, Marim et al. 2013), especially when there is an educational component which is focused on enriching carers' skills (Dickinson et al. 2017). Addressing the issue of behavioural changes was felt to be important as this is often an aspect of the caring role which can be particularly challenging (Van der Lee et al. 2017).

NICE guidelines are often used as a point of reference as they consider the evidence base and make recommendations for health care professionals to reflect on when practicing in a specific field. The NICE guidelines for dementia (NICE 2018) include several recommendations on how to best support carers of people living with dementia. NICE (2018) advocates the use of psychoeducational training approaches and the suggested content is partly aligned with that delivered as part of the programme. They suggest we should be offering carers an opportunity to enhance their skills in communication, providing care, responding to behavioural changes, utilising purposeful activities and planning for the future. They go on to stipulate that support should be provided in easy to access locations and tailored to individual expectations in a variety of potential formats including group sessions, which they report to be the most effective, but also individual sessions and online training.

Reflecting further on the range of support options recommended by NICE guidelines (NICE 2018) draws attention to forms of support that can be neglected, such as online or telephone support which can be invaluable for some (Carers UK 2011). This becomes even more pertinent currently due to coronavirus with services having to reconsider how they deliver support. At times, one can be guilty of looking straight to written information to give to carers. Although for some this is sought after, others find leaflets and other forms ineffective and can become concerned that it could upset the person they care for if it were read by them (Barnes et al. 2013). Other healthcare professionals making themselves aware of the variety of support in their areas is essential for signposting carers.

Conclusion

Although the provision of group psychoeducation is of benefit to carers, the evidence is not consistent on exactly when and where this is best offered and by whom (Hall and Skelton 2012, Bunn el al. 2015). This represents a complexity when addressing the question of where the support programme is best placed to be run. Initially, the programme was aimed at carers of those living with dementia currently in the hospital setting where it was delivered. Providing support to carers whilst their cared for is in hospital may alleviate some of the difficulties experienced by not being able to leave the person with dementia alone to attend such groups. However, most carers who attended cared for someone who had not been in the hospital recently. The inpatient experience can be a time of increased stress due to the disruption of daily life and does not necessarily represent a positive time for group support (Jamieson et al. 2014). What is apparent is that carer wellbeing has an impact on hospital admissions and delayed discharges, with 20% of hospital admissions occurring due to carer breakdown (Conochie 2011). A lack of information and ongoing support post diagnosis can lead to carers feeling unable to understand and adjust to behavioural, psychological and physical changes in the person with dementia (Van der Lee et al. 2017). Therefore, investing in support and services for carers should be viewed as a priority for an acute trust.

The group format also represents a cost-effective option if the number of sessions is limited (Hopkinson et al. 2018). However, more research is required into the cost effectiveness of support services (Thomas et al. 2017).

This is an example of a successfully run carers support programme in the context of wider carer support. It offers suggestions for improvements to be taken forward. It has drawn on the evidence base behind carer support and the feedback provided by carers who have attended the programme. Prior to running another course, there is a need for improved collaboration and co-ordination to ensure sustainability. Recruiting others to help provide this programme will allow the benefit to be felt more widely.

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