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Do the Welsh have it? Evaluating a bereavement support service supporting people bereaved by dementia.

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Abstract

Accumulating evidence suggests that a dementia diagnosis, for many, triggers feelings of grief, and often marks the first of many losses that will be experienced by both the person who has received the diagnosis and their loved ones, as the disease progresses. Previous research has also revealed that carers who report higher levels of pre-death grief are at greater risk of complicated grief after their loved one has died. Despite this evidence, appropriate bereavement support for people bereaved by dementia is a significant unmet need.

The Bereaved by Dementia project¹ was delivered collaboratively by Cruse Cymru and Alzheimer's Cymru to address the bereavement needs of people bereaved by dementia throughout Wales, United Kingdom. This paper draws on an independent evaluation of the Bereaved by Dementia Project conducted by Aston University and the University of Bristol. We summarise our main findings, recommendations, and suggestions for future research.

Background

While bereavement is considered to be a normal part of everyday life, it can also be characterised as a period of intense suffering and adjustment (Stroebe, Schut, & Stroebe, 2007). Vulnerable people, such as older people, people with dementia, and their carers may be particularly susceptible to the impact of grief and bereavement (Alzheimer's Society, 2017). For example, bereavement among older adults has been associated with: an increased risk of suicide among widowers (Li, 1995); poorer perceived health (Thompson, Breckenridge, Gallagher, & Peterson, 1984); increased risk of depression (Alexopoulos, 2005); increased risk of complicated grief

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(Newson et al, 2011); and increased psychological distress (Thompson, Gallagher-Thompson, Futterman, Gilewski, & Peterson, 1991).

A diagnosis of dementia may also trigger feelings of grief and loss for both the person with dementia and their families and loved ones (Alzheimer's Society, 2017). Indeed, Doka (2010) claimed "*grief is the constant, yet hidden, companion of Alzheimer's disease and other, related dementias*", although the extent to which this tight coupling of diagnosis and grief might also be a function of societal attitudes towards dementia as a 'living death' is insufficiently explored (Spicker, 2010).

Loss within the context of dementia is experienced in a multifaceted and idiosyncratic way for both the person with dementia and their families (Doka, 2010). People affected by dementia report gradual, but cumulative losses in multiple domains, including but not limited to, cognitive, physical, social, occupational, health, and identity (Cheung, Ho, Cheung, Lam, & Tse, 2018). Moreover, it has been argued that these losses are often an unrecognised feature of dementia caregiving (MacCourt, McLennan, Somers, & Krawczyk, 2017), which may contribute to disenfranchised grief – characterised as "*a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported*" (Doka, 1999).

Research suggests that carers who experience higher levels of pre-death grief are at higher risk of health complications post-death (Chan, Livingston, Jones, & Sampson, 2013; Givens, Prigerson, Kiely, Schaffer, & Mitchell, 2011; Sanders, Ott, Kelber, & Noonan, 2008; Shuter, Beattie, & Edwards, 2013, cited in Blandin and Pepin, 2017). Pre-death and post-death bereavement support for people affected by dementia is a significant unmet need as well as an under-researched field of bereavement support,

particularly the bereavement support needs of people with a diagnosis of dementia (Dooley and Stewart, 2015).

The Bereaved by Dementia project, therefore represents a timely and potentially significant advance in supporting a growing group of vulnerable and overlooked people through their feelings of grief and loss. Funded by the Welsh Government Sustainable Social Services Third Sector Grant 2016-2019, Cruse Cymru and Alzheimer's Society Cymru joined in a partnership to address the bereavement needs of:

- People with dementia who's loved one/carer has died;
- People who have been bereaved through the death of someone with dementia;
- People who are experiencing dementia as an on-going loss.

The Bereaved by Dementia Project has been evaluated by an independent research team based at Aston University and the University of Bristol, led by Professor Karen West. This paper presents a condensed summary of the project evaluation extracted from the final report submitted to Cruse Cymru in May 2019.

Methods

The Bereaved by Dementia Project has been evaluated holistically. Broadly, the project has been evaluated in terms of: the content and quality of information delivered through training; outcomes for individuals – both Cruse Bereavement Volunteers (CBVs) and bereaved clients; and the wider awareness and impact across the networks of Cruse Bereavement Care and Alzheimer's Cymru. To do this, we utilised data collected by the evaluation team as well as evaluation data made available to us by Cruse Cymru. While some numerical data was collected in order to provide a snapshot of pertinent experiences, we focused our attention on

qualitative methodologies (interviews and focus groups) which permitted rich and detailed accounts of how individuals experienced and made sense of their experience. Qualitative data were analysed by the research team following the six-stage process suggested by Braun and Clarke's (2006) thematic analysis:

1. Familiarisation with the data through reading and re-reading the transcripts;
2. Systematically identify interesting features of the data (coding);
3. Collation of codes into potential themes;
4. Generation a 'thematic map' to gauge the applicability of the theme(s) against the data set as a whole;
5. Define and name themes;
6. Report themes using compelling extract examples.

The Aston University School of Languages and Social Sciences ethics committee granted ethical approval for this research.

Findings

What is presented here is an amalgamation of our wider findings. We intend for this to provide a snapshot of the Bereaved by Dementia Project, capturing the experiences of: CBVs; clients who have dementia and are bereaved; clients whose loved one has/had dementia (pre and/or post death bereavement); and the wider impact within the partner organisations. This will be achieved by attending to the three themes that encapsulate our main findings; training, support, and wider impact.

Training

First, the design, development, and delivery of the Bereaved by Dementia one-day training was one of the core outcomes for the project. This training has been delivered in locations across Wales to 404 delegates, consisting of 241 CBVs and 163 external delegates (from public and private sectors). Overall, 96% of delegates

reported that the training had met their expectations, and 91% reported that the training had increased their awareness about dementia and supporting someone close to them following a bereavement.

Furthermore, the majority of delegates commented on the quality and quantity of the information that was provided, and the awareness it generated.

“Enhanced my knowledge of how to deal and support patients grieving with dementia” [CBV]

“Provided a chance to think more deeply about bereavement and dementia and about being human” [CBV]

Delegates were particularly enthusiastic when the training was co-facilitated by a person who has dementia. This provided them with unique insight into how life, and loss, is experienced by a person with dementia, thereby bringing the material to life, and humanising people with dementia through empathy and understanding.

“Learning about dementia from a person with dementia was insightful” [CBV]

“Enabled me to look at things differently rather than just through ‘nursing eyes’” [CBV]

The most striking feature of the training for delegates were activities, analogies, and discussions that demonstrated the emotional experience of people with dementia.

“Most useful session was sharing of experiences and live examples”

“Bookshelf with emotion. I hadn't realised that the emotions have not been lost”

For many, this was an unexpected feature to the training and gave rise to profound changes in perspective and understanding. This is a remarkable achievement for a

relatively short training session considering the cascading impact this is likely to have for the delegates personally, professionally, and within the context of their role within Cruse Bereavement Care.

Furthermore, CBVs argued that the focus on emotional integrity provided a shared understanding which, if explored sensitively, has the potential to transform the ways in which they perceive and treat people with dementia. As Judith perceptively articulates (below), the 'problem' with dementia or the 'challenging behaviours' a person with dementia may exhibit stem from our own problems; our lack of understanding and perhaps our lack of trying to understand. It is suggested that the inclusion of Kitwood's (1993) approach and the incorporation of case studies encouraged delegates to think differently about people with dementia, and consequently to seek to build a connection between a person with dementia perhaps on the basis of personally significant rituals, customs, and features of personal biographies.

“Behaviour is a form of communication so that behaviour might look bizarre actually is the person trying to communicate something to you and it's our lack of understanding that makes it difficult because we're not getting it, what they're trying to express” [Judith]

Support

The Bereaved by Dementia Project provided person-centred bereavement support to 228 clients who were bereaved by dementia. Both CBVs and clients themselves reported that bereavement support had provided a platform for clients' grief to be heard; an opportunity to share their experience, their pain, and their hopes for the future. For instance, Mr White, a man in his late eighties, living with dementia who

received bereavement support from Judith (CBV introduced in the preceding theme) explained;

“because of the bereavement, I could do with being around people instead of on my own because erm I don’t want to err go inward on myself and lose touch with everything, I still want to have a life erm that I feel is worth living”.

Here, Mr White reflected that since his wife died his social network has significantly diminished, and he feared isolation and loneliness which he perceived would compound his dementia symptoms. Despite his grief, and despite his own progressive decline Mr White asserted several times throughout the interview that he prioritised companionship and activity and sought a *“life worth living”*. Indeed, Mr White and his family had begun to discuss his priorities and needs for the future and whether moving into sheltered accommodation would be an appropriate transition for him. A discussion which his family reported he had been reluctant to have prior to receiving bereavement support.

Furthermore, CBVs reported examples of the ways in which their clients were reclaiming previously avoided activities, starting new activities, or looking to the future following bereavement support.

“Maybe he [client bereaved by dementia] will start to look forward to reading his Sunday paper again because that was the loneliest day for him a Sunday so I guess the impact it’s had on him is that he’s tryin’ to make that day good, or better again” [Shirley, CBV]

It is noted that CBVs found it difficult to gauge the impact of the bereavement support on their clients, with one CBV asserting *“it is not our practice to follow clients up”*. However, Shirley (CBV) explained that she encouraged clients to identify

activities that were personally meaningful (as well as practically and physically possible) and begin to make changes to incorporate them into their life, a process which she referred to as *“growin’ a bit more life”*. It was through these small, but significant changes within her client’s life that Shirley was able to assess what impact bereavement support had made.

Finally, there was evidence that clients’ bereavement needs had been met on terms that were meaningful and valued by them. For example, James whose father had recently been diagnosed with dementia, accessed the *“Bereavement, loss and dementia”* resource booklet which was developed as part of the Bereaved by Dementia Project in collaboration with people with dementia and their families (the resource is freely available via the Cruse Bereavement Care website:

<https://www.cruse.org.uk/get-help/local-services/wales/wales/bereaved-by-dementia-project>). James asserted that it *“offers a simple way of breaking the whole thing down”*, and that he felt it helped *“to break down some of the stigma and some of the things that we were collectively experiencing”*. For James, the resource provided a channel through which he could orientate and navigate his own grief, but he had also used it as a vehicle to help drive and guide his mother along her grief journey.

Wider Impact

The final theme captures the wider impact and learning generated from the Bereaved by Dementia Project. Delegates to the Bereaved by Dementia one-day training –both internal and external delegates- reported that they would be able to apply their learning beyond the ‘classroom’ in their professional or volunteering role and/or their personal life.

“Something I would have found scary- but now feel better equipped to deal with - certainly will endeavour to get more knowledge! Build confidence” [CBV]

“I will take the knowledge back to my team. Workbook will be very useful for staff training” [External delegate]

“A very clear and informative presentation which dispelled anxiety about how to support a bereaved person who was diagnosed with dementia” [CBV]

Moreover, we received 116 responses to the impact and reach survey that was disseminated throughout Alzheimer’s Society Cymru and Cruse Cymru networks during December 2018 and January 2019. The vast majority of respondents (66%) were aware of the Bereaved by Dementia Project, and 92% believe that the project is important, which is an important step towards building awareness about bereavement and dementia. Of those who had referred a client/family member to Cruse, 79% rated the process as either excellent or good. Respondents advocated for a dedicated and specialist bereavement support service that was sensitive to the needs and experiences of people living with dementia and their family, to be available and easily accessible.

“Understanding the complexities of dementia and how memory loss impacts on their understanding of loss”

“Ensure support/information on support is provided before death”

We argue the Bereaved by Dementia one-day training has, and could continue to, contribute to this recommendation through the development of CBVs who are sensitive to the needs of people with dementia who are bereaved.

Conclusions, Recommendations, and Future Directions

This evaluation has demonstrated that the Bereaved by Dementia one-day training increased delegates’ awareness of bereavement, dementia, and how bereavement may be experienced differently within a dementia context. Further to this, it has

provided delegates with some core skills that will facilitate better support provision for people with dementia and their families as well as enriching how they understand and navigate their personal relationships.

Critically, many Bereaved by Dementia one-day training delegates suggested that the training had elicited a shift in how they understand, and relate to people with dementia. By focusing on the emotional integrity of people with dementia the training builds empathy and provides opportunities for connection. This is especially significant in the context of the dominant discourse of dementia as a “living death” (Peel, 2014), in which individual experiences are obscured and which tends to give the impression that people with dementia do not need, or would not benefit from, support. However, more focused research is required to examine how grief and bereavement are experienced by people with dementia, and what bereavement support services they value.

The client and CBV narratives included within this evaluation illustrate the benefit of the Bereaved by Dementia Project in supporting people through a variety of bereavement journeys. Grief, and dementia, are experienced idiosyncratically (Doka, 2010), consequently the support needs of someone bereaved by dementia are likewise individualistic. Evidence from client and CBV interviews, and the ‘impact and reach’ survey demonstrate that there is a demand for bereavement services that are sufficiently flexible to meet the oscillating needs of people bereaved by dementia, including pre-death bereavement support. The Bereaved by Dementia Project has made a significant step to address this significant and growing unmet need.

Further to this, through collaboration, Cruse Bereavement Care and Alzheimer’s Society Cymru have played an important role in raising awareness and profile of

bereavement and dementia. Through this effort, it is becoming increasingly apparent that the emotional toil, constant change, and loss experienced by people with dementia and their families is largely 'managed' in isolation. At present, while Cruse Bereavement Care recognise the significance of pre-death bereavement for both the person with a dementia diagnosis and their loved one(s), fiscal limitations are a fundamental barrier to delivering this urgent service. We would like to see funds invested in furthering the scope of the Bereaved by Dementia Project by enabling pre-death bereavement services – services that would have a significant bearing on the post-death bereavement experience - to be established, and evaluated.

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