

Bereaved by Dementia Project Evaluation (May 2019)

Executive Summary

Caity Roleston¹, Karen West², and Rachel Shaw³

1. Caity Roleston, Doctoral Researcher, Department of Sociology and Policy, Aston University, Birmingham, B4 7ET, UK. Email: rolestce@aston.ac.uk

2. Karen West, Professor of Social Policy and Social Gerontology, School for Policy Studies, University of Bristol, 8 Priory Road, Bristol BS8 1TZ. Email: karen.west@bristol.ac.uk; Tel: 0117 331 0836 (Principal Investigator)

3. Rachel Shaw, Health Psychologist, Reader in Psychology, School of Life and Health Sciences, Aston University, Birmingham, B4 7ET, UK. Email: r.l.shaw@aston.ac.uk; Tel: +44 0121 204 4050. (Co-Investigator)



Background

While bereavement is considered to be a normal part of everyday life it can nevertheless 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. 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 (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). 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 for people with dementia is a significant unmet need as well as an under-researched field of bereavement support (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 whose loved one/carer has died;
- People who have been bereaved through the death of someone with dementia.

Collaboration between partner organisations Cruse Cymru and Alzheimer's Society Cymru, Cruse Bereavement Volunteers (CBVs), and people affected by dementia were critical to the design, development, and delivery of the Bereaved by Dementia Project.

Over a period of three years (2016-2019), the Bereaved by Dementia Project delivered:

- A volunteer Recruitment Campaign – 131 new trained volunteers over 3 years (exceeding the target of 40 per year);
- A Bereavement Support & Dementia Awareness training module;
- A large proportion of the Bereaved by Dementia one-day training sessions were co-delivered by a person living with dementia and a Cruse Bereavement Care trainer;
- A jointly branded awareness raising/information resource booklet;

- Four information sessions per annum to statutory and third sector organisations;
- Raised awareness of Cruse services in the wider community;
- Bereavement support to 228 clients bereaved by dementia.

An independent evaluation of the Bereaved by Dementia Project has been conducted by a research team based at Aston University, Birmingham and the University of Bristol. What is presented here is therefore an executive summary of the wider evaluation the Bereaved by Dementia Project conducted, and delivered, by Aston University and the University of Bristol.

Our Approach to the Evaluation

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 CBVs and 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 and 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 for how individuals experienced and made sense of their experience (Yardley, 2000). 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.

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. Delegates were particularly

enthusiastic when the training was co-facilitated by a person who has dementia as 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.

Secondly, CBVs were better equipped to support clients who were bereaved by dementia through increased knowledge, empathy, and confidence cultivated through the training they received. CBVs and clients who are bereaved by dementia 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. Furthermore, clients reported examples of the ways in which they were reclaiming previously avoided activities, starting new activities, or looking to the future following bereavement support. Finally, there was evidence that clients' bereavement needs had been met on terms that were meaningful and valued by them.

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.

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. Indicative that through the efforts promoting the Bereaved by Dementia Project an important step towards building awareness about bereavement and dementia has been made. Of those who has 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 to be available and easily accessible. 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, we have observed a shift in how attendees to the Bereaved by Dementia one-day training 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 within the current climate of dementia discourse as a "living death" (Peel, 2014) which obscures individual experience and denies many avenues of support by giving the impression that people with dementia do not need, or would not benefit from, support. 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, 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. The Bereaved by Dementia project has made an important 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 within the context of dementia 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.