

Bereavement and loss support for adults with learning disabilities: An exploratory research study using Photovoice

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Loss and bereavement are devastating life experiences for anyone, including people with a learning disability. This qualitative research study was designed to engage with bereaved adults with learning disabilities using Photovoice. Photovoice is a method using photographs for community-based research, to find out or explore different things. In this instance it was used to explore the experiences of loss in the lives of people with a learning disability and their perceptions of support available in the local area (Staffordshire, UK). This research was carried out at Reach, Asist, Staffordshire, where I worked for several months on placement.

With extended support from staff at Reach, participants were recruited and a preliminary Photovoice workshop was organised for 10 bereaved adults with learning disabilities in order to provide technical training and good practice around using a camera; engaging participants creatively to participate in research; and to provide information on the photographs they would subsequently take as part of this research. The Photovoice workshop was followed by 10 semi-structured interviews with adults with learning disabilities to identify the support available and accessed; the impact of both loss and support; and the coping strategies used following bereavement. Interviews were

facilitated through discussion of participants' photographs taken after the Photovoice workshop.

Underpinning these research activities, clear information documents were designed and used in conjunction with guidance from staff at Reach. Data collection went impeccably because of the expert guidance provided by the research site in order to work with adults with learning disabilities. Additionally, data were gathered from focus groups with advocates; focus groups with professional carers; and interviews with family carers. These activities were conducted to explore key issues and support needs and roles in supporting bereaved adults at home, in an advocacy organisation, and in a care setting. All data, including the photographs taken by participants, were analysed using Thematic Analysis.

The four main supportive themes emerging from the photographs taken by the bereaved adults with learning disabilities included: (1) people (the deceased family members; living family members; friends); (2) personal assistants; (3) support staff; a range of daily activities (such as drama; pottery; dance); and (4) objects inside/ outside the home. Thematic analysis of the remaining data highlighted five main themes namely: (1) multiple losses, (2) communications related to loss, (3) support and barriers to support, (4) impact of bereavement and (5) continuing bonds.

The experiences of bereaved adults with learning disabilities mirrored the usual responses displayed by non-disabled people, but also

illustrate differences in the support, communications and other events after loss. Creative methods (such as Photovoice) together with clear information are beneficial to engaging adults with learning disabilities in research and in enabling them to share their viewpoints around sensitive topics.

Overall, the benefits of using Photovoice extended beyond engaging participants, teaching them skills and collecting data, but also in providing evidence of its success that bereaved adults with learning disabilities are able to share their viewpoints on difficult topics such as loss and bereavement with the support of photographs for future research involving vulnerable groups. Participants also learned a new skill, photography, some of whom were able to continue with following the completion of the research.

“Reach at Asist has wealth of experts working with people with learning disabilities who were all fantastic in providing support during my research and always made me feel a part of it. Thank you to the people with a learning disability and the staff for all the support”

Gulshan Tajuria, PhD student, March 2018