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Using Photovoice as a method to engage bereaved adults with intellectual disabilities in research: listening, learning and developing good practice principles

Background and rationale

It is widely accepted that people with intellectual disabilities are at increased risk of developing mental health problems, and that these problems are often overlooked. The recent introduction of UK guidelines on mental health problems in this population (NICE, 2016) confirm and highlight the importance of prevention and early identification of such problems. The guidelines specifically call for research into people's experiences during a crisis, and the effectiveness of support in promoting recovery. Loss and bereavement are often crisis events triggering trauma, and without adequate and timely support, can lead to long term mental health problems

Loss and bereavement

Bereavement encapsulates loss, grief, and mourning and has been defined as "the period of mourning and grief that follows the death of a loved one" (Travers et al., 2013, p. 223). Most adults with an intellectual disability will have had some experience of loss generally and bereavement specifically, but will have varied in their understanding of its impact (McEvoy, 1989). Indeed, adults with intellectual disabilities are likely to experience multiple or successive losses (Read and Elliott, 2007) because of being marginalised, and reliant on other people for (variable) support. The death of a relative is difficult in itself, but if the relative was the main carer, additional transitional losses are inevitable; for example, the family member with intellectual disabilties may have to move into respite or alternative care (Hubert and Hollins, 2000). It is also well documented that the death of a family member can trigger the need for crisis intervention and cause symptoms of complicated grief (e.g. Bonell-Pascual et al., 1999; Dodd et al., 2005; Emerson, 1997; Kloeppel and Hollins, 1989; MacHale and Carey, 2002). Hidden losses may accompany the death of a parent or primary carer, and limited experiences of grief and grief rituals, and perhaps not knowing about the death until long after the event itself (Cathcart, 1995), can lead to delayed and disenfranchised grief. Disenfranchised grief occurs when the grief is not recognized by society (Doka, 1989; 2002) and usually applies to marginalised groups such as prisoners, people with mental health problems and people with intellectual disabilities.

Adults with intellectual disabilities are never completely protected against loss and its impact, and need opportunities to grieve in their own unique way (Blackman, 2003). Over time, there has been a shift in attitudes towards a shared understanding that hiding information about loss and death from someone with intellectual disabilities "is neither useful, healthy, nor a mark of respect" (Foundation for People with Learning Disabilities, n.d). However, people with intellectual disabilities often do not have the bereavement support they require at the time they need it most, and this is likely to impact on their mental health status. Some people may be unable or reluctant to talk about bereavement for a host of reasons, such as limited (or no) spoken language to express feelings or describe their reactions to loss (McEvoy, 1989). When losses go unrecognised, and accumulate, the original grief may compound and the person is more likely to have mental health difficulties and distress associated with their grief (Blackman, 2003; 2008). Additionally, families and professional carers may be unsure about how and when to support grieving individuals, and may be unfamiliar with the available resources to help them.

Study aims

Bereaved adults with an intellectual disability experiencing grief will require individually tailored help and support. Some may rely on family, friends or other social support networks; others may need specialist support, but may lack the knowledge or ability to access it (Read, 2005). While there has been an improvement in recognising the need for bereavement support for this population, there is little available research exploring whether adults with intellectual disabilities can easily access what they need and what is the best form of intervention (Read and Todd, 2009). It is important, therefore, to understand the resources and therapeutic interventions that are available for bereaved adults with intellectual disabilities and to evaluate critically which are the most effective in minimising distress and promoting recovery. Resources available include bereavement counselling; support groups; crisis teams; booklets and workbooks such as the ‘Books Beyond Words’ series (e.g. ‘When dad died’ Hollins & Sireling, 2004); life story work (Hussain and Raczka, 1997; Botsford, 2000; Hollins et al., 2003) and memory box that is created using range of mementos related to the deceased person (Young and Garrard, 2015).

There is a growing recognition that adults with intellectual disabilities do grieve and do respond to loss, and a pressing need to explore the interventions and tools used for supporting this population at this sensitive time; to explore the situations in their lives where therapeutic support may be most effective (Willner, 2005). Against this developing backcloth of bereavement support for adults with intellectual disability, a

PhD study was designed. The PhD study aimed to identify and critically explore the tools and interventions used to support bereaved adults with an intellectual disability, and assess their effectiveness, using Photovoice as a key methodology. This paper discusses adaptation of Photovoice as a research tool with bereaved adults with intellectual disabilities, specifically focusing on preparing participants for the research.

Methodology

It is not possible to have a single ‘safe’ methodology suitable for all research, but adaptations to techniques can maximise participants’ potential during research (Nind, 2008). Considering the potential vulnerability of participants, and to provide maximum opportunity for their experiences to be captured, this study used mixed methods, including Photovoice. Photovoice is an approach that ‘uses photography as a means of accessing other adults’ worlds and making those worlds accessible to others’ (Booth and Booth 2003, p. 431). It is a “process by which people identify, represent, and enhance their community through a specific photographic technique’’ (Wang and Burris, 1997, p. 369). Methods such as Photovoice can be very helpful, as people with intellectual disabilities may sometimes need different approaches to facilitate their inclusion in research and to help them to be heard by the world (Cluley 2017). Hence, participants were introduced to Photovoice at a preliminary workshop, where they were prepared to take photographs reflecting their loss experiences. In line with Photovoice methodology, these photographs would later be used to facilitate discussion in a face-to-face interview. Data was also gathered from open-ended questionnaires and focus groups with advocates; focus groups with professional carers; and interviews with family carers, to explore key issues and support needs and their role in supporting bereaved adults at home or in a care setting. However, the focus of this article is on the preparation, delivery and evaluation of the Photovoice workshop.

Photovoice as an inclusive research method

Historically, adults with intellectual disabilities have not been included in research about sensitive issues such as death and how it affects their lives (Tuffrey-Wijne et al., 2007). Inclusive research is described as research with, by and for vulnerable people and not on them (Nind, 2014; Walmsley, 2004; Nind, & Vinha, 2014). A good quality inclusive research approach can be summarised as one that answers the questions; reaches participants; provides knowledge; includes in-depth information about people by people; is accepted by people themselves and influences their lives in a way that is not common (Nind & Vinha, 2012; Nind, 2014). This is true even with research with children with profound and multiple disabilities (see, for example, Simmons and Watson, 2014; 2015). Thus, Photovoice was explicitly selected as a tool to facilitate the engagement of people with intellectual disabilities in this research and to share their experiences of loss and support.

Photography has previously been used for public health research (Strack et al., 2004; Wang and Pies, 2004); in art and design (Stanley, 2003); to explore immigration experiences among people from a Latin-American background (Streng et al., 2004) and with people with mental health problems (Bowers, 1999). Its use with people with intellectual disabilities is limited, but it has been used successfully, such as raising awareness of health discrepancies with people with intellectual disabilities from a Latin-American background (Jurkowoski & Paul-ward, 2007). It has also been used with mothers with intellectual disabilities to find out what is most important in their lives (Booth and Booth, 2003), and as part of biographical research by people with intellectual disabilities themselves (Brake et al., 2012). Jurkowski, (2008) conducted a Photovoice study with people with intellectual disabilities for a period of one year to understand their health beliefs, health needs and interests related to health promotion, concluding that 'Photovoice enables a sense of ownership among people with intellectual disabilities in the research process' (p9). Obrusnikova and Cavalier (2011) used Photovoice to assess the causes that children with autism spectrum disorder perceived stalled and encouraged after-school participation in physical activity. Photovoice has been successfully used with people with profound and multiple intellectual disabilities; for example, Cluley (2017) asked such participants to take photographs (with support from carers) of their daily life.

Photovoice is thus a creative and innovative research method that can be useful for sighted adults with intellectual disabilities (Booth and Booth, 2003). It can be adapted and used flexibly as a method to engage, a method to capture memories and a research method to enable people with a range of abilities to describe different realities or viewpoints (Lucy Williams, 2014, personal communication). Within Photovoice, photography can be used in two ways:

1. The researcher takes photographs for the participant or photographs taken by someone else are used.
2. Participants take their own photographs and then talk about them. This method helps adults with limited verbal communication skills to participate actively by adding a visual component to the discussions.

The second approach was used in this study.

Consent and Ethical approval

A University Research Ethics review panel approved this research study in April 2015. All research that involves people carries with it potentially ethical tensions and photographic methods pose challenges to researchers, predominantly in relation to consent and confidentiality (Aldridge, 2007). Gaining consent is an important part of any research process, but traditional consent forms may need to be adapted further using clear words and pictures so that they can be better accessed by adults with intellectual disabilities. Adapted forms were therefore used in this study. Additionally, an explanation of the project by staff members at the research site was important, as they knew potential participants well and could repeat explanations of their involvement in this research. Verbal and written consent for the use of photographs was obtained from all participants; photographs remained the property of the participants and would not be used without explicit permission. Informed consent was reinforced throughout using the principles of process consent (Beaver et al., 1999).

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors however, the University reimbursed participants' expenses for refreshments, room hire and taxi fares.

Procedure: Developing the Photovoice workshop

Consultation

Two bereaved adults with an intellectual disability acted as consultants before recruiting participants for this project, since research methods are more likely to be effective when there is genuine involvement of people with intellectual disabilities (Ward and Simons, 1998). The two consultants were invited to a meeting at the research site, where the Photovoice workshop was fully explained to them. All draft documents were designed using clear information and photosymbols© (a unique photo library of Easy Read common symbols). Both consultants were given a copy of the participant information sheets to take away and give feedback over the telephone about the different activities and expectations required regarding getting involved in this research. This was very useful; as both consultants pointed out things they really liked and made it very clear where they could not understand information. For example, they both liked the idea of taking photographs related to loss and sharing stories afterwards. One of the consultants was not clear and asked for more information on what would happen with the photographs at the end of the project. This exercise also nurtured confidence in the researcher around using the tools with other participants.

Recruitment

Ten adults with an intellectual disability, who had experienced loss and bereavement within the previous five years, were recruited from an established local self-advocacy organisation that supports people with disabilities to have a voice and to speak out. Members of the advocacy organisation acted as gatekeepers, contacting potential participants and passing contact details of those interested in receiving more information to the researcher. The researcher then briefly explained the study to those interested over the telephone and oral consent was obtained. Detailed participant information sheets and consent forms using clear information and pictures were then posted to participants. Consent was subsequently confirmed face to face and in writing.

All participants had mild to moderate intellectual disabilities, with loss experiences ranging from deaths of people (parents, grandparents, siblings, friends, cousin); deaths of pets; loss of people still alive but living far away, imprisoned, or disabled; parents remarrying; loss of jobs, homes and holidays; loss of freedom to speak or freedom to go out; loss of activities done with a deceased person; loss of family stories/jokes; loss of places, resources, health, social worker visits; loss of ambition; and loss of contact with friends.

Practical organisation

It was anticipated that some participants might not have used a digital camera before. To maximise effective use of the cameras, a workshop was organised to introduce participants to Photovoice, and camera use if required. A written and pictorial information sheet about the camera, its different components (such as the battery and memory card) and how to use it was produced as an accessible resource. Each participant was given a copy of this resource to take home as an aide memoire.

Each participant was allocated a unique identification number, to store information across all documents, the camera and its different components. All cameras, memory cards, batteries, and battery chargers were individually numbered before packing into individual boxes, and a folder was prepared for each participant containing pictorial information sheets and prepaid envelopes to post the memory cards back. Folders were created on a laptop beforehand, for organisation and storage of images taken during the workshop.

The workshop

The main aims of the workshop were to:

- assess the level of support required for using a camera.
- enable participants to explore and use their camera with support as required.
- provide simple training on ethical and safe photography.
- provide technical information and training to participants for the next phase of this research.
- promote understanding and encourage questions about the research.

The workshop was held at the advocacy organisation, which was a familiar and fully accessible environment for all participants. Various objects were scattered around the room, to provide ideas to capture photos from different angles and then to discuss them. The participants had previously been invited to bring one photograph from home to share with the group as part of the introduction to the workshop. Whilst 10 people were invited, only five were able to attend, and a further workshop was rescheduled for those who could not make it. Also in attendance were two supervisors, two advocacy staff members and the researcher.

Simple ground rules were initially established, agreed, and clarified using pictures, symbols and colors. Traffic light cue cards (using red, amber and green colors) were adopted, since the participants were familiar with using these, and used if they wanted someone to stop talking and ask questions (red), if they agreed (green), or if they did not agree (amber). The researcher explained the research again, before going through the consent forms and checking that participants had understood what the project was about, and if they had any questions about the workshop or the research project itself. Consent forms were then signed. Three participants had brought photographs from home (of their family members or favourite pets), which they shared with the group.

Each participant was given a camera and the researcher talked through the functions of the camera and its components and the process of taking a photograph; while each participant followed the instructions using their own cameras. All required support in using the camera as none had ever used or owned a digital camera, although three participants had previously taken photographs with their mobile phones or iPads. Supporters helped participants to explore and understand the basic functions of the camera (e.g. how to switch it on/off; how to insert batteries; how to charge the batteries etc.). Coloured stickers were used on the camera as cues for ease of recognition, such as to highlight the on/off button and the simple click button.

Treasure hunt activity

To explore individual knowledge and ability, participants were invited to take photographs of something in the room such as their favourite colour, a shape, or something no one else had noticed. This information was also available in written and pictorial form on an instruction sheet, to promote understanding, memory and recall.

The pre-prepared accessible instruction sheet for camera use and photography was explained. Participants were then given 15 minutes to move around the room and take photographs, after which a viewing and discussion of the photographs produced took place.

Outcomes of the workshop

All five participants were enthusiastic about taking photographs, making full use of the objects placed around the room; some also took photographs through the window of the outside car parks, road and buildings. All photographs were downloaded from the memory cards and saved using their unique identifying number on the researcher's laptop. Photographs were then shown on the projector and participants were asked to guess which photographs belonged to whom. Most were able to identify their own photographs, and showed interest in the whole activity. They were able to say if there was something fundamentally wrong with the photograph's composition, even if not always able to clearly articulate why it seemed wrong. The researcher made a list of the apparent learning needs of each participant, such as support to use the camera initially; support in inserting the memory card and batteries; and support in aspects of taking a good photograph such as focus; framing; follow through and using flash. On the basis of this needs assessment, and after looking at the photographs themselves, participants were again given one to one support to use their camera, focussing on areas where they needed most help. They were then given more time to use the camera in the room with support.

Ethical issues explained

Viewing the photographs enabled a discussion of ethical issues, supported by an ethics information sheets using clear information and pictures. For example, the importance of gaining permission to take photographs of people was explained. One participant had taken some photographs of the researcher, which initiated discussion on the ethics of taking photos of people without permission.

Consolidation of the workshop

Towards the end of the workshop, all participants were given their own numbered camera with all parts identified and numbered, information sheets, and a prepaid addressed envelope. They were all shown how to remove and post the memory cards back. They were reminded about the project aims and were asked to take photographs during the next two to three weeks of things associated with their loss and grief experiences.

Examples were discussed, as participants suggested a few ideas they had about what photographs they wished to take. For example, one participant wanted to take a photograph of a church that was associated with his loss. Another participant wanted to take a photograph of a shop where her loved one used to buy spectacles. The researcher deliberately did not give much direction about the content of photographs, in order for participants use their own creativity. Participants were informed how to contact the researcher should they need additional support.

Ending exercise

At the end of the workshop, participants were asked to share one thing they liked about participating. Responses were recorded and transcribed, with examples as follows:

"I think the photograph work is good…"

"…learning about the digital camera, what you have to do, all the different angles, show you how to put batteries in, charger in, card in and out…", "Didn't like when

picture didn't work…"

"going to bring memories of mum and dad…"

"liked knowing about different support I had and going to have"

At the end of the workshop, participants were reminded that, cameras were for them to keep and memory cards to post back; they would be invited to attend an individual interview with the researcher at a later date, where the photographs they would be taking would be discussed. All participants then had a shared lunch before leaving.

Evaluation of the Photovoice workshop

The aims of the workshop were met since:

- Everyone knew how to use camera after the workshop and had some practice in using it; some needed extra support to do this confidently
- All participants asked questions about the type of photos they could ethically take
- Everyone participated in the workshop and agreed to take photographs and return for an interview to discuss, using their photographs, what helped them to cope with their loss

Discussion

As anticipated, the Photovoice workshop required a great deal of planning and preparation beforehand, to clarify each step clearly, due to the individual needs and potential vulnerability of the participants. Special attention was given to planning everything for the participants' comfort so that individuals could fully engage in the project. Stakeholders (advocates, professional and family carers) were approached and the use of Photovoice was discussed to get the dynamic of participants with intellectual disabilities and the knowledge gained was used in the research. While Booth and Booth (2003) and Jurkowski (2008) refer to the difficulty of getting participants to follow through with picture taking assignments even when given multiple prompts, in fact in this study eight participants who attended the preparatory Photovoice workshops were able to use the cameras independently at home and to post the memory cards back. Two participants required extra support from the researcher and the family to use camera. Four participants found use of camera difficult initially; however, practicing helped them. All attended the follow-up interview where the photos were discussed. This suggests that the extensive preparation of Photovoice combined with a flexible approach was effective in engaging participants in this inclusive research in line with Cluley (2017); and contributed in following results:

- All participants started to use the camera regardless of the quality of photos.
- All participants took photos during the 2-week time period as instructed.
- In total 410 photos were taken by the participants.
- All returned the memory cards and came back for follow up interviews.

It was established as expected that most of the participants (seven out of 10) had not used a digital camera before the workshop, and none of them had owned a camera before in their lives. This Photovoice workshop gave each participant a platform to share their experiences of loss as well as think about showing the support in form of photos. The whole focus of the PhD research study is to engage with the participants, to explore experiences of loss and bereavement and support, and their impact on participants' mental health and daily life. The Photovoice workshop helped in the initial engagement and interest of the participants in this early preparatory stage of the research study, and informed the next stage of data collection. The results outlined are not part of this paper but are a measurable outcome of the success of using Photovoice workshop to engage participants in research using this method.

The participants in the workshop taught the researcher much about the importance of communication, preparation and presentation as precursors for meaningful engagement in the research process. While participants enjoyed taking photographs the researcher has experienced a unique way of talking about sensitive issues such as bereavement with a potentially vulnerable population. During the Photovoice workshop and other meetings with the participants, a key learning point was to be non-judgmental about the likely abilities of the participants. Principles of good practice arising from this Photovoice workshop include:

- **P**lanning, preparation and flexibility are the basis for good outcomes. The whole workshop was conducted using a flexible approach to respond to individual issues.
- **H**aving an accessible venue is crucial, and decisions about where and when to conduct the workshops are fundamentally important.
- **O**vert practical involvement and rehearsal promotes concrete understanding.
- **T**reating people as adults, making participants feel welcomed and listening well is important to encourage a sense of belonging and active participation.
- **O**pportunities for creativity and practice were an important aspect. Objects used in the room to make it more colourful and give people more ideas to take

photos worked well.

- **S**haring reflections and consolidating practice experiences are essential components of qualitative research. Following this workshop, the research team briefly reflected on what had worked well and identified tips for good future practice.

Photography is a creative activity generally, and it can be used within research; however, it can be most useful when combined with discussion of the photographs taken by participants to gain further understanding of the personal meanings of the photographs taken. This is especially true with unique loss experiences where each individual has their own experience and understanding. Participation of bereaved adults with intellectual disabilities in this project also facilitated greater understanding of their needs and abilities. For example, staff at the care home attended by some participants appreciated the way participants were involved and how some of them managed to take photos beyond the expectations of the staff. Almost all participants received commendations from staff/carers and family members on taking photos and getting involved in this research. In line with the findings of Boxall and Ralph (2011) where staff at the research site became more interested in the life of a participant even after the research project had finished.

Conclusion

Using clear information together with creative methods like Photovoice to explain difficult concepts and procedures to adults with an intellectual disability is time consuming, cost and labour intensive compared to other methods, but is crucial in order to involve difficult to reach groups in the research process. Creative methods of working with adults with intellectual disabilities such as Photovoice help to engage them in ways that are meaningful and enjoyable. Thus, the research is strengthened, enriched; more focussed and can provide outputs that are more effective (Ward and Simons, 1998). It not only helps people with intellectual disabilities to take part in research but also offers an opportunity to help them to learn and apply new skills in their daily life (Povee et.al., 20014), thus becoming an empowering experience. This workshop effectively engaged participants who would then go on to meet and discuss their experiences of loss and bereavement in greater depth with the researcher, using their own personal photographs as practical prompts and focus for the discussion. Whilst the outcome of these future interviews will remain important to the researcher, the process of reaching the outcomes will be important to professionals hoping to engage other people with intellectual disabilities using Photovoice as a methodology.

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