A focused mapping review and synthesis of current practice in qualitative end of life research with the bereaved.

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Abstract:

Background. Nursing research is dedicated to improving care, but research into end of life care can be challenging because of a possible reluctance by researchers to invite bereaved people to take part in studies.

Aim. To use a focused mapping approach to explore the recruitment to studies of grieving and bereaved people.

Discussion. There is no 'gold standard' method of recruitment and no best way to approach participants. The outcome of each method, measured by the percentage of potential participants recruited, appears to be unrelated to the approach used.

Conclusion. There is no evidence that participation in research harms those who have recently been bereaved, but there is evidence of benefits from participating.

Implications for practice. Researchers should not feel they need to protect the bereaved from participating in research and can invite bereaved individuals to join a study without worrying about causing them harm.

Introduction

Grief comes from the loss of someone important to the grieving person, and is an expected reaction following a death (Nyatanga, 2018); it is also known that experiences of grief are individual to each person and that over-broad generalizations about grief should be challenged (Rosenblatt, 2017). In a world respectful of cultural diversity, it is important to understand that there is no 'normal' standard of grieving (Rosenblatt and Bowman, 2013, Rosenblatt, 2017, Schwartz et al., 2018, Neimeyer, 2014). Grieving is not a pathological process that requires medication (although it may do), but a fluid process which changes with each person and can alter throughout the persons life without ever completely disappearing (Stroebe and Schut, 1999, Rosenblatt, 2017).

Grief can be hugely overwhelming and very isolating (Arizmendi and O'Connor, 2015). It has long been observed that one of the most isolating things about grief is that bereaved people feel others do not know what to say and therefore avoid them out of embarrassment, making the isolation even more acute (Whitaker, 1984). Because of this, there is a sense that research into end of life care situations is intrusive and even potentially unethical (Casarett and Karlawish, 2000, LeBlanc et al., 2010). However, research with bereaved individuals is necessary to assess and improve the quality of care given to loved ones at the end of life and to monitor the success or otherwise of any innovations or interventions (Stiel et al., 2015). The presumption is often made that any research with bereaved individuals following a death is unduly burdensome and therefore not 'appropriate' (LeBlanc et al., 2010, Bentley and O'Connor, 2015).

However, when the evidence is examined, it becomes clear many bereaved people actively want to take part in research. Colin Murray Parkes, a psychiatrist who is credited with setting up the first hospice based bereavement service, states: 'anyone who turns towards the widow and the widower and gives confidence that they do have something to

offer at moments of utter despair helps to reassure them that all is not lost '(p xi) (Whitaker, 1984). Supporting bereaved people to use their experiences in ways that can help others, adds dignity and shows they are valuable as a person, and their experiences are important (McLoughlin, 2010, Monroe, 2003).

It has been suggested that participating in research, particularly qualitative research, can help individuals who are grieving, not just by demonstrating they and their experiences are helpful, valuable and of use (Monroe, 2003), but also because of the therapeutic effects of sharing their experiences with a researcher (Bentley and O'Connor, 2015). East et al (2010) write that personal stories gained through research, particularly healthcare research, may focus on sad and potentially life traumatic experiences, the exploration of which can lead to healing and contribute to the building of resilience . Bereaved people talk about the importance of someone listening (Klass, 2013), and in a research situation, the researcher is that person listening to the bereaved individual (Norberg et al., 2001). Rosenblatt (2013) writes that in working with bereaved people it is important to move away from any sort of preconceived ideas or theories and just be open to the realities for individuals; therefore, self-doubt and caution on the part of the researcher are more important than certainty (Rosenblatt and Bowman, 2013).

The aim of this paper is to examine the current thinking behind the recruitment of grieving and bereaved people into research studies. The objectives are:

1. To review a selection of the recent literature to understand the current practice of recruiting bereaved people into research studies.
2. To gain a thorough understanding of the current practice to help inform methods of recruitment for a planned study.

Methods

Methods

Following the methods described by Bradbury-Jones et al (2017), which built on the work of Grant and Booth (2009), a focussed mapping review was designed

(Bradbury-Jones et al., 2017, Grant and Booth, 2009).A focussed mapping review explores a sample of literature in detail in order to explore common trends and to identify contemporary practices. The justification for using a sample of papers to explore the methods used is further described by Platt (2016), in her paper examining the methods employed when samples of journal articles. Bradbury-Jones et al (2017) claim that the distinctive feature of the focused mapping review is that it seeks to establish trends from an appropriate body of literature. In this study the aim of the mapping review was to identify how researchers manage the recruitment of participants who had been bereaved into a study. We were interested in exploring current trends in recruitment in this sensitive area. To do this, we sought to identify recent papers where recruitment of those who had been bereaved had been undertaken.

Rather than scan a pre-identified selection of journals for potentially relevant papers, which would have been an inefficient process given the limited number of potentially relevant papers, we used a database search to identify ten recent papers where participants who had been bereaved had been recruited. The following key words were used in xx database... Papers were then read to ensure that they met the inclusion criteria (table 1).

All research articles that discussed original research with bereaved individuals were included. Articles were scrutinized against the inclusion and exclusion criteria. The first? Ten articles that met the inclusion criteria were identified and a proforma was developed as per the work of Arksey and O'Malley (Arksey and O'Malley, 2005). Table 1 shows inclusion and exclusion criteria. The proforma is presented in Table 2.

Table 1.

Inclusion criteria	Exclusion criteria
Paper describes direct research with bereaved individuals	Systematic or other review papers
Original research	
Published between 2013 and 2018	

Table 2 Proforma

Journal name	
Country	
Publication details	
Study populations	
Aims of the study	
Methods of recruitment	
Opt in or opt out?	
Eligible participants approached	
Final number of participants	
Recruitment detail	
Time since death	
Tool	
Important results	

Findings.

The following chart presents the methods of recruitment of bereaved people, how many people were recruited, whether this was opt in or out and evidence of harm or benefit from inclusion in the study.

Table 3. Different approaches to recruitment

Method of recruitment	Papers	Percentage recruited	Opt in or opt out	Evidence of harm	Evidence of benefit
Method 1: The participants are approached via a national registry or other directory of deceased persons	(Eilegard et al., 2013)	73% of potential participants responded	Opt in	13% of participants reported some negative effects	84% of participants reported positive benefits
	(Holdsworth, 2015)	16% of potential participants responded	Opt in	Not discussed	Not discussed
	(Roza et al., 2015)	42% of potential participants responded	Opt out	Not discussed	Not discussed
	(Bentley and	23% of potential	Opt in	No evidence of	100% of

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	O'Connor, 2015)	participants responded		negative effects	participants reported positive benefits
	(Stiel et al., 2015)	76% of potential participants responded	Opt in	Minimal evidence of negative effects	Some evidence of benefit
	(Sque et al., 2014)	30% of potential participants responded	Opt in	No evidence of negative effects	100% of participants reported positive benefits
Method 2: The participants are recruited via an advertisement on social media, other internet resource or by paper advertisement at a hospice or hospital	(Hirooka et al., 2017)	15% of potential participants responded	Opt out	Not discussed	Not discussed
	(Harrop et al., 2016)	30% of potential participants responded	Opt in	Not discussed	Not discussed

Method 3: The participants are approached before the expected bereavement	(Tsai et al., 2018)	40 % of potential participants responded	Opt out	No evidence	Not discussed
Method 4: Participants are approached via specific hospital records of deceased persons	(Lees et al., 2014)	25% of potential participants responded	Opt in	No evidence of negative effects	100% of participants reported positive benefits

Results

As can be seen from table 3 four main methods of recruitment of bereaved people into research were identified. In method 1, participants are recruited using a national registry or other database to recruit carers. This was the most common method of recruitment. In Method 2, participants are recruited using social media, the Internet and direct advertisement. In Method 3, participants are recruited prior to the death of the loved one, using as an example a study in which the participants were recruited from a convenience sample of relatives who were spending time at a hospital. Finally, method 4, participants are recruited through the use of hospital records of deceased persons. 'Opt in' was the most common strategy for recruitment (7/10 papers) where participants had to specifically elect to join the study; whilst 'opt out' (where participants have to specifically state they do not want to join the study) was used in 3/10 papers. All methods of recruitment resulted in successful recruitment of research participants.

A major concern throughout all the papers was potential to cause harm. Ethical research practice is commonly assessed against four principles: beneficence, non-maleficence, autonomy and justice (Beauchamp and Childress, 1994). The principles of beneficence and non-maleficence are reflected in many professional codes, for example in the UK, nurses must act within the limits set down by the Nursing and Midwifery Council Code (NMC 2015). This includes the instruction to '*Be aware of, and reduce as far as possible, any potential for harm associated with your practice '*(NMC 2015). This includes research as well as clinical practice. As table 3 shows, there was no evidence of serious harm associated with taking part in any of the studies under discussion, although some studies indicated a small amount of transient emotional burden associated with participating. Tsai et al (2018) started with 877 eligible caregivers of whom only 88 refused to participate initially, perceiving amongst other reasons that there may be an emotional burden to participating. The feelings of the participants at the end of the study are not recorded, but a total of 354 individuals voluntarily participated and were retained over the thirteen months of the study; therefore they clearly wanted to

participate. Eilegard et al (2013) did specifically discuss the issue of harm coming to the participants. Their findings concluded that 12 % of their participants admitted to being 'negatively affected' at the moment of filling out the questionnaire; however, they all stated that they did not anticipate that they would be affected long term. This echoes the work by Dyregov (2004) who found that the majority of his participants experienced their involvement in the study to be painful at the time of interview, but all stated they did not regret participating. Of the papers in this review, four did not discuss or mention potential negative effects and it therefore cannot be assumed that there were no negative effects whilst four did ask participants about harm and stated that no negative effects were noted by the participants. Five studies reported positive benefits to the participants as reported by the participants themselves.

Furthermore, there is evidence of beneficence, or a positive outcome resulting from participation in research. Hirooka et al (2016) found that their participants wanted to talk about their bereavement experience and indicated that it helped in their grief reactions. One of the main conclusions from this paper is that nurses should encourage bereaved individuals to talk about their feelings (Hirooka et al., 2017). This result was mirrored both by the work of Eilegard et al (2013) who found that 99% of their participants stated that the study was valuable and they welcomed the chance to tell their bereavement story, and also by Stiel et al (2015) who found that their participants had a high willingness to participate and stated they benefited from the research discussions, reporting low to moderate levels of burden (Stiel et al., 2015). Lees et al (2014) also reported that a specific finding from their work was that participants positively welcomed the opportunity to talk about their experiences of being alongside a loved one at the end of life.

Four of the papers (Harrop et al., 2016, Holdsworth, 2015, Roza et al., 2015, Sque et al., 2014) do not specifically concentrate in their findings on the possible benefit to the participants of taking part in the research. However on reading the papers, positive elements are visible -: comments such as an individual saying that it's comforting to go over things with an uninvolved person (Sque et al., 2014, Harrop et al., 2016), or that it would have been helpful to have been given the

opportunity to talk to a health professional after the death (Harrop et al., 2016), and the importance of aftercare for grieving families (Holdsworth, 2015), all lead to the conclusion that participation in research is genuinely therapeutic.

Bentley and O'Connor (2015) specifically focus on the issue of exactly when researchers should approach grieving families after a bereavement. The findings indicated that it very much depends on the individual person and that any time at all (following a few weeks after the death) was appropriate to approach potential participants. One finding suggested that some individuals actively try to move on after the death and put thoughts of the death behind them; therefore if they decline to participate in research around the death experience it may not be due to direct distress but more due to dislike in looking back and being reminded of something in the past that they may wish to keep to themselves. The message from this study- that individuals should be asked when they would like to talk- is useful for future studies and mirrors the earlier observation in this paper that grief reactions are entirely individual (Rosenblatt, 2017).

The study with the highest recruitment rate, carried out by Stiel et al (2015), may have owed its success to the persistent approach taken during the recruitment process – the researchers made an initial telephone call to all eligible participants, and followed this up with another call before being invited to either a face to face meeting or a telephone interview, which was an extensive interaction consisting of three questionnaires. If the eligible participant was unsure about taking part during the initial or the second phone call, they were called again. This was unusual, as most of the 'opt in' studies using telephone calls (Eilegard et al., 2013, Harrop et al., 2016, Holdsworth, 2015), did not offer several calls to the participants. There is therefore some evidence that offering multiple entry points into a study may lead participants to have a more favourable attitude towards taking part in the research, and also recognises the individual nature of the grief experience. This is borne out by the study by Hirooka et al (2017), which had the lowest response rate, despite being an 'opt out' study; the researchers approached 800 eligible individuals and only recruited 124 participants, using a web-based survey only with no online, telephone, or in person contact.

Discussion

For those undertaking research, any ideas for strategies to improve participation in research are useful and it is important both from a clinical and from a research perspective to attempt to understand different perspectives particularly among this group of potentially vulnerable research participants. What really interests qualitative researchers is people and the way people make sense, both of their world and also their experiences of the world (Yazan, 2015). From this perspective, the results found in this review study are encouraging. There is no evidence that participation in research causes harm to those who have recently experienced a bereavement. In fact, there is evidence of a positive effect of participation. Furthermore, studies that used an opt out approach did not show this approach was unacceptable to participants. In fact it could be postulated that this made the decision to participate easier. This should be reassuring for researchers and members of ethics committees who make decisions about the appropriate method of recruitment for studies involving vulnerable participants.

There is evidence that researchers should consider the method of recruitment which allows the participants as much choice as possible and gives as many options regarding contact with the researcher. This is in line with the earlier discussion regarding the variation in individual reactions to bereavement.

Conclusion

This review indicates that there is no one 'gold standard' method of recruitment and no best way to approach participants. The outcome of each method, measured by the percentage of potential participants recruited, does not appear to be related to the approach used. All the included papers confirmed that participants were able to refuse to take part and very few did so, indicating that the approaches used to recruit and the actual research were acceptable to participants. The papers also indicate that, despite their bereaved status, people were willing to be invited to be involved in a research study.Papers in this review indicate several principles to guide the method of recruitment. Firstly, the

bereaved need to feel both mentally and physically safe. Bereavement is a time of vulnerability and some people find going out of their own environment is too taxing; hence phone conversations can be preferable. (Thomas, 2015, Perreault et al., 2004). Other participants may welcome a chance to go out and meet a researcher face to face. It can be hard for those who have experienced a bereavement to make decisions; therefore being contacted several times in an appropriately sensitive way can be more productive than being sent a form through the post or an internet link (Rolls and Relf, 2006). More options can lead to empowerment for the potential participants who may be feel somewhat overwhelmed by their bereavement (Thomas, 2015, Neimeyer, 2004, Schwartz et al., 2018).Pesut (2018) discusses the language of palliative care, death and dying. She purports that attention should be paid to the language of palliative care, as she puts it, to open up new spaces for ideas within this language. She does this by asking 'who is dying and

what is death' , describing how she interviewed older adults about the death of their loved one, noting that while the language used was itself important, attention also needed to be paid to what was not said . There is much work to be done to further uncover the mysteries surrounding death and how nurses can best work to support the dying and bereaved. To do this, it is essential to have conversations with bereaved individuals in a research context. This paper has shown that there are varied approaches to enable these conversations to happen and ultimately researchers need to promote the involvement of the bereaved with inclusive and encouraging recruitment practices to give them a voice. They may have important things to say.

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