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From a good death to a better bereavement? The impact of the end of life experience on bereavement adjustment, a thematic analysis.

Abstract

To date, the majority of research into a good death has focused on the experience of the person who is dying. Taking the perspective of bereaved individuals, this qualitative study explores which elements of the end of life experience constitute a good death and how these elements influence the process of bereavement adjustment. Following interviews with ten bereaved adults four themes were identified which together define a good death; a lack of physical distress, emotional resolution, 'naming death as death' and death at 'the right time'. The value of open communication prior to death is highlighted. For those working with bereaved individuals these results support an understanding of the impact of the manner of death on bereavement adjustment. For those in palliative care settings, potentially modifiable elements of the end of life experience which may support better bereavement are suggested.

Keywords: good death, bereavement, end of life, palliative care.

Introduction

Bereavement, the experience of the loss due to death, is a very common life event but one which can be devastating for individuals. Whilst the effects of grief can differ greatly between individuals in terms of duration, intensity and impact (Strada, 2013), research has demonstrated that bereavement adjustment can be predicted by the circumstances of the loss (Costello, 2012). Recent research has demonstrated that the end of life experience of an individual has a potential long term impact on bereavement outcomes for their family members (Wilson, MacLeod, & Houttekier, 2016) and that the quality of death is related to the quality of bereavement (Garrido and Prigerson, 2014).

A good death

The concept of a good death is multifaceted and not clearly defined. In general, however, it is understood to include a death which reduces both physical and emotional suffering (Miyashita et al., 2008), is congruent with the personal values and stated wishes of the dying person (Balducci, 2012), takes place at a time where death is accepted and planned for (Semino et al., 2014), meets the spiritual needs of the individual (LeBaron et al., 2015) and maintains close relationships and open communication with family members throughout the final illness and death (Carr, 2003).

To date, research examining what constitutes a good death has focussed on the perspective of the patient experience (Kastbom et al., 2016). Bereaved family members are frequently involved as participants in research post-death but their role in these studies is primarily providing information about patient care. However, the factors which comprise a good death are dependent on the role and perspective of the individual, for example as the person who is dying, the family member or the professional involved in providing care (Semino et al., 2014). In a qualitative study of culturally diverse bereaved individuals, Lee (2013) identified differences between patients and family

members in terms of the perception of a good death and further study is required in order to understand what a good death looks like from the point of view of bereaved individuals.

Context and intended contribution

Recent literature suggests that bereaved individuals define and experience a good death differently from those who are dying (Lee et al., 2013) and that factors of the death experience can improve bereavement outcomes (Kim et al., 2015, Wilson et al., 2016)). Taking the perspective of bereaved individuals, the objective of the current study was to investigate which elements of the end of life constitute a good death and to consider the effect these elements have on subsequent bereavement adjustment. Limited research directly connects these two areas from the perspective of the bereaved individual. This study will use qualitative data from bereaved individuals who have experienced normal grief reactions. Many previous studies have recruited participants via clinical services for bereavement suggesting a bias towards people who are struggling to find balance in bereavement. With a focus on participants who are dealing with their grief within their own personal and social support networks it is anticipated that findings will be able to highlight some of the potentially modifiable factors of the end of life which positively influence normal bereavement.

This study will aim to answer the research question: From the perspective of bereaved individuals, which elements of the end of life experience comprise a good death and how do these elements relate to the process of bereavement adjustment?

Method

Design

This research was conducted using a qualitative design to allow the richness and depth of the individuals' lived experience to be portrayed (Butcher et al., 2001). The approach was to use semi-structured interviews followed by thematic analysis (Braun and Clarke, 2006) of the transcripts.

The use of a qualitative methodology ideally enables the participants own social reality to be safeguarded rather than producing results that are the construct of the researcher (Fereday and Muir-Cochrane, 2006). However, the author of this study recognises the impact of previous values and life experience, as a bereaved person and bereavement counsellor, on the research process. Prior to commencing this study, the research and its protocol received full ethical approval from Northumbria University's Faculty of Health and Life Sciences Ethics committee.

Participants

Ten adults (8 female, 2 male) participated in this study (40-75 years, mean age 54). Participants lived in the North East of England and were recruited through word of mouth, including advertising on social media, or through email contact with interest groups. All the participants had experienced the death of someone they were close to within the last six months to five years and had been either present at, or felt they were able to comment on, the experience of the death (see Table 1 for further demographic information). In order to enable maximum diversity of experience no exclusion criteria were set as to the cause of death, place of death or relationship between the participant and the person who died. All participants are identified by pseudonym.

Data collection

Data were collected using semi-structured individual interviews. Author CW carried out all the interviews and they were audio recorded and transcribed verbatim within 48 hours. The interview schedule was piloted and the final version was designed to ensure that data was collected about the participants' experience at two key time points; the time of the death and their subsequent bereavement. The interview began with very open questions to allow each participant to describe

their personal experience of bereavement and to feel emotionally comfortable. The researcher then asked specific questions to elicit data that linked the end of life and bereavement, for example 'Are there any factors about the death of the person that you think had an impact on your own experience of bereavement?' Throughout the interview, participants were encouraged to consider the death from their perspective rather than that of the person who died. If participants displayed any distress during the interview, the researcher suggested taking a break or ending the session. In all cases participants were happy to continue and despite many finding the interviews emotionally challenging all participants expressed gratitude for the opportunity to tell their story. Finally, participants were thanked and given contact information for local bereavement support services.

Data Analysis

Data was analysed following the procedure of thematic analysis described by Braun and Clarke (2006). The transcripts were read and re-read by the researcher and initial codes were generated from the whole data set. To identify common features and patterns, each code was reviewed and initial themes, or central organising concepts, were developed. These candidate themes were discussed by both authors and assessed against the full data set to ensure that, when taken together, they told a 'faithful' story of the data. Finally, all formulated themes were given names to provide a succinct and evocative sense of what the theme was about (Braun and Clarke, 2006).

Findings and discussion

Four themes were identified that comprise, from the perspective of a bereaved individual, the elements of the end of life that constitute a good death. These themes are; 'lack of physical distress', 'emotional resolution', 'the right time' and 'naming death as death'. The results of this study suggest that if any one, or more, of these elements is missing, then the experience of bereavement

adjustment can be more difficult for the bereaved individual. A thematic map (see figure 1) visually demonstrates the integrated nature of these themes. Results will be discussed for each theme relative to literature and supported by theories of bereavement.

Theme 1: Lack of Physical Distress

The results of this study, in line with previous research, provide evidence that a 'bad death' is one where bereaved individuals have witnessed physical suffering (Balducci, 2012). For those who witness physical pain or distress there is additionally a negative and potentially long term effect on bereavement. Bereaved individuals describe being unable to let go of the mental image of the death or having their memory of the person who died tainted by the nature of their death.

... but there are certain things that I can't forget, I mean it was thick, black, horrible... certain things that to the day I die I just won't forget.

Worden's task theory (1991) connects the 'mode of death' with the ability of the bereaved individual to make sense of the loss. Where an individual is observed to die in pain and without physical dignity, the bereaved person may find cause for anger either towards themselves or care professionals for not enabling a good death to take place. A negative memory of the death can make it more difficult for individuals to make sense of their loss in bereavement (Neimeyer, 2000). The findings of this study reinforce this impact on bereaved individuals.

Potential physical distress for the dying person includes medical treatments and loss of dignity due to symptoms of the illness. For example, one participant identifies an occasion where, during the period of palliative care, an invasive treatment was given to her close friend;

They had given her one dose of chemo the December before she died it was horrendous she should never have had that because that made her little bit quality of life she had took all of that away.

For this participant the use of a perceived Non Beneficial Treatment (NBT) was associated with a bad death and that as a result grieving for her friend was 'harder' than for other deaths she had experienced.

Interestingly, this study found limited evidence of physical distress during the end of life suggesting that, in most cases, pain management and other physical symptoms were well controlled.

...our local doctor was also very good and so pain wise um it was well controlled... it's funny I had this form from the doctor afterwards what could have been done better and I said the care was fantastic, it was.

In line with these findings, a recent review of good death literature identifies distress from pain as a less significant factor than in earlier research (Cottrell & Duggleby, 2016). This may be a result of changes over time in the most common causes of death from acute conditions to slower chronic illness where symptoms can be more easily managed (Cottrell & Duggleby, 2016). The current study, which included a variety of causes of death, adds support to these findings and suggests other factors, such as advance planning, which may have also improved physical care for patients.

For participants in this study a lack of physical distress was typically attributed to well communicated care plans, including the withdrawal of NBTs prior to death. The results of this study may suggest that care plans are successfully implemented and that, at the time of death, pain and the treatment of other physically distressing symptoms are well managed.

We started to talk to the consultant about where we would go from there because, well he did have a feeding tube in at one point, and he didn't tolerate it well, he made it quite clear that he did not want that again. Em, so basically...we'd keep him comfortable, but they'd not be using a feeding tube, you know we'd allow him salt, water, dextrose and things and obviously the chances were that nature would take its course.

The ability to openly talk about and plan in advance for death supports bereavement by limiting guilt about the nature of death. If, as in the case of this participant, bereaved individuals are able to take a role in forward planning and are clear that they are acting on the wishes of the person who is dying, they are better able to make sense of the death (Neimeyer, 2000). This finding of this theme suggest that where care plans are well communicated and successfully implemented, the treatment of physically distressing symptoms are well managed. This finding resonates with previous studies which show that open forward planning with the use, for example, of Do Not Resuscitate (DNR) orders enables relatives to know prior to the death what is likely to happen and can be predictive of better mental health during bereavement (Garrido & Prigerson, 2014).

It is important to note that despite relatively little data evident in this study concerning physical distress during the end of life, this does not diminish its fundamental importance as an element of a good death from the perspective of a bereaved individual. There is a sense that physical discomfort is only noticed when it is not achieved. In fact, improvements in aspects of physical comfort in palliative care in recent decades may have allowed the opportunity for consideration of a good death to include more psychological, emotional and spiritual elements.

Theme 2: Emotional Resolution

The realisation of emotional resolution, where any outstanding conflicts are resolved before death and there is an opportunity to 'say goodbye' is important for both the person who is dying and the soon to be bereaved person. The emotional resolution of the dying person as well as the emotional support given to the soon to be bereaved person can affect the subsequent bereavement. A good death, in terms of emotional resolution, is one where death is free of emotional distress, and where both those who are dying and soon to be bereaved feel able and ready to 'let go'.

The importance of emotional resolution was seen as an integral part of a good death and of equal importance as physical comfort.

It's spiritual isn't it yeah... it's the resolution of death... so a good death being without pain and without discomfort and without any sort of panic but actually whether someone has resolved themselves... And that for me that makes a good death as well.

Individuals took great comfort following death from the opportunity they had to spend time with their loved one prior to death. For some bereaved people having the time to say goodbye or spend some final hours with the dying person can provide a sense of completeness in their relationship that can support moving forward in bereavement.

...and the most precious thing I've ever done was holding Jill's hand all night all her last night...because obviously it made it all so much better for me that we had spent so much of our lives together and we were together on our last night.

In contrast, not being there at the time of death can leave unanswered questions about the emotional state of the dying person;

As I say I wasn't there and I would have liked to be there and I think that in turn it would have been better for me in the long run because it would save me worrying because you know I sometimes think back and worry what about his last moments like was he frightened?

The dual process model of bereavement (Schut, 1999) suggests that the process of finding balance in bereavement involves an oscillation between loss and restoration orientation, over time looking forward more than looking back. For this participant, with a focus on loss orientation due to a lack of clarity about the emotional state of her father at the time of his death, there is a potential negative impact of a lack of emotional resolution during the end of life.

However, being physically present at the time of death is not seen a determining factor for bereavement adjustment if the bereaved individual is confident that their relative or friend had the death they wanted. When describing the death of her mother, who died alone, a participant suggests a more individualised concept of a good death as 'the right death' for that individual;

Maybe she waited until everything had calmed down and everyone had left the room and went to sleep she didn't look fearful at all... and that's how...exactly how she wanted to go so maybe it was the right death do you know what I mean?

The theme of emotional resolution includes the role of the soon to be bereaved person in the death as well the emotional state of the dying person. Bereaved individuals feel a potentially conflicting pressure to provide support for the emotional needs of the person who is dying, as well as being able to accept emotional help for themselves as they transition into grief. When this is achieved, there is evidence that the resulting lack of regret can support bereavement.

I would always try to be there ... that one did the best one could do obviously that's always helpful 'cos guilt or regret is a really sad thing and if it's there it's there and you have to cope with it but I don't feel I would have done anything differently and that's a really nice thing.

However, when bereaved people feel unable to protect the dying person from emotional distress, even when this would have been impossible, this is carried forward into bereavement in a very personal way.

I know that he didn't have that closure and it took a long time for me to get over the fact that he was probably very sad when he died.

The tasks of mourning are more difficult and longer lasting where guilt about not providing good enough care during the end of life is experienced (Worden , 1991). For participants in this study, the definition of good enough care is explicitly linked to the provision of emotional support alongside physical care.

In addition, bereaved individuals consider resolution of their own relationship with the dying person a benefit to their bereavement and that professional support to enable this, usually in the form of talking therapy, may be useful for them prior to death. However, participants identified a disparity between the support given to the dying person and the support they were offered.

When the person's dying and they're offered counselling and they're offered so much you know even 'til their death so they can have a good death I think more should be done for the family around someone who's dying... I think that would make it a lot easier for everyone... then the family might come to terms with things easier for afterwards.

This finding is supportive of previous studies which suggest that pre-bereavement care may be important for the bereavement outcomes of individuals (Wright et al., 2008). However, there is evidence that individuals close to the dying person, particularly those with a caring responsibility, can be unwilling or unable to consider their own needs as a priority. This can affect their ability to obtain emotional support.

I would have valued more talking therapy and by the time I got to make a phone call that was properly asking for it it was err too late... I never followed it up because it wasn't that important but it would have helped me it would have made it easier and I know there are people who do that so I em anyway it doesn't really matter.

This participant, fully aware of his own needs, was able to request appropriate emotional support but when it was not forthcoming he quickly downgrades his own request for help. It is suggested that the findings of this theme highlight the importance of focussing on the emotional requirements of soon to be bereaved individuals as well as on those of the person who is dying.

For bereaved individuals, a good death leading to a better bereavement is one where emotional resolution is witnessed in the person who is dying, but is also one where they themselves are supported to make their own peace with their loss and with the person who is dying. The importance of professional support for the soon to bereaved person is clearly highlighted in this theme.

Theme 3: 'Naming death as death'

This theme is defined as an open understanding of the knowledge, nature and expectations of the process of the end of life between all the individuals and groups involved; the dying person, their next of kin who often acts as a decision maker, the wider family and friends and any professionals involved in the death. In circumstances where death is anticipated in advance, 'naming death as death' includes an honesty about both the inevitability of death and, as far as possible, what the physicality of what death might look like. Where there is poor communication, or even conflict, between those involved in the death the subsequent bereavement can be more challenging.

A good death for bereaved individuals is one where they, and the dying person, are able to speak openly about the inevitability of death. In circumstances where soon to be bereaved people know that death is imminent but this knowledge is not shared with the dying person problems in bereavement adjustment are identified. One participant was told by doctors that her father was dying, however, despite him being fully conscious and cognitively able; no one in the hospital had discussed his prognosis with him. Following his death, she identifies the impact not sharing his prognosis had on her bereavement;

I think they're the... things that have kind of haunted me em for the two things I did worry about were the fact that in those three days he didn't he clearly didn't realise how poorly he was and whether I was right in not telling him... my great dilemma is whether I take comfort in the fact that he didn't know he was dying or whether a part of me thinks I should have told him, but I didn't.

The knowledge that things may not have happened in a way which met the specific needs of each individual at the time can lead to a sense of guilt and isolation which is linked to a more challenging bereavement (Worden, 1991).

The current study suggests that in terms of supporting a good death family members value honesty, even if this means clinical staff openly stating that they don't know when or how the death is likely to happen. However, this is difficult in a culture where death is increasingly medicalised and death is more usually considered as something to fight against rather than accept (Greenwood, 2015).

Doctors, and other clinical professionals, value open communication in order to support a good death but face a range of barriers in discussing end of life issues with patients and family members, not least that they are not able to accurately predict how death will be for each individual (Periyakoil et al., 2015).

In contrast with a view of preserving life at all costs, when all individuals involved in the end of life are able to 'name death as death' and to understand death as a natural and inevitable life event this contributes to a good death. This in turn reduces anxiety, guilt and fear and can contribute to better bereavement outcomes.

Theme 4: 'The right time'

The timing of death is an area where the needs of the dying person and the bereaved can diverge. A sudden, pain free death can be seen as a good death for the dying person but, for the soon to be bereaved individual, there is no time to resolve psychological or practical matters (Carr, 2003). Evidence suggests, in line with Worden's theory of the tasks of mourning (Worden, 1991), that when death is very sudden bereaved relatives describe a feeling of shock and report the process of bereavement adjustment taking longer and having a greater impact.

The grief does hit you... this was very much [claps hands suddenly] like a railroad, so yes [pause] I suppose it did come as a shock, quite hard to go from one extreme to another.

In contrast, in situations when death is known about in advance, participants in this study suggest that they can benefit from a chance to prepare for their loss and can, in some situations, begin to grieve prior to the death occurring.

Really the grieving for him started the minute he had that stroke. You do still feel the loss but in a much more reflective way.

Niemeyer's theory of benefit finding in bereavement (Neimeyer, 2000) suggests that a traumatic death negatively impacts on bereavement by initially making the death more difficult to process and make sense of. However, participants in this study suggest that a sudden death can affect bereavement in more nuanced, not necessarily negative ways. In the longer term, whilst initially more challenging, a sudden and traumatic death can lead to a deeper level of engagement with the death and, as a result, a more profound, and potentially more positive, identity change (Tedeschi et al., 1998).

In a funny kind of way it's helped me appreciate bereavement more... because I've thought about it more... and it's made me do more with my life I've made decisions and pushed myself out of me comfort zone which I didn't normally do because of that experience.

When the end of life is extended this too has a negative impact on bereavement. Interestingly, a number of participants identified that the length and type of illness prior to death, particularly where the dying person has a minimal quality of life, overshadows other elements of a good death such as the lack of physical distress.

Interviewer: Would you say he had a good death?

Participant: No. I think in the end he did go quite quietly but I mean for the life he had led to get to that point...would you let a cat or dog get to that point? You wouldn't.

Participants suggest a number of negative impacts of an extended end of life. These include physical distress and reduced quality of life for the dying person, and increased trauma and stress for the soon to be bereaved person due to caring and other practical responsibilities. A combination of these negative conditions for the bereaved person during the end of life is identified as having a long-term effect on bereavement.

Maintaining a good quality of life during death is of paramount importance both to the dying person and on the perception of a good death by bereaved relatives. In addition, the findings of the current study suggest a link between patient quality of life before death and bereavement adjustment.

Interviewer: Are there any things you could have changed about the death that would have made your bereavement better?

Participant: I think really had it happened earlier yeah the NHS were too good.

For one participant, appropriate use of medical treatments during the last hours of her mother's life supported emotional resolution for her and other family with no adverse effects;

It was a positive intervention get fluids in get the rehydration back and purely by doing that she was able to see her sister and see her son.

The experience of this participant suggests that the use of non-beneficial treatments (NBTs) in palliative care is further complicated by the potential positive effects of medical interventions during the period of palliative care at the very end of life. The ability to discriminate between supportive treatments and negative interventions is a very complex one but is considered to be a key factor in realising a good death from the point of view of bereaved individuals. Aggressive care has previously been associated with poorer bereavement outcomes (Wright et al., 2008) and this study strongly supports the view that the use of NBTs in order to extend life has a negative impact on bereavement adjustment. For bereaved individuals, a good death is one where unnecessary distress is avoided and life is allowed to end naturally, even if that means death comes sooner.

Conclusion

The results of this study suggest there are four elements which together constitute a good death for bereaved individuals; a minimum of physical distress for the person who is dying, death at the 'right time', the ability to openly 'name death as death' and an emotional resolution prior to death for both the person who is dying and the soon to be bereaved individual. If any of these elements are not present at death, the experience of the participants in this study suggests that bereavement adjustment can be more challenging.

The four themes in this study need not be viewed as isolated concepts but rather as an interconnected explanation of what a good death means to bereaved individuals. However, in each end of life experience these elements will vary according to circumstances and, for individual

bereaved people, each will take different importance. For bereaved people, a key aspect of a good death is to openly accept death as a natural process. Where possible, bereaved relatives can be supported in bereavement by a death where all those who are involved in the end of life (the dying person, professionals involved in the care and the soon to be bereaved individuals) are able to openly acknowledge that death is inevitable. This minimises conflict between individuals and allows advance planning, thereby minimising physical distress. By making the inevitability of death explicit, both the dying person and those close to them would be better able to engage in a process of emotional resolution and have the opportunity to say goodbye. Fear about the physicality of death would be able to be minimised through open communication thus reducing the likelihood of distress and feelings of guilt following the loss. A good death, for bereaved individuals, is one where it is not considered necessary, or in fact desirable, to extend life with the use of NBTs. Openly naming death as death could enable the reduction of such treatments.

Strengths, limitations, implications for practice and future research

The current study, in contrast with the majority of previous research into a good death, has placed the focus on bereaved people. By making connections between the two study areas of end of life care and bereavement, new insights bridging the experience of bereaved individuals both before and after the death have been generated. In addition, a UK based study was valuable as previous similar research in other countries (Bussmann et al., 2013, Witkamp et al., 2015, Lee et al., 2013, Dumont et al., 2008) is potentially limited in a UK context due to different palliative care policies and settings (Ahmedzai et al., 2004).

As participants in the current study were from a culturally homogenous group (all were white, British and the majority were female) future research could include participants from more diverse ethnic, spiritual and cultural groups and could add weight to the development of culturally sensitive support programmes for bereaved individuals. In addition, whilst the circumstances of death were varied for

this participant group, a number of specific death loss situations were not included in this research; for example families with young children who experienced loss or adults who experienced the loss of a child. Future research into the impact of the manner of the death on bereavement of those groups, and its relation to a 'good death' would be valuable. Finally, the use of an opportunity sample may suggest a bias towards those individuals who felt better able to talk openly about death and, as a result, may represent more positive bereavement experiences; the ability to talk and share experiences has been linked to better bereavement outcomes (Chapple et al., 2015). Whilst this does not limit the validity of the individual experiences of participants, a more balanced participant group may potentially yield further insights. The results of this study have potential implications for clinical practice. By providing evidence for the impact of the end of life on longer-term bereavement adjustment, the findings highlight the value of supporting the needs of soon to be bereaved individuals in palliative care settings.

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Table 1. Summary information for each participant

Pseudonym	Age	Gender	Relationship to participant of person who died	Time since death	Cause of death	Place of death	Length of illness preceding death	Age at death
Peter	75	Male	Wife *	3 years 2 months	Cancer	Home	2 months	63
Sue	70	Female	Friend	3 years 7 months	Cancer	Hospital	Undefined	46
Karen	58	Female	Father *	1 year 3 months	Age/Kidney failure	Hospital	One week	89
Heather	45	Female	Father-in-law	2 years 7 months	Age/Stroke	Nursing home	Nine months	93
Anne	47	Female	Mother *	3 years	Age/Heart failure	Hospital	Gradual decline, two days in hospital	78
Rachel	48	Female	Father *	3 years 10 months	Cancer	Nursing home	Six months	76
Holly	49	Female	Mother *	4 years	Alzheimer's/pneumonia	Nursing home	Five years	74
Rebecca	42	Female	Grandmother	2 years 6 months	Pneumonia	Home	Sudden death	87
Carol	40	Female	Father *	11 months	Alzheimer's/chest infection	Nursing home	Sudden illness	78
Tom	61	Male	Father *	1 year 6 months	Dementia/Old age	Nursing home	Undefined	94

* Next of kin

Figure 1: Thematic map showing integrative nature of themes

