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I no longer feel alone': meeting the needs of bereaved grandparents through a children's hospice support group

Item Type	Article
Authors	Tatterton, Michael J.;Lyon, J.A.
Citation	Tatterton MJ and Lyon JA (2020) 'I no longer feel alone': meeting the needs of bereaved grandparents through a children's hospice support group. International Journal of Palliative Nursing. 28(5): 193-201.
DOI	https://doi.org/10.12968/ijpn.2022.28.5.193
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Download date	2026-06-06 02:38:13
Link to Item	http://hdl.handle.net/10454/18216

'I no longer feel alone': meeting the needs of bereaved grandparents through a children's hospice support group

Abstract

Background: Children's hospices provide a range of family-centred care services, including bereavement support. Not all hospices provide specific services for grandparents.

Aim: To explore how a hospice-based bereavement support group supported grandparents in their grief following the death of a grandchild.

Methods: Grandparents attending a group were invited to complete an anonymous questionnaire. Questionnaires from eight groups, run between 2015 and 2019 were collated and interpreted to identify themes.

Findings: 121 grandparents attended the groups; 113 returned the questionnaires (93% response). Three central themes were identified: environment and space, being with people who understand, and the opportunity to hear the stories of others. Grandparents valued hearing the stories of others, providing an opportunity to reflect on the experience of others.

Conclusion: Grandparents felt supported and validated by the group. The facilitated sessions increased coping and resilience of participants, enabling grandparents to support their partner, adult children and surviving grandchildren more effectively.

Key words

children and young people; family centred care; family nursing; grief; palliative care

Key points

- Grandparents are playing an increasing role of families of children with palliative care needs
- Grandparents experience compounded grief, from multigenerational perspectives as both a parent and grandparent
- Bereavement care for grandparents should focus on helping them to explore their experiences and provide opportunities for the sharing of stories between individuals

Reflective questions

- How can you ensure that the model of care you offer meets the needs of family members?
- How do you identify those experiencing disenfranchised grief?
- Does your approach to family-centred care meet the needs of all those who are important to the child or young person?

There are more than 86,000 babies, children and young people (children) in the UK living with life-threatening and life-limiting conditions (Fraser et al. 2020), all of whom can access paediatric palliative care services. Bereavement support is an integral element of children's palliative care (Tatterton and Walshe 2018), which enables families, as well as children themselves, to prepare for and cope with their losses. Children's hospices in the UK have taken various approaches to meeting the bereavement needs of families in their care (Mash and Lloyd-Williams 2006); the degree of emphasis on bereavement support within hospices varies throughout the UK (Wilkinson et al. 2007).

Family centred care

Family centred care is at the core of modern children and young people's nursing, defined by Smith and Coleman (2010: 31) as *'the professional support of the child and family through a process of involvement, participation and partnership underpinned by empowerment and negotiation'*. It is a multifaceted concept that has developed over the last 60 years, evolving within the culture of children's nursing to a point where it has become inextricable from practice (Smith and Coleman 2010). The practice of family centred care has been influenced by factors including changes in society, current government policy, research and development of the theoretical underpinnings of family centred care and the responses of parents and clinicians to family centred care (Smith and Coleman 2010).

Despite contemporary definitions of family centred care and statements which acknowledge the role of grandparents within families by organisations, anecdotally many services are not embracing the broad definition of *'family'* when developing or delivering care services. Like current research, the focus of services for children and families is largely on the needs of sick children and their parents. The result of this is that grandparents, and therefore their needs, remain invisible (Nehari et al. 2007; Coall and Hertwig 2010); anecdotally, this is demonstrated by the lack of dedicated support services available to grandparents of children with life limiting or life threatening conditions (LLTTCs), despite their increasing presence and role within children's hospices.

Grandparents

Grandparents play an important role in many families. Societal changes in Western culture have resulted in an increased presence and demand for grandparents within contemporary family life. Examples include the provision of regular childcare, enabling parents to work, and the provision of financial support. This is amplified in families with children affected by LLLTCs, due to the needs of the sick child, and the consequent needs of the child's parents in meeting those of their child (Corsaro 2014). A number of studies have explored the experience of grandparents, concluding that they often focus on their attention on the needs of others in the family, rather than on their own grief (Fry 1997; Hayslip et al. 2008; Gilrane-McGarry and O'Grady 2012; Tatterton and Walshe 2019). A smaller number of papers describe the dual roles of both parents and grandparents where broader responsibilities are taken for the needs of the whole family, rather than on their ill or deceased grandchild (Youngblut et al. 2010; Tatterton and Walshe 2018). The high expectations placed on grandparents by bereaved parents include being available to provide emotional and practical support, assistance in organising and paying funeral expenses, assisting with care of surviving grandchildren, in addition to other support (Youngblut et al. 2010; Danielsbacka et al. 2011). All of these factors should be taken into account when designing a bereavement services for grandparents.

Bereavement support

Traditionally, bereavement care that follows the death of a child is extended to parents and siblings with very few services offering specialist support to members of the extended family. Research exploring the effects of child death on a family has focused on the experiences of parents and siblings, with little that has examined the perspective of grandparents (Gilrane-McGarry and O'Grady 2011). With the exception of a small number of papers, current understanding of the emotional support needs of grandparents is largely limited to the generalisation of work undertaken with parents, siblings and health workers (Gilrane-McGarry and O'Grady 2012). Often, grandparents are not considered part of the '*bereaved family*' when discussing bereavement (Nehari et al. 2007).

Background

Martin House is a 15-bed hospice with community outreach for children and young people between birth and 25 years in the North of England. Unlike most children's hospices in the UK, Martin House offers bereavement support to the families of children whose deaths resulted from causes other than LLLTCs, including perinatal, sudden and acute deaths, accidents and suicides (Tatterton et al. 2019). For some years, Martin House has provided a bereaved grandparents group. Provision for grandparents has expanded to include more frequent meetings comprising facilitated group sessions, informal 'coffee mornings' and telephone calls to grandparents before and after the death of their grandchild. All those who attend identify as fulfilling a grandparent role, but include great-grandparents, and relatives who are not biological grandparents. Within this paper, the terms '*grandparent*' is used to describe all of those who attend the group, regardless of their relationship.

This paper focuses on the facilitated sessions, attended by between 6 and 23 grandparents per day (mean: 15) between 2015 and 2019. The sessions are run by nursing staff, under the leadership of one of the authors (JL), who has led the grandparents' group since 2015. At the group, grandparents are invited to bring a photograph to share with others, as a lens through which to share their loss. The session starts with an opportunity for grandparents to introduce themselves, followed by opportunities to share their stories. Grandparents are then invited to take part in a creative therapeutic activity, designed to facilitate discussion and share feelings, enabling peer support. Activities have included coloured sand 'feelings' sculptures, bauble decorating and 'mixed emotions' paper chains.

Aim

To explore how a hospice-based bereavement support group for grandparents supported grandparents in their grief following the death of a grandchild.

Method

Grandparents who attended a bereavement support group were invited to complete an anonymous evaluation questionnaire. Questionnaires from eight groups, run between 2015 and 2019 were collated and interpreted to identify themes. The questionnaires comprised a

total of nine questions, designed to explore how the group had helped grandparents to understand and deal with their grief. These included questions around their feelings, how they had been supported and how their grief had changed over time.

Participants

All participants attended the bereaved grandparents' group at the hospice. Grandparents either had a grandchild who was referred to the hospice before death, or referred to the hospice's bereavement service, following death. This includes antenatal referrals. Participants self-identified as fulfilling a grandparenting role but were not restricted to biological grandparents. All grandparents spoke English.

Ethical considerations

Health Research Authority (HRA) approval was sought (IRAS Project ID: 283012), however, it was concluded that HRA approval was not required. Local approval was granted by the hospice. Grandparents were informed in writing and verbally that completion of the questionnaire was voluntary and confidential, and that they could withdraw at any time without providing a reason (Evans et al. 2002). Questionnaires were anonymous; no personal data was collected. Data was stored electronically on an encrypted drive, complying with GDPR regulations (Summers 2018).

Data analysis

Both authors are children's nurses, experienced in the delivery and leadership of family-centred hospice care for children and in providing bereavement support. Both authors analysed the returned questionnaires independently before considering constructs and agreeing the thematic framework. Qualitative thematic analysis was undertaken, which led to the development of themes which contextualised the experience of grandparents. Themes were identified directly from the data and the authors ensured all relevant data was represented in the framework. Figure 1 shows the relationship of the themes, derived from the returned questionnaires.

Findings

121 grandparents attended the groups. A total of 113 questionnaires were analysed (93% return rate), as shown in table 1. Grandparents were bereaved for between two and 14 months; their grandchildren had died from a range of conditions, including life-limiting and life-threatening conditions, acute illnesses, suicide and accidents, and in the perinatal period. The deceased grandchildren were between the ages of birth and 31 years. A total of 21 themes were identified, arranged into three central themes, as shown in figure 1. Relevant quotes are used to illustrate our analysis and to maintain the voice of grandparents throughout.

	Female	Male
Grandparent	71	45
Great grandparent	3	1
Other relationship	1	0
TOTAL	75	46

Table 1: demographics of group attendees

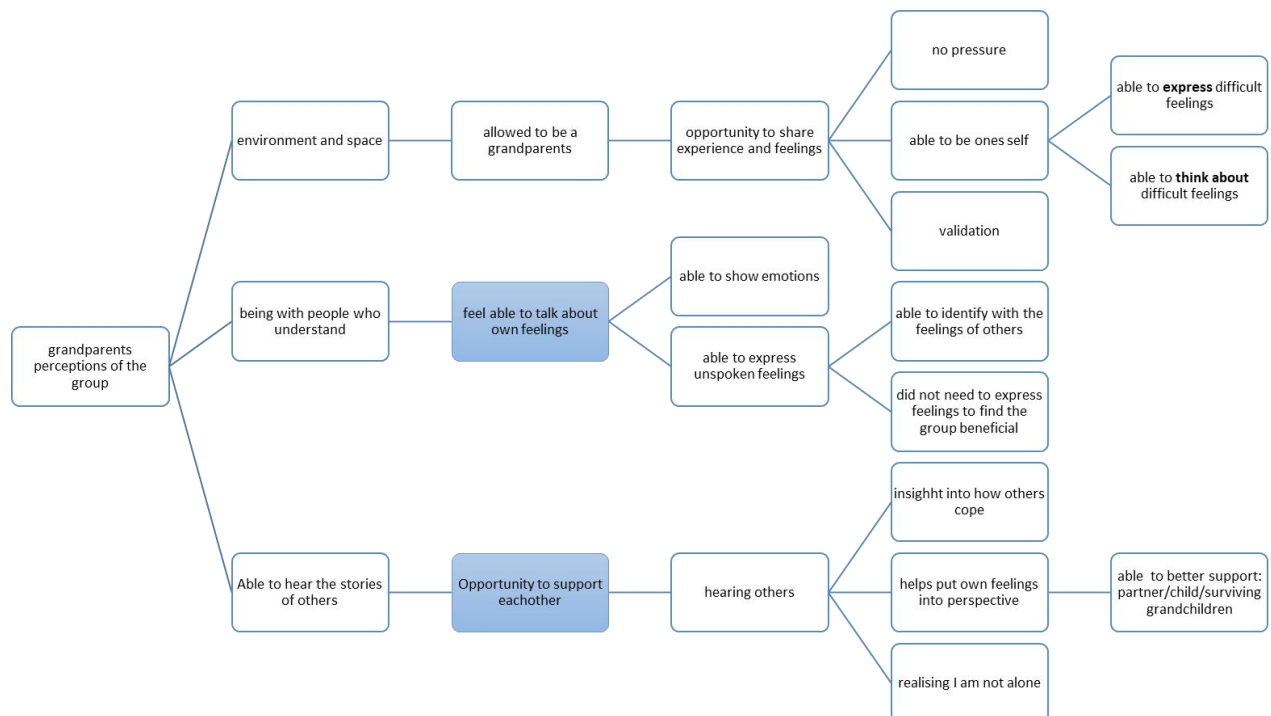


Figure 1: thematic representation of findings

Environment and space

The act of being invited to the group and the recognition of being a bereaved grandparent by the hospice was valued by the grandparents. Grandparents talked about valuing the location of the group, run at the hospice, allowing them to return to, or visit for the first time, the place where their grandchild received palliative care. For some, it connected their grief to their grandchild, allowing them to focus on the loss of their grandchild.

'Thank you for this space. I will now work for more space for myself to reflect on how the balance of my emotions change over time.' (GP49)

'Martin House is a safe place to be honest about my feelings as a grandparent – it was good to be able to talk freely, without feeling self-indulgent.' (GP12)

Grandparents talked about how the group validated their role as a grandparent and their right to grieve, which was often hidden from their support networks. Being able to acknowledge these feelings felt supportive, even when grandparents chose not to share their personal stories of loss with the rest of the group. The freedom to be able to both express and consider difficult feelings was discussed, without the pressure to discuss them either with the facilitators or the rest of the grandparents in attendance.

'I was nervous of being asked to expose the rawness of my emotions. There was no pressure to do this but they emerged anyway – it was very cathartic!' (GP7)

Being with people who understand

Grandparents recurrently described the benefit of being with people who understand their position as a bereaved grandparent, describing both their peers and professionals who were facilitating the groups. Permission to talk about their feelings, which were often hidden from those around them was highlighted, including feeling freedom to express unspoken feelings, and to show emotion. Grandparents talked about the need to protect their adult children, surviving grandchildren and their friends from their grief, by hiding their true feelings in fear of adding to or worsening the grief of those around them.

'I have not had the opportunity to speak to other bereaved grandparents until now.'
(GP81)

'I was able to cry, talk and not be judged.' (GP16)

'It really helped to share my loss with people who have known what the loss of a grandchild feels like.' (GP9)

The group gave grandparents the opportunity to identify with the feelings and experiences of others, lessening feelings of isolation and loneliness described by some participants of the group. Male grandparents in particular talked about the challenges of sharing feelings they perceived as difficult, but also that they did not need to share personal experiences in order to find the group beneficial.

'Being able to say what I felt, knowing that it was accepted and understood by people who had similar feelings really helped.' (GP40)

Able to hear the stories of others

The ability to hear the stories of others was one of the strongest themes identified in the service evaluation. Feelings of isolation were discussed alongside this, and the sense of togetherness of relief was described, with grandparents, often for the first time, understanding that they are not alone in their grief.

'I felt that chatting to others about our loss made us feel like we are not alone – for the first time since [our grandchild] died' (GP57)

'We could see similarities and diversity in our grief.' (GP77)

Grandparents gained much from being able to support each other, providing reassurance and validation to the feelings and experiences of their peers. The feeling of being useful to their peer group added to their sense of personal validation.

'a chance to hear and possibly help others who understand what I've been through' (GP38)

Though attending the group, grandparents gained insight into how others coped with the death of a grandchild, discussing coping strategies to manage senses of loss and changes within their families.

Attending the group helped grandparents to understand that they are not alone in their loss or the way in which they have dealt with it. Grandparents talked about how hearing the

stories of others enabled them to put their experiences into perspective, due to an increased awareness of the experience of others, and insight into how they have managed their experiences and feelings. This in turn helped grandparents to feel better able to support those in their family, including partners, their children and surviving grandchildren.

'Talking to other grandparents, knowing we share a common. It was great to pick up ways of supporting my daughter and son-in-law.' (GP14)

A recurrent finding from the feedback was the value of being able to share experiences and feelings within the group, and the ability to support other grandparents to do the same. The linking of these two central themes is illustrated in the below quote.

'for me, it was about sharing experiences and help each other. Grandparents together.' (GP93)

Discussion

This paper explored the benefits of a hospice-based support group for bereaved grandparents, from the perspective of those grandparents that attended the group. It is clear, both from this study, and from research published to date that grandparent grief is complicated by a number of factors, not least the multigenerational positions grandparents hold within families (Stelle et al. 2010; Tatterton and Walshe 2018), cumulative pain (Gilrane-McGarry and O'Grady 2012) and disenfranchisement (Tatterton and Walshe 2019). In summary, the perceived benefits of the grandparent group can be conceptualised into three central themes: the environment in which the group was offered to grandparents was important, connecting the grandparent with memories of care their grandchild received. Having protected space in which their role as a grandparent was recognised and in which they felt supported and validated. Being with people who understood their experience as a grandparent was important, and for most, provided their first opportunity to meet with other bereaved grandparents, strengthening identity and increasing solidarity. Finally, hearing the stories of others was valued, instilling a sense of togetherness and providing grandparents with an opportunity to reflect on the experience of others.

The findings suggest that validation of role is at the core of success of the group. The benefits of being able to share personal stories, combined with the ability to support others who are doing the same, resulted in the validation of their experience, as a grandparent, and their usefulness as an individual, shown in figure 2. The notion of personal value is discussed both in published literature (Moore and Rosenthal 2017; Tatterton and Walshe 2019) and by those taking part in this evaluation. This is made more complicated by the multiple roles held by grandparents (Hughes et al. 2007; Frisman et al. 2012; Whitbeck et al. 2013) within a family through which they oscillate (Tatterton and Walshe 2019), and their experience of disenfranchisement from their family and social support networks.

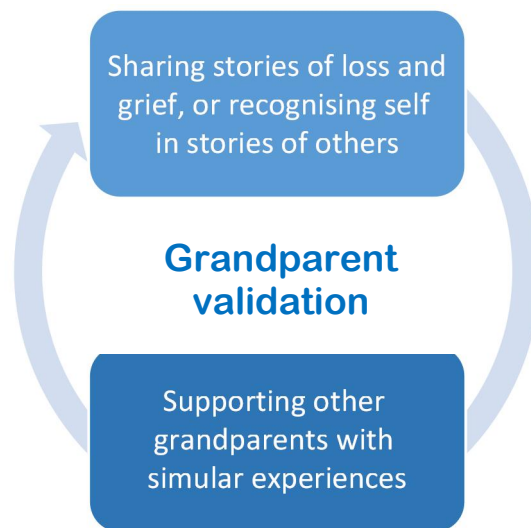


Figure 2: key benefit of the group, perceived by grandparents

Role oscillation (Tatterton and Walshe 2019) between parenting and grandparenting roles was highlighted. The group gave grandparents the opportunity to recognise their own grief connecting their experience of loss with their grandchild and exploring the impact of bearing witness to the experiences of others and recognising the impact of compounded grief. None of these phenomena are exclusive to grandparents, however, the amalgamation of these elements of grief *'create a footprint of grief that is unique to grandparents'* (Tatterton and Walshe 2019:122). In addition to these emotional responses to grief, Youngblut et al. (2010) report that between 59 and 64 percent of grandparents experience physical symptoms of grief following the death of a grandchild, most commonly sleep disturbances, but also physical pain, restlessness, altered appetite and breathing difficulties.

Our findings suggests that supporting grandparents though groups such as this one can help grandparents work through grief, strengthening coping and resilience.

The protective environment created by the group allowed these feelings to be explored at an individually appropriate pace, using various methods as a means to enable grandparents to tell their stories. Artefacts, predominantly photographs, were used by some as a lens, where others preferred to simply tell their story. This supports findings from other published studies on grandparental grief (O’Leary et al. 2011; Gilrane-McGarry and O’Grady 2012; Palmer and Yuen 2020). Some individuals found it easier to articulate their experiences of loss and the associated feelings whilst engaged in a physical activity, correlating with published findings (Palmer and Yuen 2020). It is suggested that grandmothers are find it easier and more necessary to talk about their experience of loss than grandfathers (Youngblut et al. 2010) and that grandparents suppress their grief in order to protect their adult children (Fry 1997).

Disenfranchisement, or experiencing grief that is not recognised by others, is discussed widely in the available literature (Dias et al. 2017; Kirby et al. 2018) and by grandparents in this paper. This can be due to grandparents being reluctant to burden friends and wider family members with their personal grief (Moules et al. 2012; Murphy and Jones 2014), often in an effort to protect others (Moules et al. 2012). Grandparents report similar outcomes (Hayslip et al. 2008; Gilrane-McGarry and O’Grady 2011) when reducing social interactions and engagements with others as they focus their time and attention on the needs of their child and grandchild (Tatterton and Walshe 2018). Both of these scenarios reduce the availability of social support, increasing disenfranchisement within their family and friendship networks. This disenfranchisement is characterised by feelings of isolation, insufficient emotional support and empathy from social support networks and poor understanding from those who they would normally seek support (Grinstead et al. 2003). Grandparents involved in this service evaluation suggested that the opportunity to come together and meet their peers in facilitated groups reduced this, enabling grandparents to meet their peers and to increase their social support network.

Conclusion

Dedicated, bereavement care for grandparents provided grandparents with a safe space in which to explore their experiences alongside others who had faced similar losses. Grandparents felt supported by the group, strengthening their individual identity and creating a sense of togetherness. Participants were validated, both by feeling able to share their stories with others they felt understood their experiences, and in their ability to support others who had experienced the death of a grandchild, regardless of whether or not the cause of death was similar to that of their own grandchild.

Bereavement support services for grandparents need to recognise the impact of the multigenerational perspectives taken by grandparents and address the experiences of progressive losses associated with children who required palliative care, bearing witness to the grief of family members and the compounding effect that these have on individual grandparents. The grandparent group led to grandparents recognising their own experiences, developing coping strategies, which led to increased resilience, allowing grandparents to support their partners, children and surviving grandchildren more effectively.

Limitations

Although this service evaluation has provided novel insight into how targeted bereavement support for grandparents meets the needs of those who attend, it is not without its limitations. The evaluation was conducted in one hospice, and although findings have been discussed alongside published literature, the narrow perspective of this paper is acknowledged. Secondly, with the exception of the children that died shortly before or during birth, it could be argued that the grandparents felt some loyalty towards the hospice, and therefore evaluated the bereavement support favourably.

Implications for practice

The findings of this paper support the development of grandparent-specific bereavement support that offers grandparents opportunities to explore their own experiences of grief and loss and to hear those of other grandparents. The value of peer support was clear – children’s palliative care services should strive to facilitate opportunities for grandparents to meet others, broadening their support network, strengthening identity and reducing the sense of isolation.

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