Meeting unmet need?

An initial evaluation of a groupwork approach to supporting children who are bereaved

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***Abstract**: Support for children experiencing bereavement varies considerably across the UK depending on organisational values and resources, the specific population and the individual expertise and experience of professionals. This paper describes a groupwork approach to meeting the needs of this population. It was developed by a hospice in central Scotland in response to a lack of formal support identified by both professionals and families within the community. It uses the Seasons for Growth loss and change education programme as a method of groupwork intervention. The paper discusses the initial evaluation of the groupwork service from when it was established in September 2007 to January 2010. It outlines the background to setting up the service, the sources and reasons for referral and the evaluation process and findings. Implications for group intervention with children who are bereaved are discussed in the conclusion.*

***Keywords**: children; peer support; bereavement groups; loss; seasons for growth; groupwork*

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Introduction

Bereavement is a universal experience. In the UK, 78% of children, by the age of 16, have experienced the death of a second degree relative or close friend (Harrison and Harrington, 2001). Four to seven percent of these children will have experienced the death of a parent (Ribbens McCarthy, 2006). While most people will experience the death of someone important at some point in their lives, bereavement is a subjective experience, mediated through specific factors that surround an individual's life. Although most children experiencing bereavement go on to lead 'normal' and productive lives (Monroe et al, 2008) it is undoubtedly a challenging and confusing time, compounded by wider cognitive, emotional and social aspects that influence understanding of loss and grief reactions (Rowling, 2003). Coupled with other external factors, such as gender, class, family functioning, parental ability, support prior to and after the death, the type of death and the experience of additional losses, the experience of bereavement can place children at increased risk of negative outcomes (see Ribbens McCarthy, 2006; Green et al, 2005; Black, 1998; Worden, 1996; Kiernan, 1992; Harrison and Harrington, 2011). Services that support children through bereavement are an important area of service provision (CBN, 2011). They can assist in normalising grief reactions, reducing isolation and creating opportunities for alternative coping strategies (Smith, 1999). Bereavement services are, however, patchy across the UK and there is currently an eclectic approach to service delivery, with the majority of services developing according to the individual expertise of the workers (Stirling, 2010).

This paper reports on the findings of an initial evaluation of a groupwork approach to bereavement support that was developed due to a lack of service provision in this area. It discusses the background to setting up the service, including the reasons for using a groupwork approach, the use of the Seasons for Growth groupwork programme, the process and findings of evaluation. It identifies a need for services providing bereavement support and suggests that groupwork can be a useful mode of service delivery. It highlights some of the strengths and weaknesses of this approach and discusses implications for service development.

Background: Intervention choice and literature

The Hospice has offered a bereavement support service since it opened in 1981. This has primarily consisted of one-to-one support using person-centred counselling skills of trained staff and volunteers. The service operates at full capacity and, although offered to children, has been utilized primarily by adults. There was an increased recognition from workers that the needs of children were possibly not being met. This was due to the 'invisibility' of children in the current service and recognition that there were no additional bereavement services for children in the area, other than specialist mental health services and some schools offering support. Discussions were therefore held with stakeholders, various funding options were explored and secured and a staff member was hired to take forward a bereavement service specifically for children.

A UK survey of bereavement services identified a variety of methods currently employed to support bereaved children (Rolls and Payne, 2003). This includes individual work, individual family work, family groupwork, groupwork with children, information and advice provision, resource provision, training, outreach and drop-in (ibid). The majority of services were located in the voluntary sector, with more than one method of support frequently offered (ibid). Evidence of the effectiveness of these different models of intervention mostly consists of narrative and anecdotal accounts, with empirically based quantitative investigations less common (Norris Huss and Ritchie, 2001). Despite a lack of empirical evidence however, groupwork has become an increasingly common area of service provision, involving a range of groupwork approaches such as open and closed groups, day and residential programmes and online chat rooms (Chowns, 2008). The literature identifies the principal reasons for choosing groupwork approaches in this field. These reasons include its potential to:

- help alleviate feelings of isolation by providing 'opportunities for sharing common experiences with others' (Norris Huss and Ritchie, 2001, p.187);
- offer a safe place where children can practise skills such as expressing feelings and talking about the deceased (Geldard and Geldard, 2008);

- provide opportunities to learn about and normalize both grief reactions and methods of coping from peers (Smith, 1999; Geldard and Geldard, 2008);
- build an individual's sense of self esteem by empowering children to interact positively and talk freely together about personal issues (Geldard and Geldard, 2008; Kitchener and Pennells, 1990);
- and its ability to support a greater number of children at one particular time therefore being less resource dependent and more financially viable. (Worden, 1996).

The literature offers little on the challenges of this groupwork, perhaps due to a lack of attention being directed at identifying unwanted effects (Curtis and Newman, 2001). One significant challenge, however, is attempting to meet individual need within a group setting and the subsequent effect this has on keeping a group within planned timescales (Kitchener and Pennells, 1990). Such challenges may account for why services often offer a range of service provision rather than a 'one service fits all approach'.

In this project, groupwork was chosen as the primary method of service delivery, with some one-to-one work offered to children whose needs would not be met in a group. 'Seasons for Growth' (SFG) loss and change group education programme was chosen as a framework to deliver the service. SFG originated in Australia and is based on Worden's (2009) four tasks of mourning that include:

1. To accept the reality of the loss
2. To experience the pain of grief
3. To adjust to the environment in which the deceased is missing
4. To emotionally relocate the person and move on with life.

These tasks have been modified for work in 'an education setting as distinct from a clinical setting' (SFG,1996, p.5) and are combined with the seasons, which are used as a symbolic framework to describe how loss and change are part of life. Through a variety of activities, including journaling, crafts, story-telling, games and so on, the programme aims to give participants opportunities to 'integrate, at his/her developmental level, the appropriate knowledge, skills and attitudes to understand and to cope with change, loss and grief […] in an atmosphere of like-to-like peer support' (SFG,1996, p.4). This particular model was selected for several reasons. These include its educational goal (teaching children 6-18 about loss and change), its specific learning outcomes (in line with the group's remit to develop skills that aid grieving), its short-term nature (8 weekly sessions), specific boundaries around time commitment allowing management within available organizational resources and a short (2 day) training period for staff and volunteer that minimizes time and cost.

The initial idea of the service was to offer support to children only. On further consideration, however, it was accepted that children do not exist in isolation but rather as part of a wider familial, social and cultural context. If parents are not adapting to the loss, any work with children may not be beneficial (Worden, 1996). It was therefore decided that the service would also provide an opportunity for parents/carers to attend an adult group. The latter uses both group therapy and psycho-educational group approaches (Geldard and Geldard, 2008) which incorporate SFG materials. All referrals to the service require the child's consent. Moreover, referrals would be allowed from anyone in the community in an attempt to meet both hospice and the wider community need. The groups run for eight sessions, in line with the SFG programme, followed by one celebration session. Children and their parents/carers arrive simultaneously and spend a short time together, with light refreshments available. They are then separated into a child group and an adult group, which last for approximately one hour. Participants are requested to attend all sessions, in order to gain maximum benefit from the programme while also maintaining group dynamics. If a participant misses two consecutive sessions they are asked to join another group. Each group is facilitated by a trained staff member and a trained volunteer.

Evaluative methodology

In order to better understand the demand for bereavement support for children within the local community, data were collated at the point of referral on: the child's gender; their relationship to the deceased; the type of bereavement they had experienced; reasons for referral; and who made the referral. A formative evaluation was then carried out of the groupwork programme, using a participant-oriented approach (Trochim, 2006). This was done in line with both hospice audit procedures and SFG programme requirements, as a form of continuous monitoring, to assist in improving delivery (Blaikie, 2010). All groupwork participants were asked to complete an evaluation. The evaluation forms for children were supplied by SFG in 5 different variations designed to be developmentally appropriate (ages 6-8, 8-10, 11-12, 13-15 and 16-18). A parent/carer evaluation form was designed by the service coordinator. Each evaluation form included a series of questions that directly related to the learning aims of the programme as well as generating information on both positive and negative experiences in the group. Participants were asked initially to indicate their level of agreement by answering 'yes', 'no' or 'maybe', to statements such as 'It's normal for things in life to change' and 'I can take care of my feelings'. They were then invited to complete a series of open questions, such as 'I learned'. 'I liked' and 'I didn't like'. Adults were also asked to comment on the benefits of the group for their child. All evaluations were anonymous.

The findings below describe both the type and level of demand for the service and the data collated as part of the evaluation procedure.

Findings

Referrals to service

Since the service started in September 2007 until January 2010, 144 children were referred for bereavement support. Of the 144 children referred, 120 (83%) were referred for groupwork, 10 (7%) for one-to-one work and 14 (10%) for both. 35% of those referred were boys and 65% girls, ranging from age four to eighteen. Children were referred primarily by their parent/carer (32%) or a social worker (27%). Referrals were also made by GP's (12%), Education staff (11%), Child and Adolescent Mental Health Service (5%), Hospice staff (7%), Health Visitor (5%) and one self-referral (1%). The majority of children were referred due to the death of a parent (54%) followed by the death of a grandparent (29%). Other deaths included siblings, extended family members or friends. Forty-four percent of the children had experienced bereavement through cancer, 24% sudden death (e.g., heart attacks, murder, accidents or suicide), 7% of referrals had experienced both and 16% of the referrers did not indicate how the person had died. The time since the bereavement and initial referral varied from one day to eight years, with a mode of 6 – 12 months. Referrals were mainly due to concerns that the children were struggling to manage their grief appropriately and this was manifesting in a variety of negative behaviours, such as increased aggression; alcohol abuse; thieving; difficulties sleeping; not eating; withdrawal; somatic complaints; self-harm; and school non-attendance.

Participation and response rates

Of the 134 children referred to a group, 86 (64%) attended the whole eight week programme. Reasons given (by all but 14) for not attending or completing the group were:

- Support no longer needed (15)
- Group not an appropriate resource (5)
- Unavailable at the time of the group (6)
- Other (such as getting support elsewhere, missing multiple sessions, or noting they had only agreed to the referral to please the referrer) (8)

Sixty-two (46%) of the children attending the group were accompanied by parents/carers who participated in the adult group. Response rates for evaluation was 74 (86%) from children and 54 (87%) from adults.

Evaluation of groupwork: Observed outcomes

All the evaluation forms were analysed using headings developed to capture the same core themes: strengths of the group experience, challenges and learning.

Strengths: Children

The evaluation forms identified a wide range of areas that the children regarded as a positive aspect of the group. These are listed in Figure 1, with some participants listing more than one activity. Meeting new people/making friends was clearly the most popular reason, identified by 34% of participants of whom 5% emphasized meeting new friends who had also experienced bereavement. The activities completed within each group session were the second most popular aspect, with some children specifically stating those activities they found most helpful. For example, one participant found that '*having the journal really helped as I am the sort of person who likes to write down how I am feeling, I feel it really helps*' (girl, aged 15). Talking was the best thing about the group according to 15 participants. This mostly related to talking about both their feelings and the deceased. Other aspects mentioned included the food and drink provided, the way the programme linked with the seasons, feeling better in general, and the whole experience.

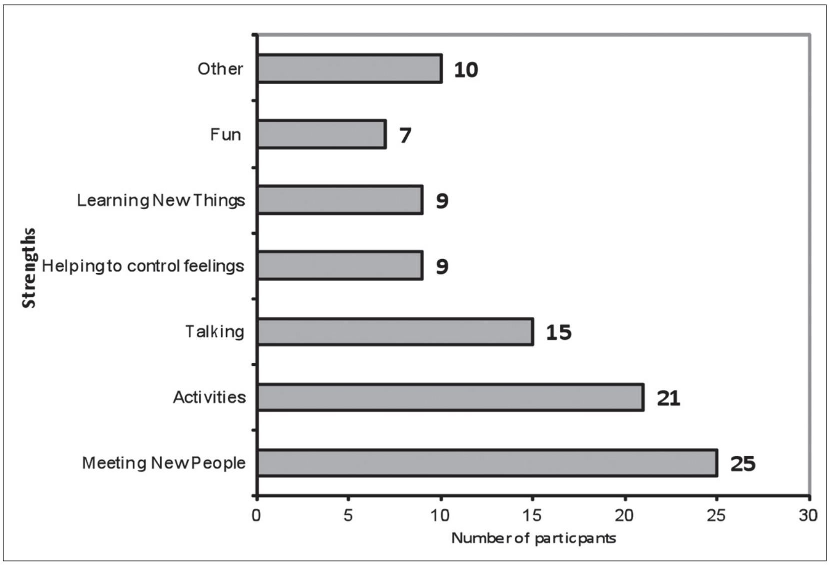

Figure 1: Aspects of group most appreciated by children (n = 74)

Strengths: Adults

Similarly, evaluations from adult participants noted a wide range of responses in relation to the best aspect of the bereavement group, as listed in Figure 2. Comparable to findings from the children's evaluations, meeting new people in a similar situation was identified as an enjoyable aspect of the programme by one-third. The group facilitation methods were also important for adult participants. 39 (72%) noted the skills of staff in creating a safe, welcoming and non-judgmental space; *'[I enjoyed] meeting people who had similar incident and the way it was handled in a friendly and open atmosphere'* (adult participant). Other specific aspects noted were the continuity and gender balance of staff, feeling listened to, providing food and the programme structure.

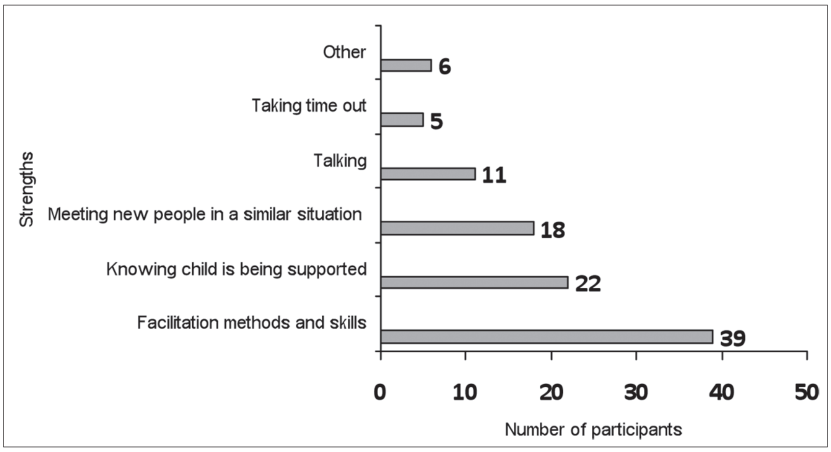

Figure 2: Aspects of group most appreciated by adults (n = 54)

The child participants, however, were seen as central in determining the adults' experience of their own group. Knowing that their child was being supported was clearly important for the parents/carers, identified in 40% of the evaluations. 'Other' best aspects of the adult groups included: being able to understand emotions better; following a specific programme; and getting advice on how to support their own child.

Challenges: Children

Throughout the children's evaluations five dislikes and/or challenges emerged. The most common was around talking within a group setting. This was raised by 9 participants in relation to both starting a group with new people and sharing their bereavement story. For example, '*talking about the loss and coming when I didn't know anyone*' (girl A, age 16) and '*actually telling my story because I hadn't told many people*' (girl B, aged 16). Concerns about managing feelings within a group setting was raised by 2 participants, while other challenges included wanting more time for games (2), ''*having a sore pain*' (girl, age 10) and worrying about being liked by other participants (1).

Challenges: Adults

For parents/carers, challenges related to both themselves and their child. Adults had initial concerns about attending and about the group support format. 20% stated that they did not feel adequately prepared prior to attending the group, stemming from either a misconception about the group or personal anxiety such as being '*in too much of a state to prepare – could not handle the death or guilt*' (adult participant). Half the adult participants noted these initial worries about attending soon dissipated, but 43% found it difficult to open up and share thoughts and feelings about the loss within a group setting. Nearly a quarter of adults noted their anxiety in relation to how their children might react to the bereavement focus of the group. These concerns centred on whether the group would heighten and/or rekindle their child's grief, as well as how their child would react in a group setting, particularly in terms of their ability to share feelings.

Learning: Children

84% of child participants found they had learned better ways to cope with feelings of grief and loss. 82% acknowledged the reality of change and loss in their life. Participants aged nine and over (n = 52) were also asked to comment on their most important learning from the group. As shown in Figure 3, 54% of them identified managing feelings connected to loss and grief as their most significant learning. Answers included: '*You don't have to cry there is other ideas to do'* (boy, age 11); '*It's okay to be sad*' (girl, age 10); '*To be with someone when you are upset*' (boy, age 11); and '*Learning it's okay to laugh and have fun even though the person you loved the most is gone*' (girl, aged 15). Talking about feelings and learning about other people's experiences was also significant, such as learning '*that other people share the same feelings and I'm not alone*' (girl, age 16).

Continuing to learn was also an area that was addressed. Learning more about feelings was identified by seven child participants as something they would like to achieve in the future, with anger, in particular, being raised by two participants. Learning about death in general was mentioned by two participants and two participants mentioned they would just '*like to learn more about life*' (girl, aged 12). Two participants said they would like to learn more about how to talk about bereavement with other people and one said they would like to learn more about how to help other people.

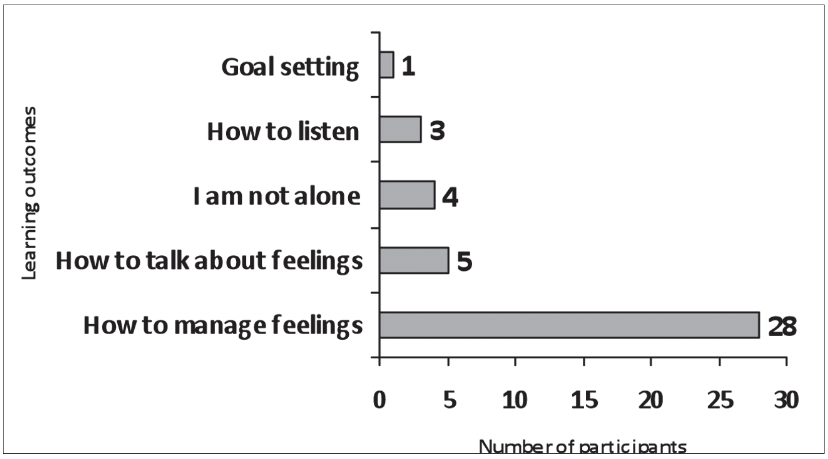

Figure 3: Most important learning identified by children (n = 52)

Learning: Adults

The adult discussed learning outcomes in relation to themselves and observations of their child. Nearly all the adults stated that they felt more confident and hopeful about the future, as well as more able to identify their feelings and reactions to change and loss. 94% said they were able to explore better ways of coping when difficult things happen. Meeting others in a similar situation ('realizing I am not the only one') was an important area of learning for 22% of adult participants. In a similar vein the most meaningful learning for ten adults was having their feelings and reactions 'normalized' by other participants and/or by the group programme.

Six participants identified developing approaches to best support their child as an area of learning. This included not judging particular reactions (2), feeling more confident to talk to children honestly about the deceased (3) or about family problems (2), and to prioritize their child's needs regardless of other people's views (1). One participant also identified they had learned that their child was able to talk with people about the bereavement, something of which they were previously unsure. 80% of parent/carers viewed the children's programme as either good or excellent in assisting their child to understand and cope with the effects of change and loss. Figure 4 shows children's learning observed by adults. Awareness that they are not alone in experiencing bereavement (31%) and an understanding of grief reactions (19%) were identified by the majority of parents as the biggest areas of learning in their child. 'Other' areas of learning observed were understanding the permanency of death and being able to work in a group.

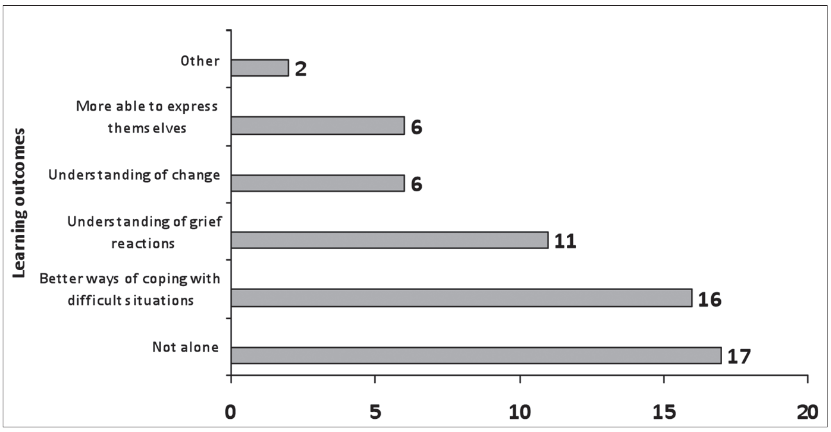

Figure 4: Parent/carers' observations of their children's learning (n = 54)

Discussion

The above findings raise a number of issues around the provision of a groupwork bereavement service. The data indicate that there was an average of five referrals received each month, which does not take into account advice calls received about children that were not later referred. This amount of referrals is considerable, given that the service was new and not fully known or established within the community. It confirms the need for bereavement support to be available, as highlighted in the literature (Rowling, 2003; Ribbens McCarthy, 2006).

Despite the level of referrals for groupwork there was a 36% dropout rate, which raises questions about the appropriateness of the intervention. Only 8% of those who did not participate and/or complete a programme opted for alternative support, while 31% said that they did not attend as they felt they no longer needed support. It is unknown if participants felt that support was unnecessary at initial referral, or if this was due to the passage of time between being contacted and the group intervention. This finding opens up debate around the referral process, appropriateness of the referral, expertise of the referrer in identifying bereavement support needs and timing of the intervention. Levy's (2004) survey found that only 7% of calls to a bereavement service resulted in a formal referral for bereavement support. Such findings echo a need to develop approaches of support and assessment that 'discern who requires intervention to 'normalise grieving' [...] who require more specialist interventions' (Stirling, 2010, p.33), and who does not need any intervention. The level of drop out also has considerable implications on staff resources in terms of time spent responding to referrals and organising groups, amidst already busy workloads.

Despite the child focus of all initial referrals, less than half the adults completing the programme identified getting support for their child as an important part of their experience. Similarly, 43% of adult participants were more concerned about themselves attending and receiving group support than their child (24%). Literature on children's bereavement asserts that understanding the experience of death in children's lives requires looking at the beliefs and behaviours of the adults who surround them as well as the wider society (Silverman, 2000; Rowling, 2003; Worden, 1996). Children are often viewed as a neglected and problematic group with regards to talking about death owing to their status as 'child' and potential vulnerability (Wass, 2004; Jackson and Colwell, 2001). Thus, adults may avoid addressing bereavement with their child, as managing their own grief may limit their potential to harness and provide appropriate support (Melvin and Lukeman, 2000). This underlines the need to involve families in bereavement assessment, so that any intervention is appropriate to the needs of the child within his or her own familial and social context (Silverman, 2000).

It appears that the main benefits of the group approach was the learning achieved as part of the programme. Both child (84%) and adult (94%) participants felt they had learned better ways of coping and over half of child participants identified learning about feelings as important This suggests that participants were unfamiliar with both feelings connected with grief and ways to manage and cope with them. It also relates to the wider agenda for encouraging and assisting individuals in viewing death, loss and grief as a normal part of life that can be talked about and supported in the community (Department of Health, 2008; Scottish Government, 2011). Although such learning might have been achieved through one-to-one support, it would have been impossible within available staff resources to reach as many children over such a period of time. Furthermore, over 30% of both children and adults highlighted meeting new people and hearing others' experiences as important and enjoyable. This indicates that, despite initial concerns round talking about the bereavement and managing emotion within a group, both children and adult participants identified that the group itself, specifically meeting new people and hearing others' experiences, was important and enjoyable. This finding echoes discussion on the benefits of groupwork in providing a sense of belonging where people do not feel alone (Geldard and Geldard, 2001; Kitchener and Pennells, 1990). It also draws attention to the extent of preparation work that is needed in terms of encouraging participants to try something they feel initially anxious about but may ultimately benefit from.

A number of methodological challenges accompany evaluation of bereavement services, including relatively small sample sizes, the varied situations surrounding the death, existing support mechanisms in place, and the child's personal development (Curtis and Newman, 2001; Norris Huss and Ritchie, 2001; Stokes, 1997). Such factors pose limitations on the data gathered and suggest the need for further evaluation. Nevertheless, these findings provide useful data on the need for support amongst bereaved children, as well as an initial evaluation of a groupwork response and implications for the future development of the service. Based on that evaluation, a number of changes have already begun to take place within the current bereavement service. These include the refinement of assessment criteria and processes, increased family work, emphasis placed on education in the community around the bereavement needs of children, and developing further evaluation tools. It is hoped that this paper has highlighted some of the strengths and weaknesses in a groupwork approach to bereavement support as well as the need for bereavement services for children and their families that involves appropriate assessment and holistic support.

References

Black, D. (1998) Bereavement in Childhood. *British Medical Journal,* 316, 931-933

Blaikie, N. (2010) *Designing social research: The logic of anticipation (Second edition)* Cambridge and Malden: Polity Press

Childhood Bereavement Network (2011) {Accessed 18 July 2011 at www.childhoodbereavementnetwork.co.uk]

Chowns, G. (2008) 'No, you don't know how we feel': Groupwork with children facing parental loss'. *Groupwork,* 18, 1, 14-37

Curtis, K. and Newman, T. (2001) Community-based support services for bereaved children in Child Care. *Health and Development*, 27, 6, 487-495

Department of Health (2008) *End of Life Care Strategy - promoting high quality care for adults at the end of life.* London: Department of Health

Geldard, K. and Geldard, D. (2008) *Counselling Children: A Practical Introduction.* London: Sage

Green, H., McGinnity, A., Meltzer, H., Ford, T. and Goodman, R. (2005) *The Mental Health of Children and Young People in Great Britain 2004.* London: Office of National Statistics

Harrison, L. and Harrington, R. (2001) Adolescents' bereavement experiences. Prevalence, association with depressive symptoms, and use of services. *Journal of Adolescence,* 24, 2, 159-69

Kiernan, K. (1992) The impact of family disruption in childhood and transitions made in young adult life. *Population Studies,* 51, 213-34

Kitchener, S. and Pennells, M. (1990) A Bereavement Group for Children. *Bereavement Care,* 9, 3, 30-31

Levy, J. (2004) Unseen support for bereaved families. *Bereavement Care,* 24, 2, 25 - 27

Melvin, D. and Lukeman, D. (2000) Bereavement: A Framework for those Working with Children. *Clinical Child Psychology Psychiatry,* 5, 4, 521 - 539

Monroe, B., Hansford, P., Payne, M. and Sykes, N. (2007) St Christopher's and the future. *The Journal of Death and Dying*, 56, 1, 63-75

Norris Huss, S. and Ritchie, M. (1999) Effectiveness of a group for parentally bereaved children. *The Journal for Specialists in Group Work*, 24, 2, 186-196

Ribbens McCarthy, J. (2006) *Young People's Experiences of Loss and Bereavement: towards an interdisciplinary approach*. Maidenhead and New York: Open University Press

Rolls, L. and Payne, S. (2003) Childhood bereavement services: a survey of UK provision. *Palliative Medicine,* 17, 423-432

Rowling, L. (2003) *Grief in School Communities, Effective Support Strategies*. Buckingham: Open University Press

Scottish Government (2008) *Living and Dying Well: A national action plan for palliative and end of life care in Scotland*. Edinburgh: Scottish Government

Seasons for Growth (1996) *Companion Manual Level 5*. Sydney: The Mary MacKillop Foundation

Smith, S. (1999) *The Forgotten Mourners; Guidelines for Working with Bereaved Children*, *(Second Edition)*. London: Jessica Kingsley

Silverman, P. (2000) *Never too young to know: death in children's lives*. New York and Oxford: Oxford University Press

Stirling, I. (2010) The influence of research in the development of a bereavement support service. *Scottish Journal of Healthcare and Chaplaincy,* 23, 1, 32-36

Stokes, J., Wyer, S. and Crossley, D. (1997) The challenge of evaluating a child bereavement programme. *Palliative Medicine*, 11, 179-190

Trochim, W. (2006) *The research methods knowledge base (second edition)*. {Accessed 17 May 2012 at http://www.socialresearchmethods.net/kb/]

Worden, J. W. (1996) *Children and Grief: when a parent dies*. New York: Guildford

Worden, J. W. (2009) *Grief Counseling and Grief Therapy: A Handbook (4th ed.)*. New York: Springer