

A Study of the Therapeutic Journey of Children who have been Bereaved

Executive Summary

Research Team

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Introduction

This report describes the research study entitled *A Study of the Therapeutic Journey of Children who have been Bereaved*. This study was conducted by a research team based in Dublin City University and University College Dublin in conjunction with the Barnardos Bereavement Counselling for Children (BBCC) service.

What the literature says

The literature suggests that bereaved children may experience psychological problems, behavioural and somatic problems, problems in school performance and peer relationships. In some cases children may experience traumatic bereavement. This may follow the loss of a loved one in traumatic circumstances, or may follow death from natural causes if the young person's experience of the death is traumatic (Cohen et al., 2002). While the majority of studies report the negative consequences of bereavement, some studies report that children show resilience in the face of bereavement (e.g. Raveis, Siegel & Karus, 1999). The negative outcomes of bereavement in childhood may be temporary and coping with bereavement may result in positive changes, especially increased maturity (e.g. Balk, 1990).

Many factors influence children's bereavement reactions and how they adjust to the death of a loved one, such as age, type of death, communication in the family. Some research has found that certain age groups are more likely to have problems adjusting to their bereavement (e.g. Raveis, Siegel & Karus, 1999; Bowlby, 1980). Children's reaction to bereavement depends on their understanding of irreversibility, causality and finality. This develops over time. In terms of type of death, children may have problems adjusting when the death is sudden or unexpected (Kranzler et al., 1990), but also when the death is expected (Worden & Silverman, 1992). Many factors that impact a child's adjustment are related to the family, for example open communication between the child and parent (Raveis, Siegel & Karus, 1999; Saler & Skolnick, 1992). Furthermore, many studies highlight the role of the surviving parent or caregiver in helping children to adjust to their loss (Christ, 2000).

Children may be referred to a formal intervention to help them adjust to the death of a loved one for several reasons, such as emotional and behavioural difficulties or their parent's inability to cope with their grief. Therapeutic interventions that are used for children who have been bereaved include family therapy, bereavement groups and individual counselling therapy (Webb, 2002). In a

counselling setting with children, verbal counselling is often used in conjunction with other strategies, such as play therapy and art therapy. There are a number of family therapy based models for bereavement therapy; however, there are few individual psychotherapeutic models that are specifically used with young people who have been bereaved. Research on the effectiveness of bereavement services for children show mixed findings. There is little literature on individual counselling for children who are bereaved and no formal studies of therapeutic interventions for children who are bereaved in Ireland. In terms of general child psychotherapy research, limitations include the narrow focus of research (Kazdin, 2002). Research that focuses on the method of treatment or the outcomes of treatment may not account for the many variables e.g. child, family, parent characteristics, that may influence outcome. Most research does not question the processes involved in counselling and psychotherapy, or why it may be beneficial.

Purpose of the study

The aim of the present study was to gain an understanding of the nature and role of counselling for children who are bereaved. The objectives included: to explore children's experience of bereavement while engaging with bereavement counselling; to identify any changes in self-reported psychosocial wellbeing and coping evident during the course of engagement with bereavement counselling; to explore the wider family context of this experience through children's and parents reports; to explore children's experience of the process of counselling and counsellors' perceptions of the process of counselling.

Methodology

The study employed a complex research design that draws on multiple informants using both quantitative and qualitative components. There were two phases to the research study. The first phase was based on data collection from children and their parents at several different time points, including initial referral (T0), the start of counselling (T1) three months from the start of counselling (T2) and six months after the start of counselling (T3). Both quantitative instruments and qualitative interviews were used. The second phase involved data collection from counsellors who work with children who are bereaved in one-off qualitative interviews.

Overall, 37 families referred to the Dublin Barnardos service and 16 families referred to the Cork Barnardos service were invited to participate in the research. Six families participated in the research. The participants comprised of seven parents and eight children. The children ranged from age 9 to 15 years and comprised of two girls and six boys. All of the participants in the second phase

of the research were counsellors and psychotherapists who worked individually with children who are bereaved. In total, seven counsellors were interviewed. Four interviews were conducted with counsellors from Barnardos. One of the counsellors from Barnardos had left the organisation at the time of interview. One counsellor from the Irish Association for Counselling and Psychotherapy (IACP) was interviewed and two further counsellors were identified through other counsellors.

Main findings

For each period of data collection, the data were analysed to examine scores from the quantitative scales and to identify key themes from transcripts. This provides a profile of each time period. For the quantitative data means and ranges for all measures were computed for each time point. The quantitative data gathered from scales used in the interviews with young people and parents at each time point raised a range of issues. The first is the extent to which parents and children rate the same concepts differently. There is a consistent pattern of differences in both ratings from the Strengths and Difficulties Questionnaire¹ (SDQ) and communication. However the direction of the difference is not consistent. Parents, at least until the six month point, consistently report more negative ratings on the SDQ but better ratings of communication than children. However it is also the case that the trends in the quantitative might suggest positive change overtime. By the six month time point both groups are reporting SDQ scores in the normal to borderline range. However this is not the same across all scales, with the scores on the Impact of Events scale and subscales remaining high. A possible interpretation of this is that, while the stresses of the bereavement and associated changes remain, the expression of this as internalising and externalising behaviours is decreasing, perhaps as the family responds and adapt to the associated challenges.

The analysis of the qualitative data highlighted main topics and themes. In the children's and parents' interviews, the main topics that were explored at each time period included the death, the impact of the death/bereavement, coping and support, views of the counselling intervention, and the role of context. The topic of death included themes such as the nature of death, the type of death, and the length of time since the death of the family member. Impact of death/bereavement included themes pertaining to bereavement reactions (child and family), changes in daily life and, communication. The topic coping and support encompassed themes relating to who helped children

¹ The SDQ measures pro-social behaviour and psychopathology spread over 5 dimensions: hyperactivity, emotional symptoms, conduct problems, peer problems, and pro-social behaviour. It is suitable for use with children aged between 4 and 16 years (Goodman, 2001). Each child's total and sub-test SDQ scores are compared against the cut-off scores established for the measure. There are cut-off scores for normal, borderline or abnormal; the higher the score the more problematic the behaviour.

cope, difficulty coping and asking for help. In terms of views of the counselling intervention, themes included children's understanding of the intervention and their expectations and experience of it. From parents' perspectives, the themes related to the counselling service: expectations of the counselling, experience of the counselling, most helpful aspect of the counselling, reasons for referral and sources of referral. The topic of context was compiled of the themes of circumstances other than the initial bereavement which may have affected the young person. Themes that emerged from the interviews with children included repeating a class in school, bullying, getting in trouble in school, a child minder leaving and multiple deaths.

The analysis of the data from the interviews with counsellors highlighted a range of topics that were relevant to the aims of the study. In terms of the bereavement reactions of children, counsellors described the individuality of the experience of grief and bereavement, behavioural reactions, psychological reactions, communication, the delay in reactions and the resilience of children. They discussed many issues related to the counselling, for example: the reasons for referral, processes involved in counselling at the start and at the end of counselling, children's understanding of counselling, activities involved in counselling and their own approach to counselling. In relation to factors that impact children's grief, counsellors described factors related to parents and family and the nature of death among other things.

Overall, the findings illustrate several key patterns. The individuality of the impact of bereavement and the individuality of the experience of counselling is clear. The context in which the child is experiencing the loss of their loved one was highlighted by parents and children in terms of other factors that the child was experiencing at the same time. These factors may impact their experience of counselling e.g. a child experiencing multiple bereavements, difficulties in school and other stressors that the child or family were experiencing may have affected their perception of the impact of counselling. However, in thinking about this context it is important to remember that the service being examined focuses on the child who has been bereaved and is attending the service. Given the potential of the context to impact on the counselling process it may be necessary to reflect on the extent to which such focussed intervention can compensate for the influence of other contextual issues.

The child's knowledge about the nature of the death improved over time. In most cases the children were aware of how the person had died. However, it appeared that during the initial

interviews the participants did not always have this information, or indeed, that they had a vague idea. At later interviews, participants had a clearer knowledge of how the person died. In cases where children did not know how the person died, parents expressed that they did not know what to tell them. This was an area in which they wanted guidance from the counsellor.

In terms of bereavement reactions, many reactions reported reflect those identified in the literature. Children had very different reactions to the deaths. Two areas where the difference was obvious were school performance and social relationships. In some cases, children and parents reported no change in school performance, while others experienced a marked deterioration in school performance. In terms of friendships, again some children reported no difference with their friends, while others reported a change. The individuality of reactions supports the concept of individual counselling based on the needs of the child.

Communication was a key feature of the findings. In relation to ability to talk about the person who died, children's ability seemed to improve over time. Also, in relation to general communication within the family, both children and parents reported barriers to communication. One common barrier to communication was a reluctance of children to upset or concern their parent or other family members. The children were aware of the grief that their parents and family were experiencing. In the case of parents, some were unsure of what to tell their child about the death, which affected how they talked to them. In some cases, however, children reported good open communication with parents.

Coping and support was central to the present study. While it was difficult to separate the two concepts, some interesting data was gathered in terms of who helped people cope. Again, there was variation in terms of help-seeking, with some children finding it easy and others difficult. Most children reported turning to their parents for support. Some also relied on other family members, such as siblings, aunts and uncles. Several children mentioned that it was harder to talk to friends. It is worth noting that while children described factors that made it harder to communicate with their parents, they still primarily reported that it was their parents that they talked to the most. In terms of parent's support, most reported getting support from within the family and from friends. In terms of external support and getting support for their children, most participants reported difficulty. Issues such as a lack of awareness of where to look for help and of the Barnardos service

were mentioned by parents. Both parents and children reported who they turned to for support over time.

The concept of change over time was investigated and findings suggest that some factors had improved while the child was attending counselling, such as behaviour and school performance.

Themes that emerged in relation to the impact of the bereavement on daily life, the endurance of some bereavement reactions and children's descriptions of what happens in counselling.

Conclusions and recommendations

While there is depth in the findings of the present study, there are some limitations to be considered when interpreting the findings. The number of participants in the study does not reflect the number of children who use the counselling service each year, or the number who were invited to participate. There may have been issues with the recruitment of participants due to the complexity of the protocol for participant recruitment within the service. Furthermore, there may be an unwillingness of families who have experienced the death of a family member to participate in research.

The study provided an insight into Barnardos Bereavement Counselling for Children service. Throughout numerous issues have been flagged including, for example, the impact of losing someone close on children's well-being, the individuality of the bereavement experience, the role of contextual factors, the value of counselling and children's perceptions of the process involved in counselling. These issues and others have been distilled to produce the following recommendations:

- Children and their families experience marked distress following the death of someone close. Children benefit from an opportunity that allows them to voice their story in a supportive and understanding environment. In the midst of limited overall services in the Irish context, BBCC provides a dedicated intervention that facilitates this.
- Whilst there are commonalities in children's bereavement experience, there are also individual and unique aspects to that experience. This study also highlighted the extra challenges for children who have experienced multiple deaths and the loss of close family members. A major strength of BBCC is the fact that it is tailored to respond to the child on a one-to one basis and therefore equipped to deal with their specific needs.

- There are differences between what parents report about their child's well-being and what children themselves report. This highlights the importance of BBCC being sensitive to discrepancies and of continuing to place children at the centre of their service whilst remaining family friendly.
- Recognising the fact that BBCC is a voluntary service with a primary focus on children, this study noted the benefits associated with parents also receiving support through other services, for example, personal counselling and statutory services. This highlights the need to consider comprehensive family bereavement support as a more encompassing approach to respond to the challenge and distress associated with bereavement.
- Children's bereavement experience affects multiple contexts within their lives. While BBCC is sensitive to and works with the child's family context, there is also scope for the service to be developed so that there is a link with children's other significant contexts, most notably their school context.
- While BBCC consider it important that there is a period of time between the death and the child commencing counselling in order to facilitate the child's preparedness to engage, parents considered it would be preferable for their child to attend counselling in the earlier stages of grief. This discrepancy warrants attention.
- Children's reports of what counselling involved, for example, *activities*, such as talking about the person who died, *processes* such as working with feelings and the *impact*, for example feeling better about the death provide useful information that could be shared with potential users of BBCC so that they have an understanding of what is involved in a counselling service.
- Recognising the limitations of this research, there is need for a structured outcome evaluation of BBCC, as had been originally envisaged, to more clearly assess the impact that counselling has for bereaved children and their families. However, the complexity and challenges of undertaking this type of evaluation in the context of the current service needs to be considered with particular attention paid to the family circumstances of those engaging with the service.

In conclusion, despite limitations, this study has been instrumental in providing an insight into the role and value of counselling, in the form of BBCC in helping to meet the needs of children who have been bereaved. These issues and others have contributed to the formulation of above recommendations regarding the provision of services for children who have been bereaved including recommendations for the ongoing development of BBCC.