

## Childhood Bereavement: A case based discussion and review of existing research evidence on the effectiveness and shortcomings of current bereavement services in the UK

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### Introduction

The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS 1997) has defined psychosocial care as concerned with the psychological and emotional wellbeing of the patient and their family/carers. This includes issues of self-esteem, insight into adaptation to illness and its consequences, communication, social functioning and relationships. Subsequently, a 'social care component' was re-emphasised by the NCHSPCS (2000) and by Hearn F, et al. (2008). As an integral aspect of holistic care, the delivery of psychosocial care cannot be separated from other forms of care and staff of all disciplines routinely provide level 1 (NICE Supportive & Palliative Care Guidance 2004) psychosocial support by active listening, acknowledging their needs and appropriate referrals. Therefore, good psychosocial care depends upon effective teamwork.

Bereavement can be referred to as the state of loss, and grief is the reaction to that loss. Grief may result in shock, emotional blunting, withdrawal, sadness, despair, disbelief, anxiety, and loneliness. Bereavement, a normal part of life for all, carries varying degree of risk when limited support is available. A case based discussion is taken for this assignment.

### Case Scenario

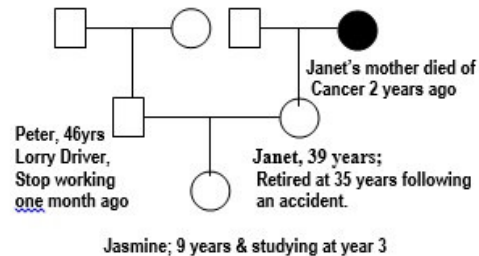
Mr Peter S, 46 years of age, was diagnosed with advanced cancer a week ago, and with no further active treatment offered was transferred to the hospice for supportive care.

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He has been living at home with his wife Janet, and they have been married for twenty years. Both were aware of the diagnosis, the poor prognosis and they were in shock. Jasmine was nine years old and much closer to Peter. Janet was using a frame for mobility after an accident.

Figure 1: Family Tree of Mr Peter



Following the hospice admission, Peter expressed his wish to die at home. Although Janet would like to fulfil his wish, she was unable to talk to him about dying, express her difficulty in looking after him and fear of telling her daughter, Jasmine about her father's terminal stage.

A consultant from the hospice team spoke to them together about his end-stage disease, which in turn helped them talk about unfinished business, funeral arrangements and Janet's new role in the family. The hospice counsellor saw Jasmine and gently introduced the facts about Peter's terminal stage. Jasmine found it very hard to accept, initially showing anger on her facial expression and then becoming quiet. Jasmine's school was informed about her father's terminal illness and their support was requested in terms of dealing with any disclosure and asked to approach the school nurse if needed or the hospice team. The social worker organised social services benefits for Janet including childcare benefits in case needed. Being a Roman Catholic, Peter wanted to get the sacrament of the

sacrament of the sick from his priest and this was also arranged. Urgent referral was made to the 'fast track discharge team' and their assessment done the next day. Essential equipment for end of life care at home was organised through the social service loan-store. The community health palliative care nursing team was contacted to prepare for end of life care at home. Although Peter's condition deteriorated further before discharge, as per his wishes he was sent home with essential medications. Unfortunately Peter died in the ambulance on the way home. He was brought back to the hospice. Jasmine sat with Peter, supported by the hospice staff and later, she managed to attend his funeral. After some months, Janet volunteered to work in a hospice shop and Jasmine started taking piano lessons 'for Peter'.

### The Psycho-social issues in this scenario

Recent diagnosis of advanced cancer, discussion of no further treatment and rapid deterioration to terminal phase were reported as major psychological distresses to this man and his family. The psychosocial impact that could have impacted Janet were feelings of loss, isolation or demoralisation, fear, anxiety, deep sadness, uncertainty, and unpredictability, insecurity, permanent changes to the pattern of her life, changes of family role, social and financial handicap and concerns about her daughter's close attachment with Peter. Bereavement risks were high with her long term marital relationship, inability to fulfil her husband's wish to die at home. Jasmine was much closer to her father than her mother. The depth of the relationship was clear from Jasmine's discussions with the hospice team. Jasmine's bereavement risks were as high as Janet's, and her age complicates her ability to handle grief. To understand and interpret child bereavement, author undertook a comprehensive review of literature.

### Literature Search

A comprehensive literature review was undertaken. The key words were constructed includes: 'child bereavement', the author included child, children, childhood bereavement, bereave\* grief and grief\*, bereavement intervention, therapy, support, counselling and therapy. Keyword searches were done via NHS healthcare databases. Human studies and articles published in English on child bereavement were included. After the duplications removed, all

abstracts electronically reviewed and relevant full 33 articles obtained. Supplemented hand search for articles in the key journals and 7 articles obtained.

### Search results:

The current 'child bereavement' work broadly studied under the following areas:

1. Bereaved children's needs
2. Age specific bereavement and immediate and long term psychosocial impact
3. Communication with bereaved children
4. Interventions / Models of service provisions / Effectiveness of the current bereavement services

### Age Specific grief and Psycho-social impact

Black, D (1998) described, "Children's understanding of death seems related to age". Gibbons, MB (1992) found that categorising the children by age is helpful to understand the way in which children deal with the conceptualisation of death. Hindmarch (2000) stated that age of the child often predicts the nature of the grieving process and the age can be used to determine how the child processes death. The work by Piaget J (1953, cited in Stuber ML, et al. 2001) and Bowlby (1969, 1973, 1980 cited by Smith, SC 1999) emphasises the age-specific grief process. The recent paper by Chirst GH, and Chirst AE (2006) proposed giving age-specific recommendations to parents to help their children during the terminal stage and after death.

Many studies highlights that children experience bereavement as intense sadness, behavioural disturbance and depressive symptoms in the early phases (Silverman PR and Worden JW. 1992; Worden JW 1996; Siegel K, et al, 1996). Dowdney, L (2000) believes that one in five bereaved children is likely to develop a psychiatric disorder, and that these children still expressed grief, distress, and non-specific emotional / behavioural symptoms twelve months after their loss. Silverman, PR and Worden JW (1992) studied children who had lost a parent two years earlier, and found significantly low self-esteem in comparison to their non-bereaved peer group. Sweeting H, et al. (1998) in a study of 1000 girls who had experienced the death of a parent in their childhood, showed that 40% became pregnant

before the age of 18, while 47% of children losing a parent have tried drugs.

### **Bereaved Children's Needs**

The process of bereavement in children varies from 'absence of grief' to symptoms of anxiety and conduct disturbances (Cheifetz PN, et al 1989). Lloyd-Williams et al. (1998) concluded that bereaved children consult their GPs more frequently, both before and following the death of a sick parent.

Interestingly, a recent systematic review from Osborn T (2007) suggests that children and adolescents do not generally experience elevated levels of serious psychosocial difficulties compared to reference groups, but they are at a slightly increased risk for internalising problems. Adolescent daughters appear to be the most negatively affected group.

Beale EA, et al (2004) investigated 28 children and their parents with terminal cancer. These children and their parents were interviewed, together and separately. Their results showed that the children displayed significant distress but greater understanding of their parents' illness than usually expected and timely intervention helped these children's early grief process. They suggested further research needed on larger sample, to quantify the level of distress and the long-term impact in the children.

Fristad MA, et al (1993) studied a group of children whose parents had died eight weeks before. 38 children from stable families compared to 38 depressed in-patients and 19 normal children. School behaviour, interest in schooling, peer involvement, peer enjoyment and self-esteem were studied and they were found to be similar in bereaved and normal children. As a group, children from stable families did not show significant acute psychosocial dysfunction. A similar study conducted two years after parental death by Cerel J, Fristad MA, et al (2006) looked at 360 bereaved children with the age of 6 to 17 years and their surviving parents who were interviewed periodically (4 times) in these two years. It is found that the parental death increased psychiatric problems in the first two years. Children with higher socio-economic status and less depressed surviving parents displayed better results.

A one year prospective study with 105 (2-17 years old) bereaved children conducted by Van

Eerdewegh MM, et al (1982) recorded children's reactions one month and thirteen months after parental death through a structured interview with the surviving parent. The results revealed a significant rise in dysphoria which then disappeared with time ( $P < 0.0001$ ), significant poor performance at school ( $P < 0.0001$ ), an increase in bedwetting ( $P < 0.03$ ) and a persistence of minor forms of depression ( $P < 0.03$ ). No major behavioural or psychological problems were reported nor any general health issues with these children. These results contradict several other studies.

In relation to Jasmine, her psychological needs were gently explored by the hospice counsellor, supported by her caring mother and other hospice professionals. Appropriate help was acquired from school. Her grief was constructively invested in learning piano for her father and this 'continuing bond' keeps her proud. Jasmine understood 'death' and showed appropriate feelings of 'grief cycle'.

### **Open communication of death of a parent**

A systematic review by Osborn T (2007) expressed that appropriate child / adolescent psycho-social functioning is consistently associated with open communication within the family. Stuber ML, et al. (2001) believes that withholding the 'parental death' information is not protective to the young child and prevents appropriate support. The children emphasised the importance of open communication with parents about the disease and death and they found it helps them during the bereavement period (Chirst GH, et al 2005 and Raveis V, et al 1999)

### **Models of current service provision**

Three models of intervention were proposed by the well-known Harvard Child Bereavement Study (Silverman, PR and Worden, WJ 1992; Worden, WJ 1996):

1. Provide intervention to selected children who display behavioural problems or emotions.
2. Provide intervention to those children identified as at risk
3. Provide intervention routinely to all bereaved children and their families

The first two models are cost effective but there are difficulties in establishing reliable assessment criteria to provide the service. MacPherson C, et al. (2007) believes that difficulties in assessment criteria may be complicated by the Dual Process Model of grief. She argues that if the child shows restorative activities (e.g. playing, doing homework) during the period of assessment, one may erroneously consider that the child 'not at risk' and therefore the first two models are not helpful.

The UK bereavement services have adopted the third model of the Harvard Child Bereavement Study proposals and intervention is mainly provided by charities / voluntary sectors. Child bereavement services are well-established in certain counties in the UK. Winston's Wish was established in Gloucestershire and promotes the psychological wellbeing of young children after bereavement. 'Face-to-face support' and 'weekend camps' are provided as a local service. Notre Dame Centre, founded in 1931 in Glasgow has a range of supports, and the St. Christopher's candle project has been offering child bereavement service for over thirty years.

Primary care and oncology teams make most referrals to palliative care, and families can contact the palliative care service themselves at any time after referral. A counselling and support service is available for all patients and their families via the specialist palliative care team, and information both printed and verbal is emphasised from the first interaction. The service aim is to facilitate communication within the family, prepare them for the terminal stage and continue to support them during the early years of bereavement.

**Effectiveness of the current bereavement services and shortcomings**

Wilkinson S, et al (2007) investigated twenty-five purposefully selected surviving parents' experiences and perceptions of child-bereavement services in seven UK hospices. The results revealed that the children and their surviving parents are clearly benefited by the hospice service, both supporting the children while they grieved and advising on ameliorating behavioural difficulties at home and school.

Despite this, there are frequent shortcomings within existing services:

1. Services are not open to every bereaved child or family in the geographical area and need referrals from other agencies or professionals
2. Financial constraints limit services, which are mainly run by charities.
3. Inadequate bereavement services with increasing volume of demand
4. Poor co-ordination among the existing psychosocial network (teachers, carers, parents, GPs and counsellors)

Online and telephone bereavement support services by 'Childline', 'NHS 24 Breathing Space', 'RD4U' and 'Winston's wish', while a growing area, are not yet available to every child.

<b>Role of the community health team and the Specialist Palliative Care team in parent education</b>
<ol style="list-style-type: none"> <li>1. Child age-specific emotions and understandings,</li> <li>2. Open communication about 'death', 'dying' and the ill parent's current state</li> <li>3. Withholding bad news from children causes more harm than good.</li> <li>4. Allowing the child to process things in their own way, supporting them and helping them to say 'good bye' to the dying parent</li> <li>5. After the death, viewing the parent's body and attending the funeral</li> <li>6. Assistance from the school such as protected time for talking with a supportive teacher</li> <li>7. Asking for help if the surviving parent is overwhelmed with loss and unable to spend time with their child, because the quality of the relationship between the surviving parent and their child appears to be the most powerful factor in the outcome of child bereavement.</li> </ol>

**Theoretical models of Grief process in relation to Jasmine**

According to Sheldon F (1997), grief begins with the awareness of the loved one's impending death. Worden W (1991) acknowledged that the 'tasks' of grief can begin during this anticipatory period. In the above case of Jasmine, the patient and family's anticipatory grief was demonstrated by psycho-social

and spiritual distresses. According to Warden W (1991), the bereavement work with the family started while Peter was in the hospice, through accepting the reality of loss by repeated discussions, using clear 'death' or 'dying' phrases and talking about funeral and rituals. The concept of psychosocial transition from Parkes C M (1972) can also be considered in this scenario. When the expectations and assumptions about the future were invalidated by Peter's diagnosis, his family as a unit needed to make adjustments and transitions which were painful and took time and energy. They had gone through the 'mourning phases' of emotional numbness, yearning, disorganisation or despair and reorganisation both before and after his death.

Jasmine's grief cycle was typical of Kübler-Ross, E (1969) and was explained by her initial denial, anger, bargaining with the hospice team for various options, subsequent silence and later viewing the deceased and her participation at Peter's funeral. Fox SS (1985) described that discussion of the permanent separation of the deceased is crucial to a child's healthy psychological development, and in the hospice team helped Jasmine with talking through this inescapable fact. Bowlby's attachment theory and loss

(1969, 1973 & 1980) cannot be considered with Jasmine because when her affectional bond was broken, she protested it but she continued to remember him rather than forget him. Taking piano lessons for 'dad' by Jasmine explains the 'continuing bond' described by Klass D et al. (1996). This new understanding of grief keeps a place for the deceased to the bereaved children and maintains a connection to the loved ones within their ongoing lives. In Jasmine's life, every time she hears, sees or plays the piano she will remember her vital relationship and this will acquire a specific meaning in her life.

### Conclusion

Evidences in this study suggests that childhood bereavement may lead as a major risk factor for psychiatric disorder in childhood or in adult life if handled in an age-appropriate way. Further research is needed to establish the long term effects of childhood bereavement, including different ethnic groups to look at the cultural diversity of responses. Cross-agency work or better co-ordinating the existing services are important to future bereavement service development for children.

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