



# The long-term impact of early parental death: lessons from a narrative study

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## DECLARATIONS

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None declared

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### Ethical approval

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### Guarantor

MLW is the overall guarantor

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All authors contributed equally

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## Summary

**Objective** To explore the individual experiences of those who had experienced the death of a parent(s) before the age of 18, and investigate how such experiences were perceived to impact on adult life.

**Design** An exploratory qualitative design using written ( $n = 5$ ) and oral ( $n = 28$ ) narratives and narrative analysis was adopted to explore the experiences 33 adults (7 men and 26 women) who had experienced parental death during childhood.

**Setting** UK

**Participants** Individuals living in the North West of England who had lost a parent(s) before the age of 18.

**Main outcome measures** Views of adults bereaved of a parent before the age of 18 of impact of parental loss in adult life.

**Results** While individual experiences of bereavement in childhood were unique and context bound, the narratives were organized around three common themes: disruptions and continuity, the role of social networks and affiliations and communication and the extent to which these dynamics mediated the bereavement experience and the subsequent impact on adult life. Specifically they illustrate how discontinuity (or continuity that does not meet the child's needs), a lack of appropriate social support for both the child and surviving parent and a failure to provide clear and honest information at appropriate time points relevant to the child's level of understanding was perceived to have a negative impact in adulthood with regards to trust, relationships, self-esteem, feeling of self-worth loneliness and isolation and the ability to express feelings. A model is suggested for identifying and supporting those that may be more vulnerable to less favourable outcomes in adult life.

**Conclusions** The findings suggest that if the negative consequences are to be minimized it is crucial that guidelines for 'best practice' that recognize the complex nature of the bereavement experience are followed.

## Introduction

The death of a parent is always traumatic<sup>1</sup> and in UK 5% of children are bereaved of a parent before age of 16.<sup>2</sup> Estimates suggest that over 24,000 children and young adults people experience the death of a parent each year in the UK<sup>3</sup> but data may be underinflated.<sup>4</sup>

The likelihood of experiencing parental death varies by locality and social circumstances.<sup>5</sup> Ethnicity, class and material circumstances have received little attention<sup>6</sup> in this area. Minority ethnic groups may experience loss through experiences of migrations, disadvantage and racism, which may increase their vulnerability when dealing with parental loss<sup>7</sup> and variations in mortality rate according to ethnic group are not well understood in the UK.<sup>8</sup>

Studies have revealed many negative outcomes associated with childhood bereavement, e.g. an increased likelihood of substance abuse,<sup>9</sup> greater vulnerability to depression,<sup>10,11</sup> higher risk of criminal behaviour,<sup>12</sup> school underachievement<sup>13,14</sup> and lower employment rates.<sup>2</sup>

Many interrelating risks and factors mediate or moderate children's experiences<sup>15,16</sup> these include factors relating to child (such as their prior experiences of loss, and coping style), their family and social relationships (including relationship with the person who has died), their wider environment and culture, and the circumstances of the death.<sup>15,16</sup>

There is little data on the long-term outcomes,<sup>17</sup> although a quantitative analysis of the 1970 birth cohort<sup>2</sup> suggests that there may be some longer-term impact, particularly for women, on outcomes at age 30 such as qualifications, employment, symptoms of depression or being a smoker. Furthermore, although there were qualitative studies identified there was little (if any) which sought to explore how the informants themselves might construct the significance of bereavement experiences in the context of individual life stories.

Given this gap in knowledge we aimed to explore through a narrative approach the individual experiences of those who had experienced the death of a parent(s) before and age of 18, and investigate how such experiences were perceived to impact on adult life.

## Methods

A qualitative narrative approach was adopted for this study. Qualitative research that is framed by a narrative approach affords the opportunity to hear the participants own words.<sup>18</sup> Therefore, this approach appears to be uniquely well suited to exploring the underlying meaning and evolving and complex nature of the experiences of early parental death, loss and grief. Purposive sampling was used to achieve maximum variation with regards to sociodemographic characteristics in order to identify core/central experiences.

## Data generation

With approval from the University of Liverpool ethics committee, we invited those who had lost a parent before the age of 18 to participate in the study via information dissemination in forms of posters press releases and radio interviews. In order to protect participants who may have been particularly vulnerable those who had lost a parent within the previous 12 months were excluded from the study. Interested respondents were sent a pack which provided information about the study before consenting to take part.

Participants could choose to write their experiences in the absence of the researcher or take part in depth narrative interview<sup>19</sup> (face to face or by telephone) with the researcher in a setting of their choice and typically interviews lasted between one and two hours.

Based on the assumption that people do not relate stories haphazardly the decision about where to begin the narrative suggests enduring personal concerns.<sup>20</sup> Thus, the narrative was elicited by simply asking the question 'Can you tell me how the death of your parent has affected your life? And participants were encouraged to find their own starting point.

When there was uncertainty the researcher offered a prompt.<sup>21</sup> After reflecting on what the participant had said the researcher sometimes asked supplementary questions designed to obtain clarification, such as 'why do you think that is?', or could you give me an example of that?' or 'how did it make you feel? The same method of eliciting the narrative was used in

information for people providing written narratives as those that had elected to have an interview.

### Data analysis

Oral narratives were recorded and transcribed and returned to the participants for verification, if the participant had consented to this. For anonymity each participant chose a pseudonym. Following Murray's<sup>19</sup> recommendations data analysis was divided into two broad phases – the descriptive phase and the interpretive phase. A thorough reading and re-reading of the transcribed and written narratives proceeded both phases, in order to familiarize with structure and content of the narrative. A short profile of each account was constructed to allow each account to 'speak for itself', before fully engaging in the analytic process. Such a reconstructive activity serves to preserve the integrity and emphasizes the uniqueness of each participant's experience and helps to dispel the resistance to the more deconstructive process of cross-sectional analysis.<sup>21</sup> Each story was then interrogated to determine how it was emplotted (i.e. how the informants organized and evaluated their stories, around what sets of issues, actors, events, the language used, etc.) and compared with establish what the individual stories have in common and where they diverged around specific social or cultural circumstances and variation in meaning for individuals. The thematic framework was applied to all transcripts and revised accordingly to illustrate similarities and difference in the experience of participants. Regular meetings took place throughout the study to discuss the emerging themes and selected transcripts with three other experts in the field and the consistency of analysis to raw data.

## Findings

### Sample sociodemographics

The study was located in the North West of England. Of the 36 people who requested further information about the study three did not contact the research again (and it was assumed they did not wish to participate) and 33 (7 men and 26 women) consented to take part. Details of participants are provided in Table 1. The age of participants ranged 20–80. At the

time of parental death, participants were aged between 13 months to 17 years. Of the seven men participants, one was Scottish, three Irish and the remainder English. Of the 25 female participants, two were Welsh, one was Yemini Arab, three were Irish, and the remainder were English. Participants' religious backgrounds included Catholic, Protestant, Muslim and Jewish.

Deceased parents included 14 mothers and 15 fathers and four respondents had lost both of them (total of 37). There were 29 sudden or unexpected deaths (at least from the perspective of the child), four of these being accidental and one being suicide, the others being from disease (i.e. cancer, cardiovascular and neurological disease) and included dying trajectories of various lengths.

In analysing the data it was clear that, while individual experiences of bereavement in childhood were unique, common themes were identified across the narratives which impacted on bereavement experience over time including disruption and continuity, communication, and social networks and affiliations.

### Disruption and continuity

The narratives were organized around maintaining continuity in the face of disruption. Ruth lost her parents within six months of each other when she was 16 and went to live with a family friend. She explains why:

I didn't want to go to family – I didn't, I think because, the enormity of what of happened and the fact that I'd lost both parents in such a short time – I had been able to stay with my aunty O... it meant that I didn't have to make new friends because it was the one constant – my school and my friends were the world that didn't change. Everything had changed, I'd lost my home, I'd lost my parents, I'd got no brothers and sisters, I'd got nobody but you know nine o'clock or half eight in the morning I went off to school and I came back at say half past three and in that time I was like any other, I was a normal schoolgirl if that makes sense (Ruth 46, aged 16 when parents died six months apart).

By expressing her preference to live with a family friend whom she called aunt, Ruth was able to

**Table 1**  
**Demographics of respondents**

	<i>Ethnic background</i>	<i>Gender</i>	<i>Religion</i>	<i>Age (current)</i>	<i>Age (when parent died)</i>	<i>Deceased (mother = M; Father = F)</i>	<i>Deceased parent(s) occupation</i>	<i>Cause of death</i>
1	English	F		33	14	F	Engineer	Cancer
2	English	F		20	17	F	Not stated	Brain aneurysm
3	English	F	Protestant	34	11	F	Priest	Brain cancer
4	English	F		25	8	M	Unemployed	Brain Haemorrhage
5	Irish	M	Catholic	72	5	F	Retail	Tuberculosis
6	English	F	Catholic	57	5	F	Coalminer	Leukaemia
7	English	F		56	16	M+F	Postman (F) Housewife (M)	Lung cancer(M) Stroke (F)
8	English	F		32	13	F	Pilot	Effects of flying accident
9	English	M	Atheist	43	13		Not stated	Bacterial endocarditis
10	English	M		33	5 M: 16 F	F + M	Microbiologist (F) Nurse(M)	Cancer (F+M)
11	English	F	Protestant	75	2	M	Housewife	Septicaemia
12	English	M		23	12	F	Note stated	Accidentally killed himself
13	Scottish	M	Protestant	62	17	F	Minister	Heart disease
14	English	F		35	10	M	Not stated	
15	English	F		51	12	F	Not stated	Suicide
16	English	F		51	17	F	Police Officer	Heart attack
17	English	F	Catholic	44	14	M	Not stated	Leukemia
18	Irish	M	Catholic	48	8	M	Housewife	Encephalitis
19	English	F		57	12	F	Dock worker	Lung condition
20	Irish	F		62	8	F	Bakers	Cerebral haemorrhage
21	English	F	Catholic	60			Civil Engineer	Plane crash
22	English	F		80	15	M	Housewife	Lung cancer
23	Irish	F	Catholic	46	9	M	Housewife	Cancer
24	English	F		16	16	M+F	Congregational Minister (F)	Stroke (F)
25	English	M		72	3	F	Not stated	Bowel cancer (M)
26	Irish	F	Catholic	53	13 months			Heart disease
27	English	F	Jewish	62	16	M	Filing clerk	Car accident
28	Welsh	F	Protestant	32	17	F		Heart attack
29	English	F		22	18 months	F	Grocer	Brain tumour
30	Welsh	F		62	16 (F) 17 (M)	F + M	Bus conductor (F) Seamstress (M)	Heart attack Stroke
31	English	F		51	9	F	Coalminer	Pneumoconiosis
32	English	F	Protestant	63	17	F	Wholesale grocery	Heart condition
33	Yemini Arab	F	Islamic	41	17	F	Retailer	Brain haemorrhage

Blank cells = data not stated

stay in familiar surroundings. This sense of continuity was particularly important to Ruth, as it provided sense of stability and normality in an otherwise chaotic life world where she could escape (albeit temporary) the enormity of such profound disruption.

In contrast, Anne-Marie was sent to live with her paternal grandmother after her mother's death without her sister. This relationship with her sister was important to Anne Marie: as far as she was concerned, it was the only source of continuity that she had been able to rely on. Anne-Marie explains:

So first of all, that was really strange because I wasn't living with my sister anymore and then just further compounded my feeling of loneliness because now I was stuck with my nana – who I loved – but she was an old woman and where's my sister gone. I had no one to confide with, or share it with and stuff like that so that was awful. I remember feeling very upset that L (name of sister) wasn't there anymore. Urm and at the time I didn't realize why she didn't want to be there, it was just like well she doesn't want to be with me either. so yeah L went and went to live with my aunty'. Urm, since then I have had real issues with loneliness – I've had real, real bad issues throughout my life (Anne-Marie 25, aged 8 when her mother died of a brain hemorrhage).

For Anne-Marie the insecurity, fear and loneliness she experienced as a result of her mother's death appears to have been intensified by the lack of support from her father and being 'stuck' with her parental grandmother without her sister providing support. At the time Anne-Marie was unaware of the reasons underpinning her separation from her sister hence she made sense of it by seeing it as rejection which further compounded her feelings of loneliness and isolation. For Anne-Marie the significance of this event is reflected in the fact that throughout her adult life she has experienced overwhelming feelings loneliness and isolation and finds it difficult to trust others.

Continuity was also affected by a reduction in parental capacity which the respondents could not make sense of, as exemplified in Winifred's story. To Winifred her mother appeared to be no

longer interested in where she went or what she was doing after her father died. Winifred believes that this change in her mother's behaviour to be as distressing as her father's death as exemplified below:

And it was a strange feeling on my part – I don't think it was exactly that I had lost two parents but that I lost [one] parent and the other one had changed so much. Now that only lasted a short time in now I understand it, but at the time I didn't and that ... distressed me in a way as much as my father dying- that might sound odd but, and I still remember that and when I was a doctor I came to be associated a lot with bereaved people, I learned the theories about loss and grief I immediately recognised that was why my mother had reacted, it didn't last very long (Winifred 63, aged 17 when her father died).

Through her subsequent experiences Winifred was able to understand that the change in her mother's behaviour was due to grief. Had Winifred understood what was happening to her mother at the time the extent of her distress might have been alleviated.

Where this reduction in parental capacity was long term the impact appeared much greater as exemplified in Jane's narrative:

She [mother] was throwing everything out in house that belonged to me dad and I was gutted ... but she started throwing things of mine out then and I just felt alone; I had no one to back me up and I couldn't talk to her about it and then it happened every single year after and I'd buy more books to replace what she'd thrown out and she'd do the same and, in the end I had to leave (Jane 51, aged 17 when her father suffered a heart attack and died).

For Jane the distress she experienced appeared to be compounded by the fact that she feels she has no one to support her during this time.

### **The role of social networks and affiliations**

Narratives were often organized around the extent to which support from social and institutional affiliations (e.g. schools, religious organizations,

neighbours and friendship networks) mediated the impact of parental death. For some this support provided access to role models, moral guidance and a sense of security as the following extracts illustrate:

I don't think actually when I was younger it had a lot of effect on me because I think I was quite social you know, had lots of friends and erm went to Sunday school and that, church youth club and had a lot of friends there. And I think cos, that I sort of had some friends with dads – they sort of, they became like surrogate dads really ... there was a guy who was like me Sunday school superintendent-, I suppose he was like a father figure really (Sue R 51, 9 when her father died of a lung condition).

My father's death caused my mother some disillusionment with religion but she was happy for me join a church choir hoping that the church would exercise a strong moral influence. She was less enthusiastic about my joining the Boys' Brigade as she still remembered its early military associations but soon came to see it providing 'manly' activities in a safe environment under the control of dedicated men who were providing a strong masculine influence, which she did accept was lacking in my life (Sam 72, aged 3 when his father died of heart disease).

The convent had given me security. It wasn't just a place of worship or a holy house. Unlike the other children who had gone off through the school gates and gone home, I'd actually seen the other side of this convent life- that was the security ... And better still I could probably walk into most convents now and fall into the routine even now quite naturally ... And it's not, they'd be no awkwardness there, or it doesn't feel right, it was a sense of security as well as a belief (Christina 57, aged 5 when mother died of leukaemia).

However, distress was compounded in cases where participants felt excluded from any support offered. Whatever the reason underpinning this, the perception was that being excluded contributed to feelings of isolation and loneliness.

And erm there was a welfare officer from the police came round to offer some assistance I don't know what, she'd[mother] talked to him in another room so I don't know, but nobody came and sat with me. Err, it was always me mum, they'd come and see me mum, I don't know whether she thought you know that I shouldn't be exposed to this kind of thing or whether I was too young to understand it but, the overriding feeling was that I felt left out. I think it was me age, I think if I'd been older I might have had some kind of, somebody to sit and listen to how I was feeling (Jane 51, aged 17 when her father died of a heart attack).

I think they might have supported my mother- I'm sure they did support my mother very well. I think, looking back on it now I think in an analytical way I think actually what it was, was that they assume that a 17 year old boy can cope and they just didn't do anything or say anything or you know really at all (Gerald 62, aged 17 when his father died after varying degrees of ill health).

## Communication

Distress was compounded when children were not given accurate information not only at the time of physical death, but when the parent they knew in terms of caring for them and looking after them is lost to them due to their illness. This lack of information was perceived to contribute to the ensuing fear and bewilderment experienced, as illustrated in an extract from Jimmy narrative.

...at the time, so kind of bewildered about what was going on around me and not really understanding or having it explained to me. But being a fairly bright kid so, with the ability to make, to create a back story which probably had no foundation in reality at all but, does that make sense? ..., I can I can remember I can remember being so scared and bewildered, I didn't, nobody had explained to me what the nature of her illness was, how she got there (Jimmy 48, aged 8 when his mother died of encephalitis).

So intense were these feelings that they have remained in his adult memory. The intensity of

this distress is reflected in the use intensifiers (*I can, I can remember, I can remember, being so scared and bewildered*) present in Jimmy's narrative. Had he been told about his mother's illness and her subsequent death Jimmy feels that he would not have had to create his own back-story which was not necessary helpful.

In some families the deceased parent could not be as talked about at all for fear that family members (particularly surviving parents) might not be able to cope with the emotions triggered by a reminder and families created implicit rules for the communication of thoughts and feelings. In some cases families often stopped functioning as a family and became 'individuals in a family'. As an adult Lucy reflects on how the subsequent lack of closeness as a family, particularly to her mother, stems from the fact that that she (and her siblings) even prior to her father's death were able to discuss this openly as a child.

I suppose we were all a bit separate in our family and still are- I don't feel that close to my mum, I had to tell her something recently and it's taken weeks of courage to tell her something and I'm not really that close to my brothers and sisters, slightly better with my sister recently, I think it was because we were separate and left to work things out for ourselves and that's how it has always been and that as I say how we found out about the accident was piece it together (Lucy 43, aged 10 when her father was killed in a plane crash).

## Discussion

A unique feature of this study was its exploration of the impact of early parental death over the life course of the participants up to as long as 71 years after the death of a parent(s). Crucially this brought into view the damage and effects on the individual overtime as a consequence of inappropriate or neglectful management. Through the analytical process it was revealed that while the individual experience of bereavement were unique, they were organized around common themes which mediated the experience of parental loss, including disruptions and continuity, the role of social networks and affiliations and communication.

In common with other studies<sup>22,23</sup> the analysis confirms that moving home and separation from family and friends made adjustment to parental death significantly more difficult and increased distress in the bereaved child. Consistent with Worden,<sup>16</sup> we found that the longer disruptions in daily life continued, the greater their impact on children. However, our analysis further suggests that when children experienced a progression of discontinues events (or continuity that did not meet their need) respondents appear to be more likely to experience emotional difficulties and feeling of insecurity and loneliness in adult life.

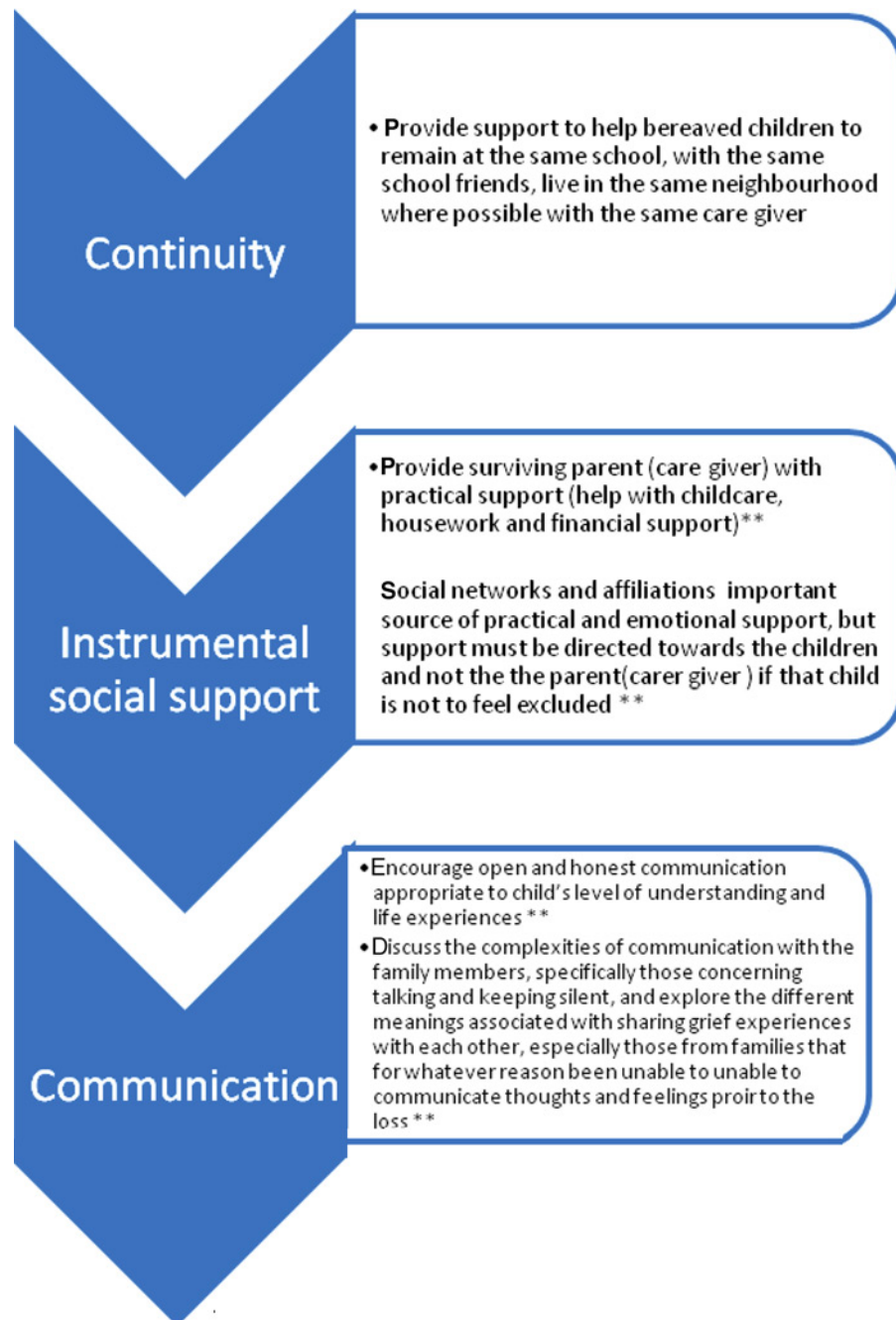
Broader research on childhood trauma suggests that the quality of the relationships within the family influences a child's recovery after trauma occurs.<sup>24</sup> An important factor is whether the child feels safe and secure within a loving supportive family, with a surviving partner who is able to parent effectively. Even temporary changes in parental capacity were found to be distressing for children as respondents often did not understand what was happening. Riches and Dawson<sup>25</sup> term this experience the 'double jeopardy' whereby the child not only suffers the loss of a parent but the symbolic or temporary loss of other parent. The analysis further suggests that where these changes are longer term the distress experienced is compounded and there may be significant impact in adult life in terms of loss of self-esteem and self-worth.

Our study also demonstrates the distress experienced by the child when their support needs are not taken into account by the social network. The findings suggest that, in order to help minimize the disruptive effect of bereavement of children's social worlds, it is essential that bereavement support consists of far more than counselling that is frequently available and offered to bereaved children. Structured support ensures the many different contexts for continuity can be harnessed and maintained. The findings suggest that where possible child/children remain in existing their social networks (e.g. live in the same area, go to the same school, and maintain the same friendships and other social affiliations). Those working with bereaved families also need to ensure that support which increases stability, continuity and cohesion is introduced at every level of the family system. This includes

**Figure 1**

**Key elements for supporting parentally bereaved children achieve better outcomes in adulthood.**

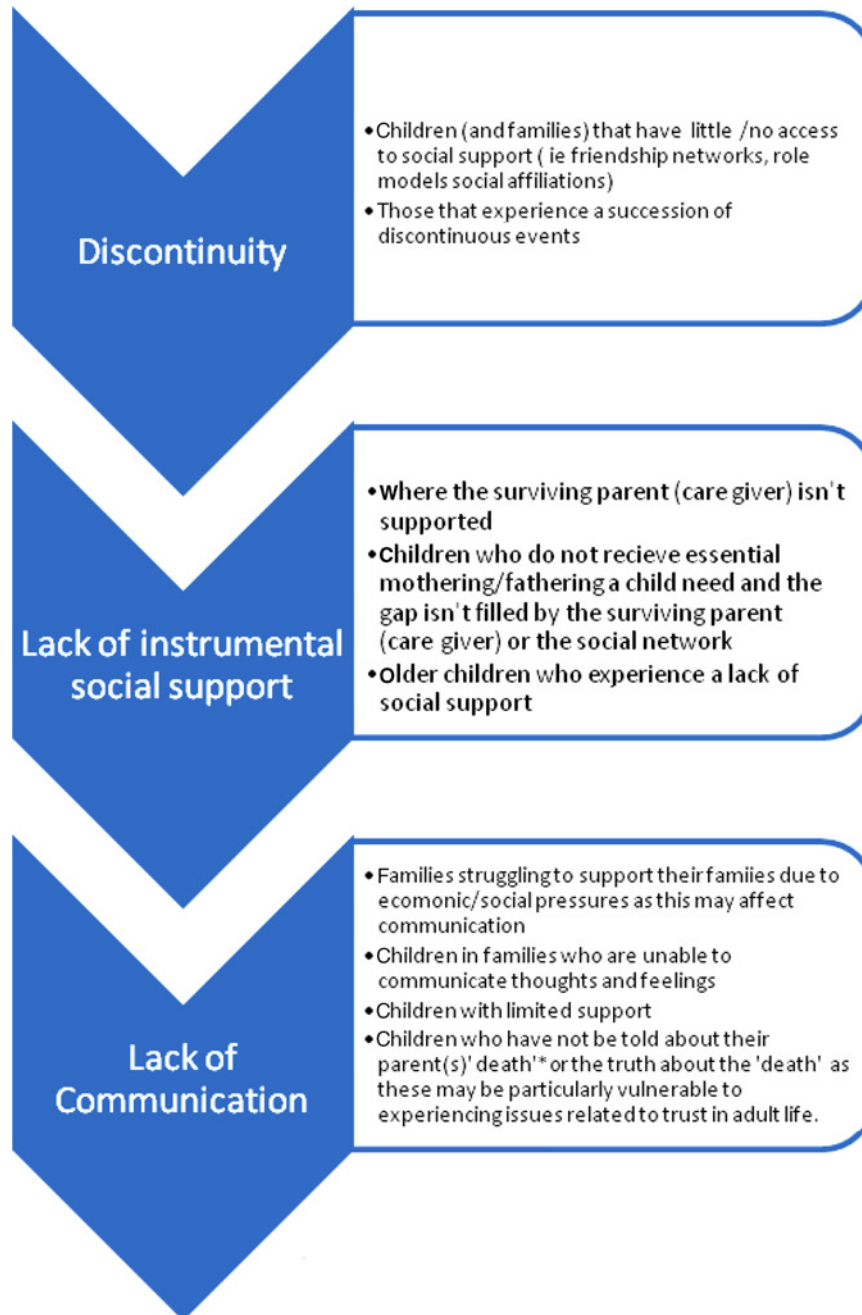
**\*\*Support needs to be sensitive to the family's cultural beliefs surrounding, death, dying and bereavement, parenting and the wider cultural practices in which such beliefs are imbedded**





**Figure 2**

**Key elements to help identify bereaved children that may be more vulnerable to less favourable outcomes in adulthood. \*Refers to both the physical death and the 'death' of the parent that was known to them**



essential practical support, e.g. practical household tasks housework, cooking, shopping and taking the children to school, as this reduces the social, economic and caring burden on the surviving parent. Our research suggests that if the social network addresses the necessary 'mothering/fathering' then a child does not appear to be affected in adult life.

Much of the literature emphasizes the need for open communication with regard to the physical death and the need for regular updates regarding the course and prognosis of the disease.<sup>26</sup> There appears to be little or no acknowledgement of that fact that children also need to be given information when the parent is no longer able to fulfil the parenting role during a terminal illness. The findings from this study demonstrate the distress experienced as children and adults when they are not given clear and honest information at appropriate time points relevant to their understanding and experience. Our study emphasizes that communication is dialectic, dialogic and dynamic in nature. Therefore, rather than unilaterally promoting open communication the findings from our study suggest that it is essential that those working with bereaved families discuss the complexities of communication with the family members and explore the different meanings associated with sharing grief experiences with each other.<sup>27</sup> This supports the family as a unit to integrate experience and adapt to changes with few attempts to control thoughts and feelings.<sup>28</sup> In the absence of resources such as economic security or social support, individuals and families are forced to rely on interpersonal, negotiated, emotional controls as a strategy of last resort<sup>29</sup> and confirmed by our study. This is likely to have a negative impact on relationships in adulthood as respondents often found it difficult to express feelings, as our findings clearly illustrate.

Based on the findings from our study a model is suggested for identifying and supporting those that may be more vulnerable to less favourable outcomes in adult life is presented in Figures 1 and 2.

A limitation of this study is the recognition that memory is a re-constructive process; hence early memories evolve under reconstruction. Respondents were asked to recall events that they had experienced in childhood and may have brought

their own prejudices and mindsets into their memories. In addition, it is important to clarify that the purpose of this study was to increase our understanding of the subjective experience of the impact of early parental death on adult life. Even though there may be inaccurate or incomplete recall due to memory attrition, it is the actual lived experience of the participants which was most important. As this was a self-selected sample, there may be some bias in favour of those who saw value in talking or writing about their experiences. The limited ethnic diversity in our sample limits the extent to which the findings can be generalized to other cultures.

## Conclusions

One of the main findings of this study relates to the damage and suffering experienced by individuals in adult life when appropriate levels of support are not provided. The Childhood Bereavement Network<sup>30</sup> developed a set of guidelines to provide organizations and individual practitioners with a baseline 'best practice' framework for support of parents of bereaved children. These guidelines recognize the importance of supporting and affirming parents of bereaved children and acknowledge that parents have the primary role in providing support for their children. The guidelines also acknowledge that parenting is challenging, varied and long-term, and families will have a broad range of practical, emotional, social and financial needs. The findings suggest that it is crucial for such guidelines to be followed if the damage and suffering experienced by individuals in adult life is to be minimized.

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