



## Loneliness despite the presence of others – Adolescents' experiences of having a parent who becomes ill with cancer



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### A B S T R A C T

**Keywords:**  
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**Aim:** The aim of this study was to describe young adults' own perspectives on the experience of having a parent who developed cancer when the young adult was an adolescent.

**Method:** Narrative interviews were conducted with six young adults aged between 20 and 26. The interviews were analysed using qualitative content analysis.

**Results:** The main message that the young adults communicated in the interviews was interpreted as the overarching theme 'Loneliness despite the presence of others'. Two domains with three categories each emerged: *distance*, comprising a feeling of loneliness, lacking the tools to understand, and grief and anger; and *closeness*, comprising belief in the future, comfort and relief, and a need for support. The young adults felt a loneliness that they had never experienced before, and they lacked the tools to understand the situation. They felt grief and anger over what the cancer had caused. However, they had still managed to regain faith in the future. They found comfort and relief in the thought that this would not necessarily happen to them again, and they gained support from talking to family and friends.

**Conclusion:** If all family members are given the same information, it becomes easier to talk about what is happening. This can reduce adolescent children's experience of loneliness. Contact with health care professionals should be maintained throughout the period of illness. Many short informal contacts create relationships and trust that can be helpful if the worst happens and the parent dies.

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### Introduction

This qualitative study focuses on experiences of parental cancer during adolescence. Worldwide, many adult people suffer from cancer. In Sweden in 2010, approximately 6600 people aged 35–54 were diagnosed with cancer (National Board of Health and Welfare, 2010). Many of these people have a family, potentially including adolescent children. A parent who is ill with cancer is not the only one to suffer; the whole family suffers with them (Visser et al., 2005).

When a parent is diagnosed with cancer, children and adolescents experience a high degree of internal and external stress. Anxiety and stress remain constant regardless of how long the disease and treatment last (Visser et al., 2005). Adolescents and young adults experience this stress more often than children (Compas et al., 1996). The degree of malaise among adolescents will

depend on their self esteem and their relationship with the ill parent before the illness (Nelson and While, 2002). The recurrence of a parent's illness affects internal stress to a very high degree (Huizinga et al., 2011). Adolescents have the ability to empathise with their parent's suffering; this empathy is reflected in feeling sorry for the ill parent and wanting to care for and try to console them. Adolescents also feel anger about the injustice of fate, and try to find meaning in their parent's disease. Despite this, adolescents are still able to be concerned about the healthy parent and the family situation as a whole (Thaustum et al., 2008).

Adolescents may develop both emotional and behavioural problems in association with a parent's illness (Birenbaum et al., 1999; Edwards and Clarke, 2004; Heiney et al., 1997; Howes et al., 1994; Huizinga et al., 2003; Welch et al., 1996). The burden of being at school, doing homework, and visiting the ill parent results in a feeling of stress, which can manifest in different ways. External stress, for example, may be expressed as unacceptable social behaviour, aggression, or criminality (Visser et al., 2005; Nelson et al., 1994; Birenbaum et al., 1999). Internal stress may be expressed as withdrawal, problems with concentration, somatic symptoms, or signs of anxiety (Huizinga et al., 2003). Some studies

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have shown a relationship between parents' and adolescents' experiences of anxiety. A deeply anxious parent will have trouble talking about the cancer and the family situation, which will further increase the adolescent's stress (Nelson et al., 1994; Edwards and Clarke, 2004). Families who are able to openly talk about the illness, express their feelings, and solve problems show lower levels of depression and anxiety (Heiney et al., 1997).

In a study by Huizinga et al. (2003), adolescents whose mothers had been diagnosed with cancer expressed a feeling of conflict, and a desire to be relieved from this feeling. In a way, they were afraid of losing their mother, and wanted to spend as much time with her as possible; but at the same time they had a need for an adolescent's natural process of liberation. Christ et al. (1994) described how girls tend to delay the normal process of liberation when their mothers become ill, and instead deepen their relationship. Adolescent boys, however, more often continue their normal liberation process. Thaustum et al. (2008) described four coping strategies used by adolescents: helping others, parentification (i.e. the adolescent takes over the parental role), distraction, and wishful thinking (i.e. the adolescent hopes for new medicines and treatments for the ill parent). Although the family share the same experience, parents' estimations and perceptions of how adolescents cope with a parent's illness do not correspond with the adolescent's own estimations (Visser et al., 2005; Huizinga et al., 2003; Grant and Compas, 1995). However, mothers' perceptions are more accurate than fathers' (Visser et al., 2005).

The parents in a study by Thaustum et al. (2008) expressed a desire for guidance in how to inform their adolescent children and what to inform them about. Since no one offered them help with this, they instead used the information they had received from health care professionals for themselves. Huizinga et al. (2003) reported that adolescents asked for abundant information about the disease, its treatment, and the prognosis. When it becomes clear that the ill parent is going to die and the family realises that the time is limited, they try to make the most of the time they have left together. Sheehan and Draucker (2011) describe this process as occurring in four steps: coming to know their time together was limited, spending more time together, extending their time together and giving up their time together.

Previous studies examining adolescents' experiences of parental cancer have been primarily quantitative, and the interviews and survey responses show evidence of parental influence.

There is a lack of knowledge about adolescents' own perspectives on parental cancer, which became evident in the review of literature presented above; this is the reason why few of the articles referenced in this introduction are particularly recent. The aim of this study was to describe young adults' own perspectives on the experience of having a parent who became ill with cancer when the young adults were adolescents.

## Methods

A qualitative design was chosen, using interviews in the form of narratives. Narratives can be used to describe a natural part of life, allowing people to introduce themselves and share their feelings and experiences with others (Skott, 2004). A narrative interview is an interactive conversation where participants tell their stories without being interrupted and are given time and space to narrate. The interviewer has few pre-prepared questions, and asks follow-up questions to help move the story forward (Mishler, 1986; Polit and Beck, 2008). In the narrative interview, participants talk freely about their experiences of the specific phenomenon being studied. This increases the opportunity for the interviewer to get closer to the complexity of experiences of the phenomena (Lundman and Hällgren Graneheim, 2008; Sandelowski, 2011).

### Settings and participants

This study took place in the south of Sweden from November 2009 to April 2011. Young adults were recruited through advertisements on a university website and bulletin boards. The inclusion criteria were: having experienced during their adolescence (13–19 years) a parent being diagnosed with cancer, and age between 20 and 26 years at the time of the interview. Inclusion took place in the order of sign-up, regardless of gender. An email was sent to the young adults including further information about the study. Six young adults participated: one man and five women (see Table 1).

### Data collection

Data were collected through narrative interviews. The informants decided where the interview should take place; two chose their own homes, three the university, and one a hospital. Two of the authors (KA and EK) conducted three interviews each. In order to better understand the context that the informants were living in at the time when their parents were diagnosed with cancer, the interview started with the questions: 'How old were you when your parent got cancer?', 'What family situation did you live in at that time?' and 'How old are you now?'. The main question of the study was then posed: 'Tell me your story, what happened when your mother or father got cancer?'. The interviewer stimulated the storytelling with follow-up questions when necessary. Each interview lasted between 40 and 60 min. The collected data were transcribed verbatim by the interviewers to avoid the risk of losing important data such as facial expressions, body language, and the meaning of pauses (Mishler, 1986).

**Table 1**  
Participant profile.

Name	Age at interview	Age at onset of parent's illness	Age at parent's death	Family picture at onset of parent's illness
A	22	16	20	Other parent never mentioned. Two older siblings moved out from home. One younger brother living with ill parent. A living on campus, just moved out from home.
B	20	16	–	Parents separated. One younger brother living at home. B living at home.
C	20	15	17	Cohabiting parents. Four half-siblings, all living away from home. C living at home.
D	20	14	15	Parents separated, both in new relationships. One brother and two stepsisters. D alternating residence between mother and father.
E	21	16	17	Cohabiting parents. One younger brother. One older half-brother living away from home. E living at home.
F	22	15	18	Cohabiting parents. One younger brother. Several older half-siblings all living away from home. F living at home.

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