

# Maintaining everyday life in a family with a dying parent: Teenagers' experiences of adapting to responsibility

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## ABSTRACT

*Objective:* Teenagers are living through a turbulent period in their development, when they are breaking away from the family to form their own identities, and so they are particularly vulnerable to the stressful situation of having a parent affected by a progressive and incurable illness. The current study sought to gain more knowledge about the ways that teenagers themselves describe living in a family with a seriously ill and dying parent. More specifically, the aims were to describe how teenagers are emotionally affected by everyday life in a family with a dying parent and to determine how they attempt to adapt to this situation.

*Method:* The study employed a descriptive and interpretive design using qualitative content analysis. A total of 10 teenagers (aged 14–19 years, 7 boys and 3 girls) participated through repeated, individual, informal interviews that were carried out as free-ranging conversations.

*Results:* While contending with their own vulnerable developmental period of life, the teenagers were greatly affected by their parent's illness and took on great responsibility for supporting their parents and siblings, and for maintaining family life. Lacking sufficient information and support left them rather unprepared, having to guess and to interpret the vague signs of failing health on their own, with feelings of uncertainty and loneliness as a consequence.

*Significance of Results:* Support from healthcare professionals should be designed to help and encourage parents to have open communications about their illness with their teenaged children. Our results add further support to the literature, reinforcing the need for an approach that uses a systemic perspective and considers the family to be the appropriate unit of care and offers a suitable support system.

**KEYWORDS:** Teenagers, Dying, Parent, Palliative care, Qualitative

## BACKGROUND

Progressive incurable illness in a parent can have a crucial impact on the structure and functioning of their family, and perhaps more so on their children. Children are deeply affected and have been described as feeling very upset and worried about a parent's

illness and deteriorating health, as well as about their own future (Bugge et al., 2008; Dehlin & Reg, 2009; Patterson & Ranganadhan, 2010). Buchwald and coworkers (2012) found that, when a parent becomes seriously ill, children most of all tend to fear for her/his death even though they are not told that the parent is indeed dying, and this fear tends to increase as the parent's condition deteriorates. Children are at risk of psychological distress due to stressful situations, and it has been suggested that such psychological distress may continue into

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adulthood if overlooked (Visser et al., 2004; Rainville et al., 2012; Bylund Grenklo et al., 2013). Studies report that, of all the age groups, teenagers may be particularly vulnerable, as their developing cognitive and empathic abilities advance their understanding and awareness of loss. Around the time of a parent's death, teenagers self-report an overall high level of stress, depression, anxiety, and behavioral problems, along with diminished social competence and school performance (Siegel et al., 1992; Compas et al., 1994; Siegel et al., 1996; Rainville et al., 2012). The teenage years are an especially turbulent time in an individual's development, when she or he is expected to disengage from parents and establish a sense of self, thereby reducing their psychological dependence (Blos, 1979). This puts the teenager in a significantly challenging situation, presented with the conflicting tasks of their needs and wishes to engage with the parent because of their illness and the need for a developmentally appropriate separation.

Bearing in mind this turbulent time when teenagers are attempting to break away from their family so as to form their own identity, it is important to gain more detailed knowledge about the way in which they describe their experiences of living in a family with a seriously ill and dying parent.

## AIM

Our objective was to describe how teenagers are emotionally affected by, and how they try to adapt to, everyday life in a family with a dying parent.

## METHOD

### Design

The study had a descriptive and interpretive design using qualitative content analysis (Graneheim & Lundman, 2004).

### Setting

Our study was carried out in two specialist palliative care units providing homecare and inpatient care for severely ill patients. Most patients in these settings have an advanced cancer diagnosis with a life expectancy of approximately three months. Both units were staffed by multidisciplinary teams that included physicians, nurses, physiotherapists, occupational therapists, and social workers—delivering services 24 hours a day.

### Procedure and Participants

Based on data from digital patient records, information about the study and an invitation to participate were sent to 13 teenagers who had a parent who had

been cared for and died in one of the participating units during 2012. The invitation was sent within 3 to 12 months after the parent's death. Study information was first sent to the surviving parent, and if he or she gave consent, the invitation was then sent to the teenager. A total of 10 teenagers (14–19 years old, 7 boys and 3 girls) agreed to participate (4 had lost their mother and 3 their father). Three of the deceased (one woman and two men) were not the biological parent, but they had shared in household and family life. The patients all had advanced cancer disease and received homecare as well as inpatient care at various times. One parent died in a private home and nine at a inpatient palliative care unit. Seven of the teenagers had siblings. Both parents and teenagers received written and oral information via telephone from the first author about the purpose of the study and the research methods to be employed, and they were assured about confidentiality and the condition of voluntary participation with a right to withdraw at anytime without explanation. Participating parents and teenagers provided written consent.

### Data Collection

Individual interviews were chosen as the data collection method and were carried out in from March to May of 2013. The interviews were informal and conducted as free-ranging conversations between the first author and the teenagers, with a focus on the study aim. Teenagers were initially asked to relate in detail their parent's illness ("Could you please tell me about your parent's illness?"). This was a natural opening to steer the rest of the interview, which explored the teenager's life experiences throughout his or her parent's illness trajectory until their death. Other questions were then posed: "Who told you about your parent's illness?" "When and how did you realize that your parent was dying?" "Who did you talk to about your parent's illness?" "How did you feel and how did you manage?" "How was your life influenced?" and "From where did you get support, if any?" All teenagers were interviewed on two occasions in order to obtain richer data, as well as to give them time to reflect and an opportunity to return to matters that were important to them. The first interviews varied between 30 and 50 minutes; the second one were often shorter and varied between 10 and 40 minutes. The time period between the two interviews varied from 1 to 4 weeks. Teenagers were offered a chance to choose the location of the interview (two preferred their own home; the rest came in to the palliative care unit).

### Data Analysis

Interviews were analyzed using qualitative content analysis (Graneheim & Lundman, 2004). After all

interviews were transcribed verbatim, the audiotapes were listened to again to confirm the transcribed text. The texts were then read to gain an overall impression of their content. Then, bearing in mind the aim of our study, the text was divided into meaning units. Meaning units were condensed without changing their central meaning and were coded. Codes were compared, and, finally, the codes with similar content were gathered into three main groups, and the interpretation of these formed three themes. Quotations from the interviews are used in this article to illustrate these themes. Ethical approval was obtained from a regional ethical review board (2013/251-31/5).

## RESULTS

Three themes emerged during the analysis: “understanding the illness and preparing for the loss,” “feeling and taking responsibility for parents and family life,” and “feelings of loneliness and support.”

### Understanding the Illness and Preparing for the Loss

All teenagers had been informed by their parents about the illness and that it was incurable. Nevertheless, they felt unable to fully grasp how it affected the parent in terms of symptoms, treatment, and capacities. They tried to understand this in different ways, for example, by interpreting the information they received by observing the ill parent. They recognized and acknowledged changes in the parent’s health and compared these from day to day. They reflected upon the parent’s deteriorating health: “More and more I began to think that it isn’t getting any better as it did earlier.” Teenagers were often loyal to their ill parents and strove to adjust to the parent’s approach to the illness. When the parent actively took on a positive approach, fighting against the illness, they tried to adjust to that and support them: “She wanted all of us to fight *with* her, to be happy when it went well, and when it didn’t, well, it will get better next time, so let’s go for it!” However, this led to some confusion and ambiguity: “Did she say so for us to really feel like that or to keep us from thinking more realistically?”

In families where the ill parent took the approach of avoiding conversation about the illness with the teenagers, this left them feeling alone, trying to understand the parent’s situation: “Maybe she didn’t want to think about it, that she was about to die. Maybe she was anxious about dying and didn’t want to leave her son.” This approach seemed to inhibit teenagers’ understanding of the gravity of the illness: “I got the answer that, well, everything was

fine, so I didn’t really think . . . So it was really difficult to realize that he was about to die sooner or later.” It became difficult to understand and interpret new symptoms and changes in the illness as signs of an advancing illness. Teenagers had difficulties believing and understanding that their parent was really dying: “Last time it was like this . . . everything went okay.” When the parent finally died, some experienced this as a sudden and rather unexpected event, even though there had been a long illness process during which the parent had overcome several temporary crises. Deep inside, they knew that the parent was seriously ill and dying, but it was difficult to take in and prepare for the inevitable: “I haven’t thought about it at all. I just kind of let anything happen.” One teenager said, “It came as a shock to me, but of course I was kind of prepared.” Another one remarked, “I didn’t really understand that he was going to die, but deep inside, in the back of my head, I did understand.”

The fear of losing the parent could become paralyzing and made it difficult for teenagers to talk about the illness. They understood that their parent would die from the disease, but they did not know when and how, and it was impossible for them to imagine what this would be like. This uncertainty contributed to various interpretations. For instance, the teenagers made wishful interpretations of the information given to them by healthcare professionals: “It is possible to prolong life, he said, if they give the treatment. So I did count on a few years, one or two.” Ongoing conversations with parents facilitated and helped the teenagers to prepare mentally for the coming loss. When the teenagers managed to talk with either of the parents or both, they expressed that it was easier for them to prepare: “Mum talked a lot with me because she knew Dad didn’t.”

### Feeling and Taking Responsibility for Parents and Family Life

The teenagers described in different ways how they tried to adjust to their changing life situation and how they felt responsible for the ill parent, the healthy parent, their siblings, and everyday family life. Retrospectively, they reflected on their perception that taking on these responsibilities sometimes contributed to their own personal growth. The concern and worry for the ill parent influenced teenagers to take on a strongly felt responsibility, and they had a hard time letting go of that. For some, the ill parent was their first priority, and they often neglected other social activities and chose not to meet with friends as much as before. Even when they did not spend time with the ill parent, they kept their feeling of responsibility alive in various ways. One teenager said,

“I really became kind of insane. I was constantly worried, of course.” As one aspect of their personal responsibility, they tried to arrange for the parent to be cared for at home: “We cared for her at home. It was her wish, and I didn’t want her to die in a hospital.” Another teenager said, “It became like an obsession just to stay home with them [the parents] doing nothing at all. My friends stopped calling me because I didn’t call them. I simply stayed at home all the time.” On their own, teenagers took responsibility for several things, such as coordinating healthcare interventions, comforting parents, and protecting parents from other persons or situations that might be overburdening or draining. In many ways, they became a primary resource for their parent. They sometimes felt that others questioned their way of assuming that much responsibility: “Some say it is too much responsibility, but I don’t think so. I would have felt worse not doing it.” They pondered and reflected on their responsibility during the parent’s illness: “I was sort of thinking, if I don’t go there [to visit at the hospital], I will really regret it if something happens.”

Teenagers also worried about their healthy parent and took on the responsibility of trying to help and facilitate that parent’s life in various ways: “She spent most of the day there [in the hospital], so I tried to make sure that she had something to eat when she arrived home.” Teenagers expressed their concern that the healthy parent might become depressed and not be able to manage life when the ill parent died. This, in turn, made them worry about what might happen to them and the rest of the family if that came about. One teenager said, “I was worried about Mum, that she would become depressed when Dad died.”

Teenagers witnessed their parents struggling to manage both illness and family life. This made them put in a great deal of effort to keep family life going. When the sick parent no longer had the strength to be a part of everyday family life, the roles within the family transformed, and teenagers described that there was a shift in responsibility for everyday-life issues, such as caring for pets, washing, cleaning, and doing other household tasks. Everyday life at home was not like it used to be, because the sick parent felt too ill to manage as they had before, and the healthy parent was too burdened and concerned about the ill parent. They took on greater responsibility and adopted a new family role: “We help each other with the laundry, shopping, and cleaning. We do everything, and therefore there haven’t been any problems at all.” They adapted to life with an ill parent: “We said that we would try to keep everyday life just like it was before he got cancer.” And, in time, these new responsibilities became

part of their everyday life: “Maybe it sounds awful, but you sort of got used to it. It was not like before, but gradually I came to perceive the constant chaos as something normal.” At times, teenagers assumed the responsibility of protecting their parents by hiding their own feelings or concerns in an attempt to avoid adding an additional burden: “I don’t act like I feel low and depressed when I’m at home, because I think that’s not what they need.” Sometimes they even chose to stay away from home: “She had a hell of a time, toiled like an animal, then I really didn’t want to stay home.” Teenagers with siblings also felt responsible for them and wanted to facilitate their everyday life, protect them from worry, and also from awareness of the fact that the parent was going to die: “I didn’t want to tell her that Mum was going to die.”

### Feelings of Loneliness and Support

While the teenagers took on responsibility and were supportive of parents and siblings, they themselves also had a great need for support. They spent more time alone as a result of the parent’s illness, ending up experiencing feelings of loneliness. The ill parent was occupied by their illness, hospital visits, treatments, managing symptoms, worries, and concerns. The healthy parent was engaged in supporting the ill parent, while managing family life and their occupation as well as their own worries and concerns. Being supported by one or both parents was considered to be of most importance to the teenagers, and if they felt they received sufficient levels of such support, they had little need for support from others. Thus, the parents were their major source for trust and safety: “We didn’t need to go somewhere else to talk, because we have always had each other, and we can talk about anything.” Conversations with their parents gave them comfort and resulted in weaker feelings of loneliness. The quality of support they experienced depended on the nature of their previous relationships with their parents. The teenagers mostly turned to the parent they had the closest relationship with for support, no matter who was the ill one. However, due to the circumstances and changes in family life, they often experienced a deepened relationship with both parents. They also felt supported by other relatives, neighbors, and friends. Some also described feeling comforted by family pets.

The school environment was of great importance for the teenagers and also a source of comfort and support. In general, most were successful in school despite their home situation. Some expressed feeling increased pressure and had difficulties in coping with their studies, and for them, their teachers and mentors played an important role: “She helped me



through this like an extra mum.” Teenagers described how they adopted different approaches to preserve their relationships with friends and teachers. Some chose to keep their experiences and feelings to themselves and to not tell others about their parent’s illness in order to maintain a normal life, trying to keep things just as they used to be. Others preferred to share and maintain open communications. Whichever choice they made, they experienced school as a possibility to have some kind of normalcy, something that went on just as it did before, independent of the their parent’s illness. Life in school was described in this way: “You don’t think as much of it [the parent’s illness] there, because you are busy doing other things.”

None of the teenagers described having been supported or offered support by healthcare professionals during the trajectory of their parent’s illness. Healthcare professionals did not seem to play an important role for our teenagers, and indeed appeared not to have tried to do so. However, all the teenagers felt that the ill parent had been well cared for and expressed great trust in the healthcare professionals and their knowledge and expertise.

## DISCUSSION

We found that teenagers were greatly influenced by their parent’s illness in their everyday lives. They took on responsibility for their parents and siblings in a remarkably mature manner, given their age, to keep family life going. Bearing in mind how the developmental period of being a teenager involves them starting to break away from parents and the family unit, this is an important finding. Our results add further support to the literature that suggests a need for an approach that uses a systemic perspective focusing on interactions within the family—how changes in one family member are related to changes in other family members and for the family as a whole (Wright & Bell, 2009; Wright & Leahey, 2009). Healthcare should consider the family to be the appropriate unit of care and offer a suitable support system (WHO, 2002). Similar to our study, Kennedy and Lloyd-Williams (2009) described how roles and relationships within a family change during a family member’s illness, and that children are motivated to absorb the roles and responsibilities they describe by wanting to support and help their ill parent in terms of such practical matters as housework and taking care of younger siblings. Sometimes questioned by their significant others, the teenagers in our study described themselves as becoming a resource for their parents and the rest of the family. It could be that, living in a family with an ill parent, they felt forced to take on responsibilities that they

would not have normally, but they reflected on this as helping them to grow and helped shaped their personality. They felt they had done something important. Appreciation from parents and family as a reward for being helpful has been found in earlier research to be valuable and reassuring for children (Bugge et al., 2008).

The teenagers in our study were informed by their parents about their illness, though not sufficiently to allow them to fully understand the illness and its consequences. Typically, parents are the ones who select which information will be shared with their children, and they also decide when to share it, the level of detail to be offered, and how the information will be shared (Ranmal et al., 2008). As a consequence of lacking information, the teenagers in our study carefully observed their ill parent, making guesses and interpretations, in order to understand the seriousness of the illness and alleviate their uncertainty. A similar finding was reported by Maynard et al. (2013), who described that the way in which parents responded to their illness affected their teenage children, who used their parents’ behavior as an indicator of how much they should worry. When no significant changes in the parents’ behavior were noticed, particularly in the way they interacted with each other, the teenager’s sense of stability was increased. In our study, teenagers described continuously observing parental behavior, acknowledging changes in health conditions from day to day in order to manage their uncertainty, understand, and prepare for what was coming.

Helseth and Ulfsaet (2003) found that children feel particularly insecure and vulnerable at the time of diagnosis and when the parent’s illness is visibly aggravated. Research has previously reported that open communications with parents and being kept up to date with what is happening are among the most important factors in determining how well teenagers will manage this experience (Singer, 1983; Sparks, 1997; Spira & Kenemore, 2000). Being well informed can help teenagers be prepared for changes they may observe in their parent and more easily understand why their parent acts in a certain way (Singer, 1984; Walsh-Burke, 1992; Sparks, 1997; Su & Ryan-Wenger, 2007). Having information about the disease, treatments, side effects, and other consequences may help teenagers cope with a parents’ illness (Barnes et al., 2000; 2002; Forrest et al., 2006; Finch & Gibson, 2009). Explaining what is happening in simple terms and avoiding medical jargon helps teenagers to understand issues related to the illness and can minimize uncertainty. In their communications, parents may be guided by their children, asking them what and how they would like to know about the illness (Maynard et al., 2013).

While teenagers took on responsibility and were supportive of parents and siblings, they also had a great need for support. Our study shows that being supported by one or both parents was considered to be the most important element for teenagers. Parents were their major source of trust, safety, and comfort. Previous research has reported that strong parent–child relationships can act as a buffer against stressful life events and that a positive relationship with at least one parent can reduce a teenager's level of anxiety (Barnes et al., 2002; Lewis & Darby, 2003; Stiffler et al., 2008). Maynard et al. (2013) identified actions that parents can take to increase feelings of safety and support, including being available, inviting their children to talk, and spending quality time together. Watching a movie, for example, provides a distraction from the illness, which may contribute to a teenager's well-being. The teenagers in our study described having close relationships with their parents along with open communications; however, they tried to hide their feelings to protect their parents so as to not be a burden, which contributed to their feelings of loneliness. The strategy of hiding feelings has been confirmed in studies by Nelson and While (2002) and Maynard et al. (2013), who also found that teenagers felt guilty and selfish when talking to their parents about their own feelings. This might be a reason for their seeking and finding support elsewhere. Our findings partly confirm earlier studies concerning different kinds of difficulties at school (Su & Ryan-Wenger, 2007; Patterson et al., 2011), but school was also an important source of comfort and support. In accordance with our study, Maynard et al. (2013) identified school attendance as being important in order to maintain a sense of normality. The teenagers in our study used different strategies to protect their sense of normalcy. Thus, some told friends and teachers about their ill parent and, for the same purpose, some chose not to.

## METHODOLOGICAL CONSIDERATIONS

Talking with a teenager about the severe illness and death of a parent is a very sensitive matter on many levels. Therefore, all interviews were conducted by the first author, who has several years' experience within palliative care, both as a nurse and a family therapist. Drawing on this experience, the interviewer strove to create a warm and safe atmosphere for participants. The interviews might have been the first opportunity for teenagers to talk about the loss of their parent with a person they did not have a relationship with. It seemed as if all participants welcomed and appreciated the opportunity to share feelings and experiences. They also expressed a

wish to help other teenagers in the same situation through their participation in our study.

Our findings are strengthened by the fact that all teenagers were interviewed twice, offering them the opportunity to revisit any issues, and provided a chance for both teenagers and interviewer to reflect between interviews. It is possible that our participants, in light of their agreement to participate, represent a group of teenagers who were coping relatively well with their situation. A limitation of our study is that the interviews were made retrospectively. Another is the rather large variation in terms of the length of time after a parent's death that interviews took place.

## CONCLUSIONS AND IMPLICATIONS FOR CLINICAL PRACTICE AND RESEARCH

Our teenagers, while in their own vulnerable developmental period of life, were greatly affected by their parent's illness and took on great responsibility for supporting their parents and siblings and for maintaining family life. Lacking sufficient information and support left them rather unprepared, having to guess and interpret the more or less vague signs of failing health on their own, resulting in feelings of uncertainty and loneliness. Support from healthcare professionals should be designed to help and encourage parents to have open communications about their illness with their teenaged children.

There is a need for future research, particularly using longitudinal methods, to offer important insights into the experience of living with a severely ill parent, the experience of the death of that parent, and the life experiences after that death. Future studies should also focus on and explore ways in which teenagers need and want to communicate and obtain support.

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