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# Adolescents' experiences of a parent's serious illness and death

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## ABSTRACT

*Objective:* Adolescence is characterized by increasing liberation from parents as the young person evolves into an independent individual. Experiencing the serious illness and death of a parent during this phase implies great stress. Serious illness involves uncertainty, worry, and hope at the same time that it is necessary for everyday life to function. This study sought to describe adolescents' experiences in the serious illness and death of a parent.

*Methods:* The study was carried out using a qualitative method. Data were collected in interviews with five adolescents who were 14–17 years of age when one of their parents died.

*Results:* The results show that the parent's illness was a strong threat, as the adolescents understood that their own and the family's lives would be greatly changed by the illness/death. The incomprehensibility of the parent's serious illness and death was a threatening condition on its own. The adolescents strived to make the inconceivable more conceivable to understand what was happening. They also described the necessity of finding different ways of relating to and managing the threat, such as restoring order, seeking closeness, adapting, gaining control, avoiding talking about the illness, not accepting and counting the parent out. The adolescents described feelings of being alone and alienated, even though they were close to family and friends and they did not actively seek support. The lives of the adolescents were changed by their experiences, beyond their bereavement over the parent. They felt that they had become more mature than their friends and that there had been a change in their thinking about life, changes in values, and changes in their views of relationships with other people.

*Significance of results:* The results of the present study can form a basis for developing a support program whose purpose would be to prevent effects on health.

**KEYWORDS:** Bereavement, Coping, Grief, Parent/parental death, Social support

## INTRODUCTION

Approximately 8,200 people between the ages of 30 and 59 die in Sweden each year (National Board of Health and Welfare, 1998), and it is reasonable to assume that they leave behind many children and adolescents. In the United States, it is estimated that more than 2 million children and adolescents younger than 18 years have experienced a parental death (3.4%; Christ et al., 2002).

The serious illness and anticipated death of a parent are the most traumatic events that can take place in a young person's life (Saldinger et al., 2003). The period of illness involves a traumatic state of stress as the adolescent sees how the illness transforms the parent both physically and psychologically at the same time that he or she knows that the illness will lead to death. Experiencing the other family members' worry and grief during the period of the illness also contributes to great stress in the vulnerable situation (Saldinger et al., 2003). Adolescents who

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are faced with the fact of serious parental illness and death are in a phase of their personal development that is characterized by greater independence from and an abating dependence on their parents (Harris, 1991). Being able to manage difficult situations such as serious illness/death requires the development of an ability to comprehend that events are predictable and unpredictable and that the world is sometimes fair and sometimes not. A good self-image is needed that comprises the feeling of being able to manage or be in control and an ability to enter into close relationships. The greater the security gained by the adolescents in each of these areas, the greater are the means for coping with difficult events (Balk, 2000).

Many researchers have described adolescent bereavement (Jewett Jarratt, 1994; Worden, 1996; Zeitlin, 2001; Christ et al., 2002). Younger adolescents (12–14 years) grieve for deceased parents from the perspective of their roles as protector, guide, the one who sets boundaries for them, and so forth. They often have a strong feeling that a deceased parent is present and carry on an inner communication with the deceased (Christ et al., 2002). Many adolescents in this age range have difficulty coping with the memories of the parent being ill (Harris, 1991). In 15–17-year-olds, bereavement expresses itself in a more adult manner, with an overwhelming sense of loss and painful memories. Older adolescents grieve for the deceased's personal qualities and can set themselves to a greater extent into the grief of the surviving parent (Christ et al., 2002). The grief of older adolescents can also be characterized by intense denial and an avoidance of strong emotional expression (Harris, 1991). A qualitative study of children's experiences during a father's chronic illness and death discusses feelings of powerlessness and isolation (Semmens & Peric, 1995).

Studies have been done on how adolescents' relations to the family and friends are affected when one of the parents passes away (Harris, 1991; Gutierrez, 1999; Stoppelbein & Greening, 2000; Christ et al., 2002; Rask et al., 2002). The results of this research are ambiguous with respect to the remaining parent or family. Many adolescents view these persons as a great support after a parent's death, whereas others see parents and friends as a burden in their bereavement (Rask et al., 2002). Some adolescents experience the remaining parent to be unavailable and as not providing sufficient support (Harris, 1991); others experience the attention they receive as satisfying (Stoppelbein & Greening, 2000). Friends are an important source of support for adolescents with a parent who is seriously ill or has died (Frydenberg, 1997; Rask et al., 2002). Nevertheless, although friendship offers special support and protection, it can make adolescents more vulnerable should the friendship fail to hold. The death of a parent can cause a relationship to change and give rise to a strong feeling of alienation when adolescents and friends do not want to talk about the death (Harris, 1991; Balk & Corr, 2001; Harrison & Harrington, 2001; Christ et al., 2002). Powerful emotions can be seen as unacceptable or frightening, and young people avoid talking to friends in order to protect themselves (Harris, 1991). Many adolescents avoid a friend in bereavement because they are unable to cope with the grief and emotions that the friend expresses (Balk & Corr, 2001).

Among other things, the grieving process involves adapting to the change in the relation to the deceased. Maintaining contact with the deceased by developing an inner representation of him or her soothes and comforts the mourner during the grieving process and allows him or her to begin to orient himself or herself toward the future. Grief and loss remain throughout most people's lives, and research shows varying reactions after a death, ranging from psychological problems to positive feelings. There is, however, a higher risk of depression, stress, and emotional problems. Bereavement itself is not the only affecting factor. Support from the surviving parent, financial difficulties, the reactions of the people in one's surroundings and other changes in the life situation also have an effect (Gyllenswärd, 1997). If adolescents do not work through their grief, they can experience great problems both immediately after the death and many years later, as adults (Gyllenswärd, 1997; Balk & Corr, 2001).

To prevent deterioration in health, it is important to consider adolescents' own experiences of parental illness and death. Available research, with few exceptions (Hindmarch, 1995; Semmens & Peric, 1995), is based on an adult perspective. It is thus important to gain more detailed knowledge about the way in which adolescents themselves describe their experiences of a parent's serious illness and death.

The aim of the study was to describe adolescents' experiences of a parent's serious illness and death.

## METHODS

The study design was exploratory and descriptive and used a qualitative method of analysis. Qualitative methods are used when the intention is to describe the properties of a phenomenon. These properties may comprise experiences, thoughts, motives, and so forth (Van Manen, 1990). The study uses a psychosocial perspective, which builds on knowledge about individuals' internal psychological life, individuals' relations with one another, and the interplay between them and the relationship between the individual and society (Bernler et al., 1999; Simon, 2003). These three aspects are connected and influence one another in an ongoing process. They are also preconditions for one another.

## Participants

The sample was strategically chosen to reflect adolescents in different ages, of both sexes, with a different number of siblings and a range of time that had passed since the parent's death. The inclusion criteria were as follows: boys and girls between 13 and 19 years of age when the parent died, the death having occurred no more than 3 years before the interview, and the parent having been hospitalized in western Sweden. The exclusion criterion was difficulty expressing oneself in Swedish. To come into contact with adolescents who could be candidates for participation in the study, inquiries were made to the staff of a gynecological and an oncology clinic and to hospital social workers with regard to adolescents who matched the sample criteria.

A total of six adolescents were asked to take part in the study. The initial contact with the adolescents was made by mail in a send-out containing information about the study. For those under age, the letter was addressed to the remaining parent. After verbal notice of willingness to participate, a form was sent for written consent. One adolescent declined because of a lack of interest. The study group consisted of two girls and three boys aged 16 to 18. At the time of the study, between 8 months and barely 3 years had passed since the death of the parent. The adolescents were between 14 and 17 years old when the parent died. According to the adolescents, the period of illness before the death was between 4 months and approximately 2 years. Two of the adolescents were siblings.

## Data Collection

The adolescents were given the possibility to choose where the interview would be held. They all chose to be interviewed at a hospital. An undisturbed and comfortable room minimized the feeling of a hospital atmosphere.

Data were collected in qualitative interviews covering the period of the illness, the time around the death, and the time afterwards. Open questions were asked in each area such that the adolescents would describe their experiences of the parent's illness and death. To gain deeper information beyond what was spontaneously offered, questions were asked about relations, memories, support, personal development, and the future. The interviews induced strong emotions at times. In that case, the adolescents were asked whether they wanted to stop the interview, but none of them chose to do so. After the interviews, all of the adolescents expressed themselves positively about the experience of participating. At times when the adolescents felt sad, questions that were considered to risk inducing strong emotions were avoided. These questions were posed again later in the interview when possible.

A trial interview was conducted with an adolescent to evaluate the content and structure of the interview. This interview was included in the study as it gave rich and relevant information. The interviews lasted between 60 and 90 min and were recorded. Notes were taken after each interview if anything of interest had occurred. The intention was for the comments to add extra information to what had been said. The interviews were transcribed verbatim. Besides what was said by the adolescents, pauses, hesitations, resistance, crying, and interruptions during the interview were noted.

## Ethics

Participation was voluntary and could be stopped at any time in the study without explanation. The information letter sent prior to the study gave an offer of support to the adolescents and the remaining parents in the case that the interviews induced painful reactions. Data collected were treated confidentially, without any risk of the participants' being identified in the study results. The research ethics committee at Göteborg University approved the study.

## Data Analysis

In qualitative research, the analytical process is active and proceeds from a clinical empirical to an abstract level of theory generation (Fridlund & Hilding, 2000). The analysis was inspired by Starrin and Svensson (1994), who describe a qualitative analytical methodology in which the researcher seeks important statements about the phenomenon under study by means of repeated readings of the material. The statements are then compared to clarify differences and similarities, and interpretations of the material are made that in further comparisons lead to new interpretations. This process continues until no new interpretations can be found (Starrin & Svensson, 1994).

The analysis began by reading each interview in order to form an overall impression of the material. Further readings were then done, setting aside the preunderstanding as far as possible. The intention was to form an unbiased picture of what the adolescents conveyed in their statements by searching for broad themes and typical words and statements. In the next step the interviews were read again, this time putting the preunderstanding in the form of knowledge and experiences about the phenomenon in the foreground. The purpose here was both to look for broad themes and to describe what the adolescents did not say but nevertheless conveyed. The notes made at the interview were used as an aid in this step. The themes that emerged from the adolescents' statements were placed into different categories. This procedure was repeated with each interview. The next step in the analytical process was to contemplate all the interviews as a whole and to proceed with the analysis from this perspective. The parts of the interviews were compared to discover differences and similarities. This process led to the creation of new categories, as the contents of the categories could change in meaning or significance at comparisons between them or between them and the original statements. This comparison was continued until no further categories could be created and the specific aspects in the adolescents' experiences were obvious.

To diminish the influence of the first author's preunderstanding on the study, repeated discussions were held during the analysis process with the second author, who has a different preunderstanding and furthermore experience of qualitative research (Mårtensson et al., 1995; Mårtensson & Dahlin-Ivanoff, 2006).

## RESULTS

The results are described according to three categories: living under a threat, I bear this alone, and a changed life. The first category is divided into two subcategories: an inconceivable state and managing the threat. Both contain different aspects of each of the subcategories. The contents of the different categories are illustrated with quotations. Ellipses that appear in the quotations indicate that irrelevant parts have been removed. Dashes signify pauses. Words within slashes describe the context.

### Living under a Threat

The adolescents described the parents' illness and death as being a great threat. The threat originated from the inconceivable state that the illness and death represented and from the situation to which it led. Living under this threat brought different ways of managing with it.

#### *An Inconceivable State*

It was inconceivable to the adolescents that the parent had fallen so seriously ill that he or she would die. The incomprehensibility itself turned into a threatening state under which they lived. They tried to make the inconceivable more conceivable in order to understand and relate to what was happening.

*Seeking existential explanations.* During the whole period of the illness and after the death of the parent, the adolescents asked themselves existential questions about why this had happened to them in particular. They thought about the justice of life. The adolescents sought answers to the questions in an attempt to make the parent's illness more conceivable. During this stage they also thought about the existence of God, and some of them experienced a change in their belief in God after the death, from a stronger belief in God to the notion that there is no God:

> The actual belief in God, it's changed since I can't understand how anybody can believe that there's a God when everything is so horribly unfair and there's nobody who's in charge of everything, and all my relatives wouldn't have died.

*Creating one's own view.* The adolescents described the information that they received about the illness and what could happen during the period of the illness as positive, because it gave them a sense of understanding. They had time to prepare themselves for changes that would come, which made the inconceivable situation more conceivable. The adolescents were ambivalent toward being given information. It may have a negative content or present facts that they, in fact, did not want to know. It was good to be given information but there was a risk that the information would have a great effect on them:

> But I don't think I could have waited because . . . I wanted to know exactly—I had so many questions. It felt terrible, depressing . . . it changes your life—life is never the same again after you get that information.

The adolescents came to their own conclusions according to the information they had received. The conclusions may have been unrealistic, but none of the adolescents asked an adult in their surroundings about whether they actually were. This meant that their conclusions became a truth to them.

> I knew that about 50% of people who have cancer die—statistically, she wouldn't make it since she had made it once before.
>
> It sounds pretty horrible when you—cancer—sounds horrible, but at first they thought it was only the ovaries, so then I thought it wasn't so bad—after the operation everything would be okay again.

*Meeting the inevitable.* The adolescents described all the changes as being very burdensome, and the physical deterioration heightened their insight about the fact that the parent would die. The adolescents had feared and tried to push away the day the parent would die, but when it was clearly drawing closer they had a strong feeling of its not being real. Intellectually, they knew what was happening, but they had difficulty accepting it. They swung between comprehending and not comprehending that the parent would soon die.

Being present at the parent's deathbed made it impossible to ignore the inconceivable fact that the parent would die. The closeness and practical health care made the death and loss clearer and more conceivable. Keeping watch over their parent made them feel good. It was important to sit by and help, and it made the unreality they experienced into something more concrete.

> /Sitting by the parent/ It was very unreal—I didn't want to sit there and think that it's close now, it was like I couldn't really understand it. It was nice to be there. . . . I just felt that—it's now that she's dying and I should understand it but—I couldn't really understand it.

The adolescents described what they experienced when they understood that the parent had died as being very strong. They explained that it was a strong feeling of unreality, but that no words could describe the feeling because words were too weak to convey it.

> I can't really describe—only saying sad feels so little.
>
> I got like—just crazy, you could say, I shook like this—my body.

Seeing the parent dead also gave a strong feeling of unreality. It was a very difficult fact to accept that the parent was not alive, even if it was possible to comprehend it intellectually. Returning to the dead parent several times made the death more conceivable.

> I remember exactly how it felt but I can't really explain it either—Somehow it's like you flinch—It was like that for me—that—almost like the air was all used up—that you breathe.

The adolescents whose parents died at home experienced the death as more conceivable because the parent was there in the home and close to the family. When the parent was taken to the morgue a few hours after the death, it was a confirmation of the parent in fact being dead.

> The ones who came with the stretcher, put him in the car—Oh my God, what are they doing, are they taking my dad! I stood in the window and watched—What are they doing! When they put him in the car—unbelievable that he's just, like, lying there—scream at them, I did that—It was like a confirmation that it's true, he's dead.

The adolescents described time as something that affected their grasping the inconceivable. It took time to grasp what was happening and to live with that before the next change occurred, to become prepared for what would come. They experienced the period of illness as having passed too rapidly and the changes coming too quickly. Still, it was the passage of time that eventually contributed to them conceiving that the parent was dead.

*Feeling of unreality.* The adolescents described a strong desire just after the death for the parent to be alive, although they knew this was not so. The experience of the parent's death was still too inconceivable and they still had hope that it had not happened.

> I wanted to imagine that nothing had happened.
>
> It was really weird because—I was in the bedroom almost all day, then I went to the bathroom and when I came back, maybe he's alive—or something like that, your thoughts are so weird!

The feeling of incomprehensibility and not grasping that fact that the parent was not alive could return in the years after the death, as a strong feeling of unreality and that something was wrong, that perhaps the parent was alive, if only for a brief moment.

### *Managing the Threat*

The threat that the parent's illness and death meant to the adolescents put them in a vulnerable situation. To create a feeling of well-being, they were forced to manage the threat in different ways. The ways that they did so could vary with time depending upon how the situation developed.

*Restoring order.* This aspect of managing the threat includes the adolescents' descriptions of their attempts to normalize the situation, create a good atmosphere, and provide relief.

The adolescents wanted and tried to make their lives function normally and as usual despite the change in the situation. Their everyday life with its routines and structure gave them a sense of security.

They wanted to bring order to the changes that the illness had forced on the ordinariness of everyday life.

> You want anyway to have your usual situation and have your usual family. Everybody tried to make everything like usual.
>
> We tried to be like usual. She wanted it to be like usual, I did too, she didn't want us to be taking care of her all the time.

The adolescents also said that, despite their strong desire for life to be as usual, they were aware that it was not. Even after the death, they attempted to make life as it was before although they knew that the death of the parent meant that it was not as it had been before.

> I still pretend that everything is like usual. So most of the time I think I'm trying to pretend that nothing happened. It's easier that way anyway! 'Cause then you feel better because you're happier than if you're going around unhappy.

The adolescents felt that it was important to create a good atmosphere at home, as that increased their feeling of well-being. A good atmosphere at home was experienced as increasing their feeling of hope.

> I tried to make the atmosphere good—'cause I believed pretty sure that she'd survive.

Family and friends involved themselves in the family, and the adolescents experienced that as a relief, although they saw it more as a support for their parents than for themselves. For several adolescents, the time spent with their closest friends was an opportunity for relief. Their friends were there as usual, and they generally did the same things that they had done earlier. They saw their circle of friends as a protected zone in which they did not have to think about the illness.

School also functioned as a relief for the adolescents, as they could relax there from the parent's illness/death. The adolescents said that it was difficult to deal with both the home situation and schoolwork, but that it was still good that school was as it usually was.

*Seeking closeness.* Another way of managing the threat was to actively seek more contact and closeness to the ill parent, for whom they had strong feelings. The adolescents said that it became more important to them to be together with the parent during the period of the illness than it had been when the parent was healthy.

> I chose to be at home during the days—There was a lot to cope with then, that she wouldn't survive—I thought then it felt better. It was calm at home.

Consciously seeking contact with the ill parent to make him or her happy was also described as a way to have the parent with them for as long a time as possible. This closeness was seen as a way of making the grief that was to come easier. The adolescents expressed satisfaction at having spent more time than before with the dead parent, which meant that they also had brighter memories from that difficult time. Not seeking contact during the period of illness was experienced very negatively after the parent's death. The wish to have talked and spent more time with the parent during his or her illness was strong, and there was great grief over not having done so.

> I tried to spend a lot of time away from home and that's the worst thing—If I could get that time back I'd talk more, I'd, like, be with her.

*Adapting*. This aspect of managing the threat includes the adolescents' descriptions of how they adapted to the changed situation and what it meant in the form of taking consideration, letting others be more important than themselves, and feeling guilt.

The adaptation to the new conditions meant that the adolescents had to help more in practical things as the ill parent gradually lost strength. The adolescents took more responsibility for cleaning, washing, and other household chores. They described this adult responsibility as natural.

> Mom usually did pretty much at home, it was fun to help. We didn't want her to be doing things, she was sick.

Adapting also meant taking great consideration of the ill parent, whose well-being came first. The adolescents could also help the healthy parent when he or she did not have the physical strength to take care of the ill parent. In addition to the situation itself forcing the adolescents to adapt, they also made their own active choice to do so.

> It was just to—like, take it during that period of time, then it would be okay!

The adolescents said that they were often forced to let other considerations go before their own wishes and needs. They felt that the parents understood this and wanted the adolescents to the greatest extent possible to live as they usually did. This frequently did not work, which might have been a consequence of the adolescent himself or herself choosing not to insist on his or her own desires, but it was also be the case at times that the situation itself thwarted plans that had been made when the parent suddenly took a turn for the worse. The adolescents could feel guilty about their inability or lack of desire to accept the consequences of the illness. It was taken as obvious that the adolescents would help the parent who was ill, but at the same time the parent's change triggered other, more negative feelings. Words such as "not disgusting, but," or "horrible," or "annoying" were used. In some situations the adolescents were ashamed of the parent and did not want the parent to come along to activities or for other adolescents to see when they helped the parent. They also felt guilty toward the healthy parent during the period of the illness, although this was primarily so after the death. The adolescents saw the remaining parent's grief but did not have the strength to help or gave priority to other things, which gave them a bad conscience. Constantly having to take consideration provoked anger, and this in turn gave them a bad conscience.

> I almost got a little mad at him! . . . Not being allowed to sleep! . . . but then you remembered that he was so affected—I got a little unfairly angry with him.

*Gaining control.* One way of managing the threat was to try to gain control of the situation, both to help prevent changes as much as possible and to prepare oneself for the changes. The adolescents experienced it as positive that the parent was cared for at home and was close at hand because they could then follow what was happening and take greater part in it. This made the feeling of having control of the situation stronger.

> /at changes/ Yeah, I knew about it, why. So it wasn't anything so—And it was nice to know, why she had to do one thing and another.
>
> And it was good to know how it was for her when she was there [at the hospital] too, it was a good thing.

*Avoiding talking about the illness.* An avoidance of talking about the illness or how the situation was being experienced was described as another way to manage the threat. The adolescents neither wanted to talk with the ill parent nor with others.

> I didn't want to talk about it—I just wanted to shove it away, I wasn't exactly the most receptive person during that time.
>
> It felt easier not to think a lot about it, not to have to think about what it is.

Still, there was an ambivalence about talking about the parent's illness and death, and they did speak about it sometimes. It was often the healthy parent who took the initiative to talk. The adolescents said that it sometimes felt good but that they preferred to avoid talking about the situation. It also happened that some special friend was appreciated for being able to be someone with whom they could talk about the parent's death.

*Not accepting.* The adolescents showed a resistance toward accepting that the parent was seriously ill and would die, and this resistance became a way to manage the threat. An important part of the resistance was to maintain hope. During the entire time until the parent died, they had a hope that he or she would survive, despite the information they had been given to the contrary. The hope for a change in a positive direction gave them the strength to continue and not to lose courage.

> I thought she'd live. It maybe would have taken time but it would be okay in the end. But that was wrong. It went pretty quickly.

The resistance toward accepting the parent's illness was so strong that the adolescent ignored the fact that the illness was a threat to the parent's life. An aversion to gathering information about the prognosis of the illness was described, and the explanation given was the strong belief that the parent would regain his or her health. Neither did the negative progression of the illness affect the belief that the parent would become well and that everything would return to normal.

> I didn't think I had to know anything more about it—I thought, it doesn't matter what it actually was. Because I anyway didn't believe it—all the time up until she died I thought it was going to be okay.

In situations in which the parent was clearly deteriorating, the resistance toward accepting it remained at the same time that there was a growing insight as to what was coming. The adolescents swung between hope that the parent would become better and an unawareness that the parent was dying.

*Counting the parent out.* Counting the parent out means that the adolescent considered the parent to be dead early on in the course of the illness. The threat of the coming death was described as being extremely strong, and a way to achieve some form of well-being in this threatening situation was to see the parent as dead and adapt life according to that. In concrete terms, this meant that being told of the parent's serious illness had the consequence that an adolescent withdrew from contact with the parent, spoke less with him or her, and did fewer things together with him or her. The adolescent tried to get out of the home to different activities and started to spend a great deal of time with friends. The parent was gradually counted out and the adolescent began to see him or her as dead before the death actually occurred.

> /after receiving information about the illness/ It was like Mum died. I counted her out as being there for me.
>
> I didn't really see Mum as a part of my life anymore like the others.

## I Bear This Alone

The adolescents said that they felt very alone in their attempts to conceive the inconceivable and find ways to manage the threat. There was a feeling of loneliness and alienation despite their having family and friends with whom they were close, and the feeling was there both during the parent's illness and after the death. The adolescents did not actively seek out their parents for support. While they primarily saw the healthy parent as an important source of support and help for the ill parent, they also viewed him or her as a background that stood for a sort of obvious security, not only for the adolescent but for all the members of the family. There were exceptions, however, and, there, the healthy parent was an important support for the adolescent. The adolescents did not seek out their siblings for support; they said it was more the case that their siblings lived in their own individual worlds and coped with the situation in different ways.

> I didn't talk to my brother about it at all—I knew that I wouldn't get an answer—he thought it was hard, he shut himself out, it just hadn't happened.

Although the adolescents felt they were alone during the period of the illness, that situation could change after the death of the parents. The loneliness and the grief they shared over the dead parent connected the members of the family again.

The adolescents said that they had not wanted the support of professionals during the period of the illness or in connection with the death because they felt that no one could help them. They said that they changed their minds after the death and that they were now aware that it may have been helpful to have had contact with adults and professionals during the time of the parent's illness or at his or her death.

The experience of loneliness was made stronger by relationships with friends. They felt that their friends never asked them about the ill parent or about how things were for the adolescent himself or herself. The adolescents felt that their friends did not understand what they were going through and said that they thought afterwards that it would have felt good had their friends asked them about it and showed more interest. At the same time, they felt that their friends' lack of understanding made them not want to talk to them. The consideration that their friends showed and their lack of understanding strengthened their loneliness. This remained after the parent's death, because some of their friends still avoided talking about the deceased parent and about how things were for the adolescent. Being able to talk about the parent was described as important because he or she was still an important part of the adolescent's life.

> They avoid the subject—don't want to stir up a lot of memories ... but it's really nice just to feel that I'm talking about her ... that she actually has existed.
>
> They were really careful, they think that I'm so unstable but ...

In the experience of loneliness there was also a feeling of being singled out because of the extra attention they received. The situation at home was sometimes so stressful for them that they did need extra consideration, for example at school. However, being the object of others' consideration could also mean that the people around them pitied them, which they did not want.

> It was alright for the teachers to know, but I didn't want the others to pity me.
>
> I wanted them to be like usual when I came back and not for them to avoid me or think "poor little M." But it really was that they looked at me—I didn't like it.

Behind the experience of loneliness was also a desire to be alone, which made the adolescents withdraw from contact with friends during their free time. The purpose here was to achieve peace and quiet after the end of the school day and have the opportunity to spend more time with the parent.

### A Changed Life

The adolescents said that what they had experienced during the parent's illness and death was something that would have an effect on them for the rest of their lives. The parent's death also meant a great change for them in the sense that they did not have the parent to talk to, ask questions of, and get support from. The adolescents expressed great sorrow over the deceased parent not being there later in their lives and not being able to share important events with them, such as graduating from school, starting a family, and so forth.

The adolescents said that, despite their grief and missing the parent, the loss also made them feel a change that they described as positive. They had been affected in their relationships with other people through their experiences, and their empathy with others had grown. The experience had given them greater respect for other people. The older generation was mentioned in particular. The older generation (grandparents) was seen as an important link to the deceased parent because of the biological connection and because of the memories the older generation had; they could tell stories about the deceased parent.

> I've gotten a lot of positive things from this experience . . . I see the world with different eyes than I did then . . . I believe a lot in the experience in the world and the life experiences that older people have. It has to do with respect because they know a lot more than we do.

The adolescents said that the experience of the parent's illness and death had made them more mature than their friends were and that there could be a great difference in maturity between some of their friends and themselves, which had not been as clear earlier. They saw their friends as more superficial and focused on material things more than they were and said that they did not think that their friends' values were as well thought out as their own. At the same time, they expressed an understanding of their friends, who had not had the same experience.

> You get smarter this way.

> Mentally superior to most of the others.

> In terms of social things and trying to think yourself into how people feel, taking consideration to people, I feel that I've come a lot farther than [my friends]—umm, I have a higher grade in that.

The experiences of these adolescents had also influenced their values about what is right and wrong and their plans for their future choice of occupation. Working with people and giving priority to relationships over making a lot of money were described as important criteria in their choice of occupation. The adolescents said that they had altered their thinking about life and its changeability. They experienced a greater awareness that difficult events can occur in anyone's life and that nothing should be taken for granted. This was expressed as a greater understanding of life.

> That this really can happen to anybody regardless of what their background is or what you do. So just that, that thing, that you don't take anything for granted, it'll never happen to me—I guess that's what you have now, that it's not happening to me but that it's perfectly possible."

## DISCUSSION

### Methodological Issues

A qualitative method was judged to be most relevant for achieving the purpose of the study, to describe adolescents' experiences at the illness and death of a parent. Interviews offered the opportunity for flexibility and a perceptiveness toward the adolescents, which is judged to be of great importance considering the sensitive nature of the study.

The knowledge and experience that make up the preunderstanding of the first author formed the basis of the perspective taken in the research process. The preunderstanding is not considered to have limited the adolescents in their narratives, as they gave a rich material concerning their experiences. Preunderstanding must instead be seen to have brought forth more material than would have been the case if the knowledge had not existed. The interviews had more of a conversational than an interview character, which meant that sensitive questions could be asked in a natural way. This study deals with strong experiences and feelings, and a further aspect in addition to preunderstanding is of a more ethical nature. It is necessary in this type of study that researchers have knowledge about people who are grieving in order to be able to say that good ethics have been observed (Skinner Cook, 2001), which the occupational background of a trained social worker provides.

The adolescents were interested in the study and were motivated to participate, which contributes to reliability and applicability (Patel & Tebelius, 1987). The interviews consisted of open questions that were allowed to develop in the dialogue with the adolescents, and they spoke about their genuine experiences. In spite of the fact that there was a risk that the interviewees could be disturbed by the questions, provoking strong emotions, this was not judged to have affected either the data collected or the results. The adolescents' experience that the interviews were positive despite their strong feelings is confirmed in earlier research (Dyregrov, 2004) and can also be understood as an expression of the research question being perceived as relevant. The purpose of the study is judged to have been satisfied, as the adolescents gave extensive descriptions of their experiences.

In the interpretation of qualitative data, the researcher is not limited to the transcribed interview but can also note information about nonverbal communication that must be interpreted in the context in which it has occurred (Van Manen, 1990; Kvale, 1997; Malterud, 2001). Considerations were taken to this nonverbal communication in interpreting the results and is of the understanding that grief is present throughout the adolescents' stories even if grief as a word is not named.

After conducting five interviews, it was judged that the amount of richly varying, concordant, and detailed data were sufficient to describe adolescents' experiences in the event of a parent's serious illness and death. The categories that developed during the analysis give a good representation of what the interviewed adolescents said.

The purpose of the study remained in focus during the entire process, both in the choice of participants and in the data collection and analysis, which contributes to internal logic, a quality criterion set in qualitative studies (Larsson, 1993). The results of the study are judged to be applicable, as adequate methods for data collection and analysis were used for this type of study. The adolescents who were interviewed were selected according to strategic principles and were to the greatest possible extent affected by the study questions. The results are judged to agree with the complex reality that is and was the life world of the adolescents, in spite of the fact that no words can completely describe their experiences. The fact that the interviews were conducted in certain cases almost 3 years after the parental death probably contributed to the memory of the time of the illness and death having been worn down to some extent (Patel & Tebelius, 1987).

The aspect of accuracy should be satisfied considering the repeated testing and comparisons that were a part of the analytic process, such as observations of contradictory information, both decontextually and contextually. The carefully transcribed interviews and the notes concerning pauses, reactions and so forth that were made during the interviews were used as complements to the narratives, which is seen to increase the trustworthiness of the results (Patel & Tebelius, 1987).

## Issues Related to the Results

A clear part of the adolescents' experiences during their parent's illness is their strong desire for the parent to survive. This may seem to be natural, consistent, or simple behavior, but the results indicate that there is a more complex meaning in this desire. It seems that the threat that the illness poses made the adolescents' desire so strong that it gave them extra strength to manage their difficult situation in some cases. It also seems that the desire nurtured the hope that they harbored during the whole period of the illness and that it allowed the resistance toward accepting the fact of their parent's serious illness to be maintained. The adolescents swung between an intellectual understanding of the incurable illness and the hope or belief that the parent would regain his or her health.

The many expressions concerning how the threat of the illness was managed indicate that the adolescents were in a situation of stress (Frydenberg, 1997) during the parent's illness that they were forced to address in some way. The approaches described by the adolescents are judged to correspond to different forms of coping strategies (Frydenberg, 1997; Folkman, 2001; Stroebe & Schut, 2001). Developing coping strategies is an important part of working through different events and losses to achieve some form of health and well-being (Frydenberg, 1997; Stroebe & Schut, 2001), and the adolescents' descriptions show that managing the situation was an obvious fact and a challenge as they were forced to deal with a situation that was new and unknown to them. Coping strategies that are applied in the case of grief are ones that focus on the problems and the emotions at hand as well as confrontation (moving closer) and avoidance strategies (Stroebe & Schut, 2001). Confrontation strategies with a certain measure of avoidance strategies seem to be positive in working through bereavement. Too much confrontation or too much avoidance is damaging to adaptation (Stroebe & Schut, 2001). The different approaches to managing the situation that were manifested here clearly show that the adolescents consistently used emotion-focused and avoidance coping, even though some of the coping methods (gaining control and not accepting) can be considered more as confrontation strategies. The adolescents' use of more emotion-focused and avoidance strategies agrees with research showing that these types of strategies are used in situations that cannot be changed or over which one has no control, such as an illness that will lead to death (Frydenberg, 1997; Stroebe & Schut, 2001). It would be possible to use Stroebe and Schut's (2001) Dual Process Model (DPM) of Coping with Bereavement to understand and support adolescents whose parents are ill or have passed away. This is a process model developed to understand how coping adapted to stressful events such as serious illness and painful losses can lead to a good development in working through grief. The clearly conscious will and need in adolescents to manage the incomprehensible situation must be seen as an additional feature beyond what has previously been reported in qualitative research in the area (Semmens & Peric, 1995).

The two subcategories, an inconceivable state and managing the threat, are described separately in the results but can also be seen as interactive parts of the same process, which has not been seen in earlier research (Semmens & Peric, 1995). The different aspects of managing the threat affected the situation, just as the aspects of the inconceivable situation affected the coping strategy that was used. In the process, the aspects of both parts swung back and forth. At the same time it seems that the different managing aspects influence the understanding of the situation to a greater or lesser extent; for example, seeking closeness is an aspect of managing that can be assumed to diminish the incomprehensibility of the situation. Another example is that the aspect of not accepting can pose an obstacle to a growing understanding of the situation. Attempts to identify patterns and ascertain relationships between different managing aspects and an understanding of the inconceivable situation are interesting tasks that can be approached in further research based on adolescents' descriptions.

The adolescents' description of living under a threat can be related to Antonovsky's (1987) theory on factors that promote health, which brings up the experience of context by being able to comprehend the situation, manage difficult situations, and see meaningfulness in what takes place. The adolescents tried in different ways to understand what happened and succeeded over time in making the inconceivable more conceivable. The conscious attempts to understand indicate that, in difficult situations, the concept of comprehending is that it is a task that requires effort to work through and that these efforts are made in a successive manner. The adolescents sought different solutions or means to manage the situation, means that varied during the time of the illness and after the death. Some of the solutions seem to have been more expedient than others, foremost restoring order and seeking closeness, as the adolescents experienced them as positive, and these managing strategies must thus be seen as having contributed to the sense of coherence (Antonovsky, 1987). At the same time, another aspect can be added to the manageability, namely, the goal of finding ways to manage the situation. The adolescents sought different solutions or means of tolerating or managing their difficult situation. At the same time, all of the adolescents retained a hope that the parent would regain his or her health, and seeking closeness is described as a way to keep the parent as long as possible. The goal of the managing strategies can have been both to tolerate/manage and to make the parent's regaining of health possible. The goal of managing the situation also relates to being able to see what is meaningful. If the goal is to tolerate/manage and to affect the parent's return to health, it must to the greatest extent be considered meaningful to the adolescents that they find the means to manage the situation. Still, it seems that the adolescents had different experiences of being able to see what is meaningful in understanding the situation, as we observed both clear efforts to find solutions and avoidance. The extent to which the attempts were experienced as meaningful seems to vary depending upon how the situation changed.

It was found in the adolescents' narratives that they felt that they had developed as individuals through the illness and death and that they had matured, changed their values, and focused more on relationships with others. Their feelings show good agreement with the results of other studies (Balk & Corr, 2001; Schaefer & Moos, 2001). Personal development after the death of a loved one takes place when a person is actively grieving and grasping through self-reflection what the loss means. Personal development can be seen in greater empathy, greater self-awareness, and greater self-esteem (Schaefer & Moos, 2001). Greater maturity after the death of a loved one is considered to be dependent on adolescents often taking greater responsibility (whether it is of their own volition or forced upon them) during the time of the illness and at the death and their being forced to master the emotional pain that they experienced during that time (Schaefer & Moos, 2001). The adolescents' descriptions show that they took responsibility in the situation at hand and that the threat that they experienced can be compared with the emotional pain that must be mastered.

The alienation from their friends that the adolescents described has also been reported in previous research (Harris, 1991; Balk & Corr, 2001; Harrison & Harrington, 2001; Christ et al., 2002). The adolescents described their feelings of loneliness over having experienced something that their friends had not. This meeting with death early in life invokes an awareness of one's own death, and thought is given to the meaning of life. These experiences and thoughts are difficult to share with peers and can give rise to an alienation from friends and the interests that they had had in common (Schaefer & Moos, 2001). The adolescents also described their desire to talk with friends about their parent but said that most of their friends avoided asking questions or showed no interest. Balk and Corr (2001) describe similar findings and claim that it is challenge for many grieving young people to find new ways to be together with friends who avoid the bereavement.

The adolescents did not seek their parents' active support, which agrees with other research on adolescents in situations of bereavement. The result showed that these adolescents sought support to a lesser degree than adolescents generally do (Frydenberg, 1997). That the adolescents in the present study did not seek support in the ill parent may have to do with their not wanting to burden the parent and to the greatest extent possible not allowing the illness to affect their relationship. Neither did the adolescents seek the help of the healthy parent, although there were exceptions, and this can be interpreted such that they avoided talking with the healthy parent, in part because he or she was busy taking care of the ill parent and in part because they did not want to talk about the situation themselves. Many parents wish to protect their children in difficult situations, and this may result in children and young people feeling alone as no one speaks with them about their anxiety (Heyerdahl, 1999).

The adolescents' experiences indicate that the family was felt to be a support after the death and that their common bereavement bound them together. At the same time, there were feelings of guilt toward the remaining parent, as they had not had the strength or been able to support the parent to the extent they wished. This contradictory experience is supported by other research (Rask et al., 2002) that shows that, whereas many adolescents experience the remaining parent as a support, others feel them to be a burden after the death.

## CONCLUSIONS AND IMPLICATIONS

The adolescents' experiences of a parent's serious illness and death have to do with trying to make the inconceivable fact of their parent's illness more conceivable. The adolescents' inconceivable and threatening situation made it necessary for them to develop different managing strategies so that they would be able to deal with the situation, prepare themselves for changes, and also, in spite of all the difficulties, retain a hope that the parent would become well. They tried to push away thoughts about the illness so that their life would to the greatest extent possible be the way it was before the parent fell ill. They had strong feelings of being alone, despite the closeness of their family and friends. The parent's illness and death meant great changes. The absence of the parent meant changes in their everyday lives and in their future lives. These experiences led to a personal development in terms of greater maturity and an awareness of the meaning of relationships, values, and existential questions.

To test the results of the study, future research should include quantitative studies based on the results of this study. To penetrate more deeply into adolescents' experiences, the subject can be divided further by making separate studies of the period of the illness, the time of the death, and the time after the death. It is also interesting and important to investigate patterns of interaction in the process of living under the threat of a parent's serious illness and death. A longitudinal study following adolescents over a period of several years to investigate what effect a parent's illness and death has in adulthood is also an important research task. A study of this kind would allow an evaluation of the choice of coping strategies, for example, which would give important information about how adolescents with a parent who is ill or has passed away can be supported early in the process.

Losing a parent is seen as one of the greatest stress factors that an adolescent can experience (Frydenberg, 1997), and it is very important to offer support in this difficult situation. Developing a support program adapted to adolescents' experiences and needs would allow a possibility to help adolescents and their families. The results of the present study together with the DPM model (Stroebe & Schut, 2001) can form a basis for developing a support program whose purpose would be to prevent effects on health.

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