


A Qualitative Study of the Experiences of Parents With an Adult Child Who Has a Severe Disease: Existential Questions Will Be Raised

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Abstract

A prominent existential concept is that elderly parents should naturally become severely ill or die before a younger person does. If the reverse should happen, it may influence the parent's existential view of life. The aim of this study was to investigate the existential issues during illness time. This was a qualitative study with in-depth interviews and was conducted in a University Hospital in western Sweden. Eleven parents agreed to participate in individual interviews at baseline and 1 year later. The total number of interviews completed was 19. The study identified 5 areas according to an existential perspective: *life took the wrong path, the age of the child, difficult to see the child as sick, worrying about the child, and the relationship with the adult child*. Existential questions are often present in those circumstances and can be raised in conversations with parents. Existential questions began to arise for the parent when the child was diagnosed with the severe illness. The situation of having a severely ill child caused both fear and anxiety that the worst-case scenario they could imagine, that the child will die, might happen. Further research is required on this rarely investigated subject of having an adult child with a severe disease.

Keywords

adult children, anxiety, existential, parents, qualitative study

Introduction

Encountering a life-threatening illness will awaken existential issues, including those related to dying and death, hopelessness, meaning, and guilt, according to Yalom.¹ When an adult child becomes ill, this is a special circumstance where questions around the perception of life and sense-making themes can arise, as well as questions about life and death.^{2,3} The intergenerational relationship that exists between an adult child and a parent can be a lifelong one, regardless of how the relationship might appear. The ties to a grown-up child can be an older adult's most important relationship.⁴ The relationship between a parent and an adult child can vary throughout their lifetimes, from being a close relationship to a broken relationship, but also includes the strength of the emotional bonds between the generations and their exchange of social support.^{5,6} In the Western world, where the population is becoming more elderly, one widely accepted existential concept is that an elderly person (for example, a parent) naturally dies before a younger person (the child), as described by Smith et al.⁷ But what happens when an adult child becomes seriously ill with a fatal disease? There are several aspects that arise when this happens; one can be how the parent can and is allowed to support the child in a social and practical way during the time of illness. Another aspect

is the qualities of the intergenerational ties; that is, how they have reciprocally related to each other as well as what the child has meant to the parents, from their childhood to the present day as an adult person. This can be both in the form of emotional solidarity and ambivalence in their roles, as well as how each individual identity might influence the other's. When an adult child becomes ill, this might mean, as expressed by Smith et al,⁷ that the elderly person loses a sense of purpose in life, and some even feel a loss of identity when they have lost an adult child. Another aspect is how the adult children might feel the need to provide practical support to their elderly parent but are unable to do so.^{6,8,9}

A recent study investigating the experiences of being a parent to an adult child with a severe illness identified the forms of mutual support and strategies that were most helpful to the parents during the child's period of illness.¹⁰ The strategies that most helped them to cope with the situation

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Table 1. Characteristics of Study Participants.

Gender	Female (n = 11)	Male (n = 0)		
Living situation	Living alone (n = 5)	Cohabiting (n = 14)		
Age	51-60 years (n = 6)	61-70 years (n = 5)	71-80 years (n = 5)	81 years and older (n = 3)
Employment status	Employed (n = 6)	Sick leave (n = 0)	Retired (n = 12)	Sick leave and retired (n = 1)
Education	Elementary (n = 7)	High school (n = 6)	University (n = 4)	No answer (n = 2)

consisted of both thinking and doing. In addition, they had a need to be informed, and to participate by doing something useful for the child, which included providing both emotional and practical support. They also needed to have the opportunity to talk to someone about the situation as well as other things in life that were not connected to the illness, which was a strategy that helped provided them with some respite from the severity of the situation.¹⁰ Despite the insights revealed in that study, the experiences of parents of an adult child who is severely ill are not well understood, and very few studies have explored this subject; in a review of the literature, we found only 2 studies (Dean et al⁸ and Smith et al⁷). Dean et al described the element of uncertainty experienced by the parents during this stressful time, whereas Smith et al⁷ investigated what it meant to an older person to lose an adult child. Having a better understanding of these issues would assist in helping health care professionals to support these individuals. The aim of this study was to perform a deeper investigation of this issue to identify whether there are existential issues for a parent who has an adult child with a severe illness.

Methods

The data were collected as a part of an earlier study with the aim of exploring parents' experiences of having an adult child with a severe illness.¹⁰ To gain a deeper understanding of whether existential issues are raised as an issue for parents of an adult child with severe illness, the study adopted a qualitative approach and employed in-depth interviews. The study was conducted in a University Hospital in western Sweden over a 14-month period between September 2013 and November 2014. The study was conducted at the hematology, oncology, and urology departments, at any time during the child's illness.

Participants

Twenty-five patients asked their parents whether they wanted to participate in the study; 14 parents did not want to be interviewed or did not return the consent form. Eleven parents agreed to participate in an interview at baseline with an opportunity to participate in the second interview 1 year later. The purpose of conducting the second interview was to investigate whether there were any differences between the early period of the illness and the later stages of the disease.

The only exclusion criterion was that the parents could not participate if they were affected by dementia. Eight of the parents agreed to participate in a second interview after a year, even if their child had died. After a year, 6 of the adult children had died. Of the 11 participants who agreed to the first interview, only 3 did not participate in the second interview—2 because they were not willing to discuss the issues relating to the death of their child, and 1 because they could not be reached. The total number of interviews completed was 19. The characteristics of the study participants are presented in Table 1.

Sample Characteristics

All 11 participants were mothers and their ages ranged between 51 and 83 years. The participants' adult children were affected by a variety of life-threatening illnesses, such as leukemia, and cancer of the breast, kidney, testicle, and colon. The ages of the sick adult children ranged between 35 and 65 years, and 6 were daughters and 5 were sons.

Data Collection and Analysis

The parents decided where the interview should take place, and this was either at the hospital, at their home, or as a telephone interview. The interviews lasted between 30 minutes, for some, and 1 hour, for most. The interviews were conducted using a conversational approach, which means that the interview was in the form of a conversation with the parents telling their story of their experiences and thoughts. The topics of the interview questions were the same for all interviews, irrespective of whether they were first or second interviews.

To ensure adherence to the research questions throughout the interviews, certain key questions were highlighted, but if a research question had already been covered in the interview by the parent, that question was not asked. The key questions for both interviews were "What did you think when you received the information about your child's disease?" "How do you manage daily life?" "What is it like being a parent to a sick adult child?"

The interviews were analyzed using qualitative content analysis. The interviews were conducted by the first author and were transcribed verbatim. The qualitative content analysis method goes beyond counting the frequency of certain words in the text by interpreting the latent content that emerges from the text, and the analysis was done in the

Table 2. Examples of the Analytic Process.

Interview question	Theme	Subtheme	Subtheme
What did you think when you received the information about your child's disease?	Life took the wrong path	A child, regardless of their age, should not die before their parents.	Life was paused and the parent could not think that it was true.
How do you manage daily life?	Difficult to see a child affected by illness	Fear of what is going to happen, is constantly present	The parents' relationship provided various ways of coping with the fear and anxiety
What is it like being a parent to a sick adult child?	The parent had an important function, both practically and emotionally, for their child	It was a relief to be able to do something in daily life for the child	They struggled between showing their own fear and being supportive to the child.

close examination of the topics and themes defined in the research question.¹¹ The analysis was carried out in close cooperation by both authors to ensure that the results were interpreted as objectively as possible. All interviews were analyzed by both authors together. Any differences were discussed and a common description was formulated. The analysis comprised several steps. Initially, the text that was relevant to the research issues was marked. Units of meaning were then identified and grouped into codes. These codes were subsequently discussed, compared, categorized, and labeled. In the final step, the categories were structured into subthemes and themes, as described by Patton¹² and Graneheim and Lundman.¹³

For examples of the analytic process, see Table 2.

Ethical Consideration

The study was approved by the Regional Ethical Review Board in Gothenburg (680-06). The participants were given written information and gave their informed consent to participate. No reminder was sent after they were given the information, to respect the individual's decision not to participate in such a study. The choice to decline to participate in a study of this kind must be deeply respected.

Trustworthiness

Many factors need to be taken into account to ensure trustworthiness in qualitative research. To ensure credibility, all of the participants in this study were parents to a severely ill adult child. Despite the differences among the participants in terms of their age, the results reveal many similarities between them. To reduce the impact of the investigators' preunderstanding of the phenomenon, the interviews included questions that were aimed at elucidating the experiences of the participants.¹¹ Data saturation was found to have been achieved in the analysis, which strengthens the trustworthiness of the results and the transferability to others in the same context, that is, to other parents of adult children who are affected by severe illness.¹³

Results

This study identified 5 existential areas: *life took the wrong path*, *the age of the child*, *difficult to see the child as sick*, *worrying about the child*, and *the relationship with the adult child*. Existential thoughts, in relation to the parent's life, began to arise for the parent when the child was diagnosed with the severe illness. The situation of having a severely ill child caused both fear and anxiety that the worst-case scenario they could imagine, that the child would die, might happen. Life would never be the same again, even if the child were to be cured, because this experience would remain a part of them for a long time.

Life Took the Wrong Path

The parents' first thoughts and feelings were that the child was going to die. A common feeling was that this was a wrong pathway in life because children, regardless of their age, should not die before their parents. This raised thoughts about faith and belief in life according to justice as well as other existential questions.

It had been better if I had been the one to be ill, I am at least old. Your child should not be so ill. (Mother to a son with cancer)

There was also a sense that what had happened must be unreal. It was as though life was paused and the parent had a feeling that it could not be true. It was that they questioned the normal idea of life expectancy.

To be a parent to a child (who is ill) is nothing you wish, it is something you absolutely would like to avoid—it is awful. (Mother to a son with a hematological disease)

There were existential expectations that the child should be a part of the parent's life in the future. When the child became ill, those thoughts were taken into question.

You think that your child shall go arm-in-arm with you and support you, not that you shall carry the child's burden. (Mother to a son with a hematological disease)

The Age of the Child

Some parents felt that it must be worse to have these experiences with a very young child with whom you cannot speak. Others thought that having a severely ill adult child who you have known for a longer period of time and with whom you have a long relationship with, one which now shall be broken, would be more difficult to cope with. Regardless of how they approached this experience, it was the actual illness that had caused the feelings of insecurity of not knowing whether the child may have a future.

I have lost a child that was young and very ill. He was a year old but P was a grown-up and he has been around so he has made more impact inside me. (Mother to a son with cancer)

Difficult to See the Child as Sick

The parents were united in their perceptions that it was difficult to see a child affected by illness. A form of grief, in that the child is not well and the fear of what is going to happen, is constantly present. At the same time, their children were adults and the parents reported feeling that this is a situation where it is someone they must care for but that it was not possible to do so in the same way that they would for younger children. This created an inner duality to their parenthood that was difficult to cope with.

It was awful to experience that four relatives (mother and siblings) died within a couple of years but this (daughter's disease) is much worse. (Mother to a daughter with a hematological disease)

Worrying About the Child

Some of the parents felt that they must be strong to help the child. They struggled between showing their own fear and being supportive to the child. Some thought that it is possible to be strong and weak at the same time while others did not want show their own fear in case that might be a negative factor for the child.

The possibility that the illness was going to take the child's life was a constant underlying concern.

We can talk about J's situation and we do not want the scenario that he shall die . . . but we have talked about it, but we avoid it . . . we do not want that he shall die. (Mother to a son with a hematological disease)

When the parents were allowed to accompany the child throughout the progress and prognosis of the illness, it could provide both hope and/or a feeling of participation. It also could give them the possibility to prepare for what would come if the treatment was not successful and for the prognosis that the child was going to die. Often the hope was that they would not think about what might happen if the treatment was not successful.

It feels as if you can't think of anything else than that he will be better and better. (Mother to a son cancer)

The Relationship With the Adult Child

The relationship with the child was grounded in the way they had previously related to the child. The parents' perceptions of the relationship provided various ways of coping with the fear and anxiety. If the child was single, the parents could participate more than if the child had their own family. The parents' feelings were that they had an important function, both practically and emotionally, for their child. It was a relief to be able to do something in daily life for the child.

He really let us be parents and he thinks it is good that we visit him at the hospital . . . on the other hand he can say, "What are you doing here today?" (Mother to a son with cancer)

When the child had their own family, the experience was that the parents were not the closest family members. This was perceived to be difficult, depending on how the relationship with the family was configured and how well the parent could cope with that distance. In both of those circumstances, the parent relied on how well they were kept informed about what was happening. If they were not able to obtain information about the disease and its development, they were exposed to various thoughts about their future life, in either a good or a bad way.

My daughter-in-law called and told me about the result . . . she is a fantastic person and no one was left not knowing. (Mother to a son with cancer)

In the first interview, the participants had the possibility to reflect upon being a parent to an ill adult child during the present time. The second interview provided the possibility for them to reflect on this matter once again a year later. Regardless of whether the child was cured, still in treatment, or had died, the participants could still describe their feelings during the period of illness.

Discussion

Having a child affected by a fatal or severe illness triggers new thoughts about life. Being in this situation can raise questions from an existential perspective which often cover existential domains, as shown by Yalom.¹ Such existential questions often have no particular answers or any simple responses, and each person must find their own answers according to their own views on life. The possibility of losing a child is a devastating experience for a parent, regardless of the child's age, as reported by Floyd et al,¹⁴ and for those parents who have a child who is seriously ill and might die, such existential questions will be raised. This study identified 5 existential areas, according to Yalom, with 4 particular

areas that arise when illness and death are near¹: *life took the wrong path, the age of the child, difficult to see the child as sick, worrying about the child, and the relationship with the adult child.*

Parenthood is linked to accompany the child from birth, and throughout youth and the child's grown-up life in the parent's inner representation. A common view held by parents is that their offspring are expected to be healthier and to live longer than themselves and that the parents should naturally die before the children is a common view in many parts of the world, as described by Rubin and Malkinson¹⁵ and Smith et al.⁷ This can cause feelings of anticipatory grief, according to what is going to happen if the child's disease will be fatal.¹⁶ The overall existential view in the present study was that it is a wrong pathway in life where a child dies before a parent and that it is hard to care for a child who is suffering. Floyd et al¹⁴ stated that the death of a child is a traumatic experience for parents at any stage of life. So, when something happens in life and the expected order does not follow this natural pattern, the view of life can be questioned. One of the areas that this study revealed was the strong feeling of sorrow and despair in knowing that the grown-up child was ill. In light of the fatal disease, the parent can have feelings of both meaningless and loneliness for the future. The parents in the study expressed that it was so wrong that a child should die before themselves that it gave them a sense of meaningless, and that feeling was strengthened if the sick child had their own children. The feeling of loneliness was often linked to whether the parent had had dreams and expectations about the child's involvement in their future life.

The existential questions revealed in this study were mainly about finding meaning in why the child was affected by the severe disease and why the child had to suffer. However, when the parents had the opportunity to support the child and/or his or her family, they experienced the feeling that they could do something meaningful, even if the disease itself could not be seen as meaningful, as reported by Dean et al⁸ and Gilbar.¹⁷ To help and to do something practical for the child was perceived as an effective strategy, and it gave the parent something to do and helped them to feel less pain, for both the child and the parent.

Some parents pointed out that they have had a long relationship with their child and that this relationship was now tainted by worrying. These intergenerational ties can be strong, and in light of an increasingly older population, the bonds between the generations can exist for a much longer time now than they could a century ago. Bengtsson¹⁸ described how there has been a shift in the family structure, from the nuclear family to many different forms of family, but also that how these bonds are perceived is of great importance for how the family members manage the circumstances that occur in their lives. Fingerman et al⁶ pointed out the exchange of support and the emotional bonds that exist between the intergenerational ties can also

influence how the parent experiences the situation. Kim et al⁵ described how the expectations about intergenerational ties can consist of mutual support for each other and can influence physical and psychological well-being as well as how the future relationship can be changed. However, even if the relationship does not have strong ties, the existential issue can be raised. The severe illness and/or the death of an adult child raises existential questions about why it is possible for younger offspring to be sick or to die before the elder generation.

Limitations

This particular research topic was experienced as being difficult, according to the anxiety that it caused patients when they asked their parents to participate in a study about their adult child's severe illness and eventual death. The study participants only comprised mothers, so the perspectives of fathers are not illustrated. The participants in this study are parents who have such a relationship that would allow their ill child to feel comfortable in asking them to participate in the study. Thus, the results may not be representative of those who did not have that kind of relationship. The transferability of this research could be called into question because the sample is not large; however, qualitative research has the advantage of revealing a more balanced insight. In the interviews, data saturation was achieved, which gives concurrence to the results.

Conclusions and Further Directions

The conclusion from this study is that existential questions often arise in the parents' view when an adult child is ill. This means that those questions need to be discussed by the health care professionals so they can be prepared to meet these existential questions when they are raised in their conversations with the parents. Further research is required on this rarely investigated subject and should be related to the specific circumstances of those parents who have an adult child who has a severe disease, particularly because this may be a growing problem with an increasingly elderly population.

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