Parents' Experiences of When an Adult Child Is Seriously Ill—"It Does Not Matter That It Is a Grown-Up Person, They Are Still Your Child"

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Abstract: Purpose and Topic: A longer life expectancy is expected to rise continuously in all populations on all continents. Older parents are at risk of having to accompany their adult children through a severe illness, sometimes even to their death. The present study investigates the experiences of being a parent to an adult child with a severe illness and what support was helpful during the child's period of illness. Method: A qualitative approach with in-depth interviews which were analyzed using content analysis. Results: The results showed that a common perception was that it is very special to have a child with a severe illness. The underlying elements of existential experience and the relationship both influenced the parents' conceptions of life and permeated the whole situation. There were four areas that the parents found important and influenced how they could manage the situation: having information, participation, strategies to cope with the situation, and support. Conclusions: Accompanying an adult child through a severe and potentially fatal disease in the context of a growing elderly population will become an increasingly frequent problem. So far there is limited research in this area and more research should be a high priority in the future.

Key words: Parent grieving, adult children's illness, grieving adult child.

1. Introduction

In the whole world a longer life expectancy is assumed to rise continuously in all continents. For example in Europe there is currently an aging population and one cause of this is an increase in life expectancy [1, 2]. This means that older people are more likely to experience younger family members being affected by seriousness illness and risk having to accompany their adult children through a severe illness, sometimes even to death.

Being an aged parent can encompass multiple dimensions. It is commonly accepted an existential concept that elders should die before the young and therefore children should not die before their parents [3]. Many studies focus on parents losing a younger child. Studies have measured patterns of attachment

and adjustment outcomes as well as how gender, being either a mother or a father, can influence a risk of poor bereavement and an increased risk of mortality. Also, the circumstances of the death has been cited as a factor that contributes to a more traumatic experience for parents [4-9].

The parents must accompany their adult child through a tempestuous period of severe illness. The child may previously have been helpful in caring for their parents and may also have their own family with a partner and children who are their nearest loved ones. How they cope with this situation will depend on their relationship, and the strength of the bonds between the generations, as well as how they may already support each other in their daily lives [10, 11]. The authors have not found any studies that investigate how parents cope during an adult child's illness.

The aim of the present study was to investigate the

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experiences of being a parent to an adult child with a severe illness, and what support was helpful to themselves and to their child during the period of illness.

2. Materials and Methods

The present study employed a qualitative design to gain a deeper understanding. This was achieved by conducting in-depth interviews in order to explore the emotional experiences, support and strategies of being a parent to a severely sick child in an existential way [12, 13].

2.1 Settings and Participants

The study was conducted at a university hospital in western Sweden.

To identify parents as participants, patients who had aging parents were approached to ask if they could contact their parent to inform them about the research. For those who gave their permission, the parent was contacted by the first author and was sent an information letter and consent form to sign and return in a prepaid envelope if they were willing to participate. After consent was obtained, the first author contacted the participant to book the interview. Participants were guaranteed anonymity and were reassured that their responses would be kept confidential.

The adult children in the present study were affected by a variety of life-threatening illnesses, including leukemia, and cancer of the breast, kidney, testicle and colon. Some of the adult children died during the year that their parents participated in the study. Parents were contacted at the second time-point regardless of whether the child had died or not.

2.2 Data Collection

Data were collected over a one-year period between September 2013 and November 2014.

The interviews were conducted using a conversational approach to allow the participants to tell their own story. Most of these were audio-taped and

lasted between 30 and 60 min in length. The participants decided where the interview should take place; either in their home, at the hospital, or at some other convenient place. In order to ensure that the research aim was maintained throughout the interview, key questions were highlighted: What did you think when you got the information about your child's disease? How did you manage in your daily life? Where do you have your support? Can you give your child support? The interviews were audio-taped and transcribed verbatim immediately after the interview.

2.3 Drop-Out

Thirty-two persons were consecutively asked permission to contact their parents asking them to participate. Four patients had no parents in their lives or their parents were too old or sick and could not participate. Two declined to answer and one person felt it was too difficult to ask their parents. The remaining 25 patients asked their parents if they wanted to participate in the study and 14 did not want to be interviewed or did not send the consent back. Eleven parents agreed to participate with interviews at baseline and with a second opportunity to participate one year later. Of those 11 who agreed to participate at baseline, 8 participated in the second interview. Three either did not want to participate because the child had died or they could not be reached. Nineteen interviews were completed in total.

2.4 Data Analysis

Transcribed interviews were analyzed using summative content analysis, which examines the visible, surface content and deals with the explicit meaning of the text, while acknowledging that complete interpretation of meaning is not possible. The analysis was carried out with close cooperation between both authors to ensure that the results were interpreted as objectively as possible. Any differences in the analysis were discussed until agreement was reached and a common description was formulated.

The analysis comprised several steps. Initially, text relevant to the research issues was marked. Units of meaning were identified and grouped into codes, which were subsequently discussed, compared, categorized and labeled. Finally, the categories were structured into themes and sub-themes [12, 13].

2.5 Ethical Considerations

The study was approved by the Regional Ethical Review Board in Gothenburg (270-12). No reminder was sent, 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.

2.6 Trustworthiness

Conducting in-depth interviews makes it possible to acquire a deeper understanding of the phenomenon. To ensure credibility, all of the participants in the present study were parents to a severely ill adult child. Despite the differences among the participants in their age and gender, the results reveal many similarities between them. To reduce the impact of the investigators' pre-understanding of the phenomenon, the interviews included questions that were aimed at elucidating the experiences of the participants. Data saturation was achieved in the analysis, which strengthens the trustworthiness of the results [12, 13].

3. Results and Analysis

Respondents were aged between 51 and 84 years and all were women. The ages of the sick adult children ranged between 35 and 65 years and the ratio of women to men was nearly equal (see Tables 1 and 2).

The results showed the common perception that it is very special to have a child with a severe illness. The underlying elements of existential experience and the relationship influence the parents' conceptions of life and permeated the whole experience. There were four areas that the parents found important and which influenced how they perceived that they could manage the situation: Having information, participation, strategies to cope and support.

3.1 The Existential Experience

The first feeling that the patients experienced when they were informed about the child's severe illness was that it was unbelievable and incomprehensible. When the child was diagnosed with the illness, the parents assumed that the death was imminent, even if there was the possibility that the disease might be curable. That any child, regardless of their age, should not die before their parents was the common feeling.

Some parents felt that it must be worse to have these experiences with a little child with whom you cannot talk to. Others thought that having a severely ill adult

Table 1 Characteristics of study participants.

Gender	Female n=19	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 n = 3	
Employment status	Employed n = 6	Sick leave n = 0	Retired n = 12	Sickleave and retired n = 1	
Education	Elementary n = 7	High school n = 6	University n = 4		No answer n = 2

Table 2 Characteristics of the sick child.

Gender of the sick child	Female n = 11	Male n = 8		
Age of the sick child	Up to 25 years n = 0	26-35 years n = 7	36-45 years n = 5	46-55 years n = 7
Duration of sickness for the child on the first occasion	Up to 1 year n = 6	1-2 years n = 10	2- years n = 3	

child who you have known for a longer 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 thought in this respect, they were united in their perceptions that it is difficult to see a child affected by illness. This feeling was continually present in the narratives.

"It does not matter that it is a grown-up person, they are still your child."

"A child you have given birth to and lived with all their life shall not die before their parents... it is wrong. I think and feel that it should have been me instead, I am 70 years old and he has still his whole life left."

"Age does not matter ... a young person who is active in life and working and does not want anything but work, is affected with this...it is just terrible, and you cannot help the feeling of the blood relationship."

3.2 The Relationship

It was obvious that the parents' relationship with their child and the relationship with the child's family had a strong influence on all the other areas. The parents' perceptions of this relationship depended on the nature of the relationship earlier in their lives.

"It depends about the kind of relationship you have had with your child and to my daughter-in-law and grandchildren."

3.3 Having Information

To be given information about their child's disease was one of the strongest wishes expressed by the parents.

It was helpful for them to have facts. Having information means that you can follow and understand what is happening. It was very important to the parents how the information was given, particularly the healthcare professionals' expressions in the way they delivered the response, regardless of the consequences.

"She (the physician) gave us information about the present situation, and we became calm because of the way she told us about the treatment."

"Even if what we were told was the worst we could think there might be other options that were worse still. So it was really good to have information of what it was and to know what demons we shall struggle against."

There was a problem identified with the parents' wishes to have information, because, when the child is a grown-up person, he or she must decide which information the parents shall be given. For those who had young adult children without their own family, it was easier for the parent to obtain direct information and they were more involved in conversations with the healthcare staff. For those children with their own families, however, their family members were considered to be the primary loved-ones and were given the information together with the child. Then the child could choose which information they wanted to share with the parent.

"I (the son said)... it is ok that my mama and dad is here. Everything that you say to me shall be said to them."

"He told us what the doctor had said and I was with him sometimes when he met the doctor but he did not want me to accompany him every time."

3.4 Participation

Participation in the adult child's care also depended on the relationship between the adult child and the parent, and whether the child had their own family. This participation was perceived as consisting of both practical and emotional matters. The practical matters included the parent's ability to help the child himself, or to provide help for the child's family members.

"I live in S and my son lives in G so it is not so easy to be close by."

The children without their own family did, in many cases, move back to the parents' home when they had need for help in their daily life, becoming like a young child again. This was particularly true for those who were between the ages of 20 and 30 years.

"...He was very weak when he had had the chemotherapy ... you give him food and take it out

because he could not eat it ... he even could not sit on the chairs without support. At those moments I was pleased to have him in my home."

When the child was older and had their own family, the parent's participation in their care consisted of helping in the daily lives of the child's family in different ways.

"I can do the practical things so my daughter-in-law could spend time with my son. I could take care of the grandchildren and I could talk to my son about other things other than the illness. We laugh and cried together."

The emotional participation took place when the parent was invited to be given information about the disease and treatment, giving the parent the opportunity to share fears and other feelings with the child and the child's family. When they were participating in this way, they felt that it was also helpful for the child.

"My son called me on the telephone and told me about what's happening and I feel that I can be a support for him when he is sad."

3.5 Strategies to Cope

The parents found their own coping strategies in both thinking and doing. Living in the present and having hope was one of the main strategies that the participants felt helped to manage having a sick child. Living in the present is a way of being in the moment and trying to hold the fear away and let the parents take the opportunity to see what was good about life today.

"So I told myself, he (the son) is alive today, he is happy today, so be happy instead of thinking that all is bad."

The hope was that the disease should be cured or the child would get better. The hope could change, depending on how the illness developed. The parents described how they told themselves to have hope and to think in a hopeful way.

"... and we are optimists, you shall not always think the worse scenario but you try to talk about the future

and what we shall do even if there was several times when I did not think that she(the daughter) should survive...you must be an optimist, especially for her (the daughter)."

They wanted to know and have facts and sometimes it could strengthen the hope but it could also give fear of what could happen. Sometimes they reported having short moments where they thought of the insecurity of the future, but they told themselves to go back to the present.

"I do not think he shall die. I may not think that. When they told us that the disease has returned they presented a plan for the treatment and they presented a plan for an alternative treatment. My husband and I talk with each other sometimes that we could lose him. Of course I do, but nevertheless, I do not think about it."

To talk was one strategy that the parents used in order to verbalize their feelings as well as to continue doing things in their daily life. To keep themselves occupied made it possible to not think about reality for a few moments and this was a strategy to allow them to put up with the situation (to just be and face the situation).

"You need to talk about the disease but you also need to talk about other things."

"I try to do something, walking or doing daily matters with my hands and body in my home."

To take a break was also important to cope with the situation. It allowed the parents to take a break from the reality of the situation in order to help themselves to find the strength to be in that situation.

"It goes up and down. Sometimes it feels really good but you also have to leave home. That can give positive energy."

Many felt that they and the child were accompanying each other in these strategies. They used similar strategies and had a similar way of coping with the situation, and they learned together within their natural family unit. It was helpful to provide strength to each other as well as to share the pain of the situation and to

share the information they received together.

"We have laughed and cried a lot, yes we have done that. We easily laugh and cry me and my husband and daughter."

3.6 Support

Support was an important part of being able to cope with the situation. The theme of support was divided into support for the parents themselves and being a support for their child.

Emotional support was the main form of support, such as having the opportunity to talk to someone when they had the need of talking about what they feel and what was happening. The emotional support was mostly given by their friends and families and was described in both the questionnaires and in the interviews.

"It has been healing when I can talk about it."

"Our friends who live here in S have been an enormous support, they have accompanied us through the process and they call us every week asking about what is happening... so they have been our real support."

Some of the parents reported having received support from staff, for example, a social worker. But they also related how talking to doctors and nurses about the child's illness was a form of support.

The children who did not have their own family needed more practical support than the children who did, although the practical support that the parents provided to children with family was often to support the family's daily life.

"He (the son) told me that he would never have made it through this if I would not have helped him with food and other stuff."

Being informed was also experienced as a form of support, for example, having knowledge about treatment, the development of the disease and how it might influence the well-being of the child. Some of the parents were able to have their own conversations with the doctors, both for the purpose of obtaining

information about the child's disease and for their own knowledge.

4. Discussion

Being a parent to a sick child brings existential thoughts as well as sadness and fear about what shall happen. Parents must encounter the unfair succession in life that a younger person may die before the older generation does. This parental experience has been described as a terrible experience by Dean et al. [14]. and by Smith et al as having a broken heart [3]. Webster-Blank [15] recounts many stories of having an adult child with a severe illness, describing experiences similar to those found in the results of this study.

Aspects of the parents' experiences can depend on the nature of the relationships between the child and the parent and how the child wanted to involve their parents, described in the literature by others [3, 16]. Therefore, these relationships can vary and will have an influence on whether the aging parent can participate and share feelings and thoughts about the situation with the adult child.

The four areas identified in the present study that help the parents to cope with the situation were all interconnected with each other.

To be given information was perceived as important to be able to follow what was happening with the child according to the disease, treatment and care planning. This gave the parent a form of control over the situation and is common among loved ones regardless of who is dying. Many loved ones prefer straightforward information, given with empathy and honesty balanced by sensitivity and hope, as described by Clayton et al. [17] and Parker et al. [18]. Those who were not informed felt that they were left to their own thoughts and fears.

The coping strategies that the parents used were mainly similar to those identified in the literature of being a loved one to a severely sick person [19-21]. There does not seem to be any difference in who the

sick person is, whether they are a husband, a wife, or partner, except that when it is a sick child there is a strong existential component, as though the child is a link to the future generation who dies too early. A strong coping strategy was to live in the present, which included both thinking and doing, also seen in previous research [22, 23]. The participants did not want to have the worst-case scenario in their thoughts all of the time. To take every day as it comes with all of its problems and joys was a way of helping them to live in the here and now.

Keeping busy by helping the adult child or the child's family with their daily life was both a source of support and a coping strategy giving the parents something to do. To be useful for the child when the parent could not have any influence of the disease itself, which Kim et al. [11] have described, was as an exchange of support between the child and the parent.

Hope is a well-known and a strong coping strategy and used by the participants in the present study. Hope is not a denial; rather, it is a way of looking at the world and seeing that there is a possibility to feel that it must not be as bad as it looks. The parents were all aware of the severity of the disease and having hope was helpful, also described in previous studies [24-27].

The most support to the parents was given by friends and family. This is well known in support after bereavement described earlier in the literature [28, 29]. It was mostly emotional support that the parents needed; to talk about their feelings and thoughts, but also about other things. Many parents became a support to their children, especially for those children who did not have their own family. When the adult child moved back to their parents' home they needed more support with their personal needs. Grinyer and Thomas [16] posed that the newfound independence of the adult child was threatened by them having to be dependent on the parents again. For those younger adult children who were cured, there was a phase when they, like they did earlier in the life, moved to an independent life again.

For those who had their own family, the parents could be invited into the family to provide practical and emotional support

5. Strengths and Limitations

The participants in the present study are those parents who have such a relationship that would allow their sick 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 generalization 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. Data saturation was achieved, which gives concurrence to the results. Further research is required on this relatively rarely investigated subject and should be related to the specific circumstances of having an adult child with a severe disease.

6. Conclusions

The aim of the present study was to investigate how it feels to be a parent of an adult child with a severe illness and what support is helpful to themselves and to their child during the child's period of illness. Before the adult child dies, there is a time when the parents must accompany their adult child through a severe illness for either a shorter or a longer period of time. The child may previously have been helpful in caring for their parents and when the adult child becomes sick, the parent might then be needed to take part in caring for the child. On the other hand, the child may have their own family with a partner and children, who then become the nearest family and take on the responsibility to care for the sick person in daily life.

Accompanying an adult child through a severe and potentially fatal disease in the context of a growing elderly population will become an increasingly frequent problem. So far there is limited research in this area and should be recognized as a high priority in the future.

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