

It was as Good as it Could be – A Family Member’s Non-Experiences of Guilt and Shame in End-Of-Life Care

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Abstract

Objective: This study is part of a larger project, “Guilt and shame in end-of-life care – the next-of-kin’s perspective”. The aim was to explore and interpret a family member’s situation without feelings of guilt and shame and describe reasons for non-experiences of these feelings.

Methods: An exploratory case study was employed to investigate and achieve an in-depth, in context understanding of the phenomenon from an informant directly involved in the activities being studied. The data material consisted of two in-depth interviews, analyzed in a hermeneutic way in accordance with Gadamer.

Result: Seven subthemes appeared “The mother received good care with clear planning”, “They became aware of the inevitable death”, “The mother knew how she wanted things to be”, “Mutual understanding and care between mother and daughter”, “They could make the most of the time that was left”, “The family was together during the dying”, and “Both the daughter and her mother could handle and see meaning in the situation”. These subthemes resulted in a main theme: “There wasn’t much we could have done differently. It was as good as it could be”. Three interpretations emerged that can decrease the risk of feelings of guilt and shame: 1) knowing that the loved one is receiving professional care of good quality, 2) family awareness of the situation and trusting and supportive relationship with the professionals, and 3) inner and external resources and open communication with each other.

Conclusion: The study shows the importance of professionals being involved in the family situation, having the courage to be sensitive towards the patient’s and the family member’s requests in situations where there is dying and death. Being aware of the suggested interpretations can decrease the risk of feelings of guilt and shame.

Keywords: Cancer; Guilt; Hermeneutic research; Next-of-kin; Palliative care; Relatives; Shame

Introduction

Being a family member of someone in end-of-life care can in many ways be a complex life situation. Standing face to face with death can entail a sorrow that is difficult to cope with [1]. Family members are often aware that the time available is limited and feelings of helplessness about how to handle the situation can be experienced [2]. A desire to be present, supportive and involved in the care is common and can be experienced as rewarding and meaningful, since the family member feel that they are performing an act of love, fulfilling a duty and/or taking on a responsibility [3-7]. At the same time, this responsibility can lead to the family member having to carry out an increasing amount of often complex care that they might not have been prepared for [8,9]. Dealing with physical and medical tasks, being an emotional support for the loved one, coordinating care and making decisions can be a challenge that is difficult to manage. The participation of the family member can be facilitated if he/she has the possibility to choose in what way he/she wants to be involved [10]. However, being able to make choices always entails the risk of making the wrong choice, [11] especially when time is limited. Experiences of guilt and/or shame may be the result of a wrongly made choice. The

family member’s experiences of guilt and shame have, to some extent, been described and can lead to a considerable burden and distress [12,13]. Against this background, it is important that a more profound knowledge and understanding is gained of the family member’s experiences and non-experiences of guilt and shame in end-of-life care.

The project: Guilt and shame in end-of-life care – the next-of-kin’s perspective

The present study is part of the larger project, “Guilt and shame in end-of-life care – the next-of-kin’s perspective”, where the overall aim was to explore and describe the concepts of guilt and shame and to gain a greater understanding of family members’ experiences of guilt and shame in end-of-life care. The results have been published in a doctoral thesis [14], which includes four studies. The first study [15] was a qualitative secondary analysis of interviews with family members to persons in end-of-life care. In the second study [16], a semantic concept analysis of the two concepts of guilt and shame was performed, using Eriksson and Koort’s methodology [17,18]. The results of the analysis were of help in the analysis of family members’ experiences of guilt in study three [19] and shame in study four [20]. Seventeen family members were interviewed concerning their experiences of losing a loved one from a cancer disease and their

experiences of guilt and shame were specific issues in the interviews. The main findings showed that the situation of being family member to someone in end-of-life care involved a commitment to make the remaining time as good as possible for the loved one. When, for some reason, the commitment could not be accomplished, the family member could experience guilt, such as not having done enough, not having been together during important events, not having talked enough to each other, or not having done the right things. Shame could occur when the family member was involved and actually caused harm to the loved one, as well as in situations that were beyond their control. It could also emanate from being put in situations by other people. In the studies, the experience of guilt had a focus on what the family member had, or had not done, and experiences of shame had a focus on the family member's self.

All but one of the 17 participants experienced guilt and shame in connection with the end-of-life care. In order to deepen the understanding of the phenomena of guilt and shame, it was therefore important to investigate how this participant described her situation. Consequently, the aim of this study was to explore and interpret a family member's situation of being without feelings of guilt and shame during end-of-life care and to describe reasons for the non-experiences of these feelings.

Design and Method

An exploratory case study [21] was chosen for the design. Case study methodology is suitable for exploring, describing and understanding a phenomenon and for presenting rich descriptions of findings. It also provides opportunities for the analysis of important characteristics of real life events, often as one aspect of a larger research study [22], which is in accordance with the mentioned project. Case studies enable researchers to empirically investigate and achieve an in depth, overall, in context understanding of a phenomenon or an experience from an informant who is directly involved in the activities [21].

Participant and data collection

The data material consisted of two in-depth interviews with a daughter; we can call her Anna, about her experience of losing her mother to a cancer disease. The interviewer began with the question: "Could you please tell me about your experiences of being a family member of someone in end-of-life care". The participant was encouraged to elaborate on her experiences and how the situation evolved through the end-of-life care and the death of the loved one. The focus was on experiences of guilt and shame, and several questions about these feelings were asked, such as: "Was there anything that went wrong during this period?", "Did you experience guilt/shame during this period?". By elaborating the whole end-of-life experience, Anna could go into details about how her situation as a family member had developed and why she did not have experiences of guilt and/or shame. The interviewer tried to maintain an openness and sensitivity towards the narrative in order to follow the story. The questions that were used were open-ended in order to encourage further exploration of the issue. Anna decided that the interviews should take place in her home. Each of the two interviews were 50 minutes long and were recorded and transcribed verbatim.

Analysis

The interview material was analyzed in a hermeneutic way with an initial aim of finding knowledge about possible experiences of guilt and shame. When it was clear that we could not find any experiences of guilt and shame, the data material was analyzed once again in the same way, but this time with the aim of exploring and interpreting the participant's non-experiences of guilt and shame. The analysis was conducted in a dialogue with the text [23,24].

The text was read several times, sometimes separately and sometimes while listening to the recorded interviews, in order to gain a fundamental understanding of the meaning of the text as a whole. The understanding of the whole then influenced the understanding of the parts. Every single sentence or section of the text was investigated in order to expose the meaning of the participant's experiences. The parts of the text were related back to the text as a whole, something that helped broaden the understanding of the experiences. These ways of gaining new understanding and of widening the horizons of understanding were performed several times.

In a hermeneutic way, the interpretation of the experiences was challenged by and in turn challenged the researchers' pre-understanding. Both researchers have personal experience of working in end-of-life care as nurses and have met several dying persons and their family members. This pre-understanding was controlled by keeping a conscious and open-minded attitude towards the data material and the analysis.

Ethical considerations

Ethical approval for the study was obtained from the Regional Ethical Board in Stockholm, Sweden (2008/1223-31). Written and oral consent was obtained from the informant and a right to withdraw that consent was ensured. The informant was contacted again when the wish to make a specific case study about her experiences was raised and she consented to that. The informant also read the result of the study and gave her approval to it being published.

Result

Anna's story

At the time of the first interview, Anna had lost her mother due to a cancer disease four months earlier. The mother had had pneumonia and she did not seem to emerge from it quite well. She was first hospitalized at the ward for infectious diseases at the hospital. Anna, who gave birth to her second baby only days before her mother's hospitalization, could not visit her there so often because infants were not allowed at the clinic. During this stay, the doctors suspected that the mother suffered from more than just pneumonia and she was diagnosed with cancer. The consulted oncologist informed the mother and Anna that there was no cure for the cancer, but they could try chemotherapy to see if that could add a few more days of life for the mother. The mother decided that she wanted the treatment so that she could be with her family a little bit longer. After two weeks, the mother was moved from the ward for infectious diseases to the oncology ward, which allowed Anna to bring her children when she came and visited. This move also allowed the mother to have other visitors, which was important for her as the end of life drew nearer. The mother stayed at the oncology ward for the remaining time of her life, which was about one week.

The mother received good care with clear planning

Anna felt that her mother was well taken care of during the course of the illness. The care was of high quality and the professionals respected her mother’s wishes. The professionals listened closely to her mother, they were sincere when they talked to her and let her make the decisions. They were acting in her mother’s best interest. The mother said to Anna “I have the staff here and they are wonderful and amazing”, and this made it easier for Anna. The situation, in all its sadness, felt safe and both Anna and her mother were satisfied with how they were treated, both at the ward for infectious diseases and at the oncological ward. At the ward for infectious diseases, the mother had a nice room with a view of the sea and she thought that this was pure luxury. When her mother was moved to the oncological ward, Anna could visit her mother whenever she wanted, and she could bring her baby. The professionals provided an extra bed in her mother’s room and they gave her snacks and drinks when she was there.

Anna described the professionals as thorough in their medical examinations. Although, there were many investigations in order to diagnose the disease, Anna thought that the professionals planned the investigations and the medication in a good way. They made sure that the drugs were flown in from the university hospital in order to start the treatment as soon as possible. Anna felt that there was a clear plan for the treatment and care, even though there was no hope for cure. The mother had good symptom control and Anna knew that her pain treatment worked. “I saw that she was comfortable and she could regulate her pain treatment all the way to the last evening”.

The professionals were at Anna and her mother’s side when they needed help with different care actions. Anna felt that they saw both her and her mother and this feeling continued during her mother’s dying and also after the death. Anna was given a booklet about death and dying and she found it very helpful during her mother’s last days in life. After her mother had died, Anna got the opportunity to stay with her for a couple of hours. “You can sit there and talk to her, think, walk around, and sort of contemplate what has happened”. The professionals also contacted her some weeks later to ask if she had any questions and if she wanted to talk to the doctor at the ward. “The doctor also called. It was so good. We were satisfied, the ward for infectious diseases was good but I think that at the oncology ward there was a different approach which was even better”.

They became aware of the inevitable death

Both Anna and her mother were aware of the inevitable death. The information they received from the professionals was adequate and they were involved in the decision making regarding treatment and actions taken. The professionals were open to what Anna’s mother wanted and needed throughout the course of the illness. Anna had opportunities to receive information and to discuss with them. When they received the cancer diagnosis, they first talked to her mother alone. The day after, they talked to her mother and Anna together. Anna narrates: “The oncologist was at the ward for infectious diseases and talked to my mother, I was there too and it felt really good that I was. I think she thought it was good that I stayed. He talked to her and offered her chemo, he was straight forward and said that it wasn’t a cure, it was buying time. She said yes directly, I want to. I really want to try because I want to have some more time with these little ones [her grandchildren]”. Anna was not surprised by the diagnosis; in some way she had expected that her mother had a cancer disease. “She

looked malignant, you sort of feel that there is something wrong... I think mother felt and knew it... but she was hoping for the best”.

The mother knew how she wanted things to be

Anna was satisfied that both she and her mother were aware that the remaining time was short. She felt at peace with knowing that her mother knew and that it was her mother who decided how things were to be. Anna was compliant and listened to her mother’s decisions and was satisfied with that. “That was how she wanted it... It was important that I respected her wishes”. When Anna noticed that her mother was ill, she tried to persuade her to go to the hospital. It was then obvious that Anna’s mother had a plan for how she could be of help when Anna had her baby. She decided to be home and take care of her older grandchild and she would not change this plan, even though she became worse in her illness. After Anna’s daughter was born, Anna could see a change in her mother’s health. It was as if she had fulfilled her mission to help Anna and her family and that she now let go. Anna described it as follows: “Good, now it was done. She could in some way let go of her façade. And then everything sort of exploded, it happened so quickly”. Anna’s mother fulfilled her plan and was satisfied with that. Anna felt that there was nothing she could do about it; if that was her mother’s wish, she accepted that. “She knew how she wanted things to be and that felt really good for me, it made me feel safe”. Anna told of several occasions where her mother decided how she wanted things to be, which helped Anna. A further example was the last night before Anna’s mother died. Anna tried to help her turn on her side in bed, because it sounded like she had difficulties breathing. However, her mother told her that she was good as she was and said: “Tonight I decide because tonight is my night”. Anna felt that that was true and did not try to persuade her. Anna also felt a great relief in knowing how her mother wanted her funeral to be. Anna said that they had always been open to each other about death and dying.

Mutual understanding and care between mother and daughter

There seemed to be a mutual caring, respect and understanding between mother and daughter. Anna cared about her mother and pointed out the importance of respecting her mother’s wishes. It was also obvious that the mother cared for Anna. When Anna had her baby and her mother took care of her older grandchild, the rest of the family helped the mother to accomplish what she had set out to do. The family members tried to piece their lives together so that they could be there for Anna’s mother and also help Anna with her children. The mother was also very determined that Ann should not come home too early from the maternity ward. She should rest to gain strength for what lay ahead of her. The mother said to Anna several times: “We need you later; you need your strength later.” It was also clear that when the mother was in hospital, she gave much importance to her family and to their wellbeing. She told them not to make any kind of schedule to be with her during the nights. “I have the personnel here, they are wonderful and fantastic. All of you can go home... and have a good night’s sleep”. Anna laughed when she narrated this and explained that it was almost like a loving order.

They could make the most of the short time that was left

The whole family was aware that they had a short time left together. It was important to make the most of that time. This was evident in the quality of the conversations, in their meetings, and in their presence.

There was no time for trivial conversations, it was important to go straight to the point. When Anna looked back, she said: “I caught the moment, every sentence was meaningful. I have said that and she understood that so it is enough. We had to make the most of the time left... every minute... Of course, there was great concern and we talked about that. One day I asked her: Is it hard for you to talk about this? And she said: Actually not”.

Anna’s mother was clear and she was able to hold a conversation all the way into the last night of her life. This was important for Anna and for how she dealt with the situation. She was also grateful that she could bring her baby with her to the hospital. She said: “We had our time and we used it well”.

The family was together during the dying

Anna spent as much time as possible with her mother. At the oncological ward, she could bring her newborn daughter with her and she knew that the rest of the family was there to help her when needed. These arrangements gave Anna the possibility to concentrate on her mother and be at peace. Her mother decided that she wanted to see the whole family and invited them to the ward. Anna, her husband, and their children, together with uncle, aunt, and cousins, spent a couple of hours together, talking, and saying good bye. The two-year-old grandson climbed into the bed and lay beside his grandmother and patted her on her cheek. “She gathered us... I am sure she was convinced that this was a conclusion... to say good bye to us all”. Anna could see the importance of this event, of achieving a mutual conclusion both for the mother and for the rest of the family. Anna and her newborn daughter stayed when the others left. She sat by her mother’s bed and held her hand. “It felt so good to be there, to sit there and hold her hand”. Anna stayed the whole night and in the early morning her mother died peacefully. To be with her mother and share this moment with her and her newborn daughter made Anna feel that they were truly linked together.

Both the daughter and her mother could handle and see meaning in the situation

Despite the difficulties and despite the grief, Anna described a positive picture of her mother’s last days of life. “There were many things that happened that I take with me as good memories”. In the interviews, she often used positive words like happy, being lucky, amazing, easier and benefits. This shows that Anna had the strength to see positive aspects, despite the difficult and sad situation. She could handle the situation and if she felt that things did not turn out as she wanted, she did not dwell on them. “I don’t dwell on things ... or find myself stuck in them. There is no point in doing that. Instead I try to turn them around, what can I change? What can I learn from this?” Anna related that this was also due to how her mother handled the situation and explained that her mother had an inner strength, “My mother was so strong... so amazingly strong”. She also said that of course it was sad that she lost her mother, but as things were, this possibility to be together until the end and say good bye to each other was very meaningful. “It was good that we got this moment with mother. That it worked out fine to bring the baby too. In that way, it is very coherent”. Anna’s mother also told her that she had one of two good things to look forward to. Either she would spend more time with her daughter and her family, or she would meet her husband (who had been dead for several years) earlier.

Anna thought that it was easier to deal with the loss of her mother when the children came on the “right side”, there was time for them to meet their grandmother, and even if they do not remember, there will be pictures of them together. She is sad though, that they did not get more time together. “I think that it was unfair that she didn’t get more time with her grandchildren. At the same time, it was good that mother got three weeks with her youngest grandchild... It would have been hard if they hadn’t had the opportunity to meet each other. But of course, I would have dealt with that in some other way. You can always find something that is worse, thinking about that is a way to get through”.

Main theme: “There wasn’t much we could have done differently. It was as good as it could be”

Anna felt that she did the best that she could under the circumstances and was satisfied with the quality of care, the approach of the professionals and how the situation evolved for her mother. Both Anna and her mother were aware of the limited time. Her mother knew how she wanted things to be and they both had an inner strength, which helped them through the situation. They were together during important events and they had a relationship in which they could talk openly to each other. They also had good support from the rest of the family, which made it possible for them to be together. Anna thought a lot about how she felt and if she had any experiences of guilt and shame, and about why she did not feel guilt or shame, and summarized the situation with the following sentences: “There wasn’t much we could have done differently. It was as good as it could be”.

Discussion

Anna’s story gave us the opportunity to explore and interpret a situation without descriptions of feelings of guilt and shame during end-of-life care and to interpret the reasons for the inexperience of these feelings. Three main interpretations of the findings are presented in the following discussion.

A first interpretation is that knowing that the loved one is receiving a good quality of professional care can decrease the family members’ feelings of guilt and shame. Care of high quality, including respect and good symptom control, has been reported as being important and can increase the family members’ opportunities to feel at peace [4,25]. Knowing that the professionals are acting in the patient’s best interest can increase the family members’ safety and trust [10,26]. In this study, it was obvious that Anna was confident that the professionals planned the treatment and care in a thorough way and that they did what they could to alleviate her mother’s suffering.

A second interpretation is that family awareness of the situation and being met with a trusting and supporting relationship by the professionals can help the family choose how they should be and act at this time, which can reduce the risk of feelings of guilt and shame. If family members are aware of the limited time, it can be less difficult to choose how they would like to be involved in the situation and to fulfill their own perceived obligations [15]. The length of the mother’s illness trajectory was short and it was therefore important for the mother and Anna to be met in a sincere and supportive way at once. Glaser and Strauss (1966) talked about “the aware family” and mean that once a family is aware of the situation; the family management can assume new dimensions [27]. Anna and her mother knew that the remaining time together was short and that the mother’s health would deteriorate quickly. It was therefore important to make the most of the

limited amount of time. The professionals' responsibility for developing a trusting relationship and an open positive attitude, and for showing sensitivity towards the patient's and family members' needs for information, communication, education and support, has been described in several studies [4,9,28]. This professional approach helped Anna and her mother fulfil their desires and obligations.

A third interpretation is that inner and external resources, and open communication with each other, can increase the management and meaningfulness of the situation, and decrease the risk of feelings of guilt and shame. Anna and her mother had a relationship in which they could speak openly to each other. Anna's mother was explicit concerning what she wanted to do and how she wanted things to be. Anna relied on her mother and let her mother do things the way she wanted. This helped Anna to rest in the situation. It has been found in earlier studies that family members felt relief if they knew how the patient wanted things to be and if they could fulfil these wishes [29,30]. Furthermore, both Anna and her mother seemed to have an inner strength. Anna reported a number of occasions that her own and/or the mother's strength helped her manage the situation. Anna often used positive words to describe the situation and she said the words in a serious manner. This showed signs of a strong sense of coherence. Antonovsky described the confidence people have in inner and external resources that they believe they have at their disposal, which can help them attain high manageability and confront problems as challenges [31]. The mother or Anna could have experienced themselves as victims of misfortune, but instead they had an inward confidence that things would turn out as well as possible. Anna relied on her mother and on her own inner resources, and that her family in every possible way was supportive. A genuine understanding for each other's situation is also described in the result. The mother cared for Anna and wanted her to conserve her energies. Anna's mother and other family members did not require Anna to do more than she could manage, which gave her confidence in the situation. Everyone in Anna's family, including herself and her mother, contributed to a solution that was functional. Antonovsky talks about a unity that emerges through a common process, in which every individual contributes to solving the problem [31]. This left Anna with a feeling that what she did was good enough. It was also obvious that both Anna and her mother could see meaning in the situation. Meaningfulness constitutes the very heart of the sense of coherence theory [31]. People who describe a positive picture and positive memories from the end-of-life situation, despite difficulty and grief, have been reported earlier [10]. This was obvious in Anna's situation. Anna was satisfied, which affected her wellbeing and led to positive memories of the situation. This helped Anna feel that she had fulfilled her duties and responsibilities; she had done her best [32,33]. She did what she could and everyone was satisfied with that. Shame is described as the experience of not being good enough, in which feelings of worthlessness and powerlessness emerge [34]. Anna reported that she had no need to blame herself; instead she felt a sense of pride that everything went as well as it did. To be proud of one's own achievement and role can be viewed as the opposite of the feelings of guilt or shame [35].

Methodological considerations

This study is presented as a case study and the analysis was influenced by a hermeneutic approach [23]. We chose a case study to explore and interpret a family member's situation without feelings of guilt and shame during end-of-life care and we have tried to describe reasons for the non-experiences of these feelings. The data material is

part of a larger project where experiences of guilt and shame have been studied, it was therefore of great interest to find out what it was that made this specific situation different. As far as we know, similar cases have not previously been studied and this case is therefore unusual and can supply new understanding about the phenomena of guilt and shame. Although the number of informants is small, in this study only one, the number of variables can be large [21]. It was therefore important to present Anna's experiences as a case in order to obtain a deeper understanding of the non-experiences of guilt and shame.

The trustworthiness of the study has been assured by using Anna's narration of her experiences and not in any way changing these data. Since the analysis was carried out using hermeneutic interpretation, it was important to show the researchers' connection to their pre-understanding, as well as to present the research process as clearly as possible. Both the researchers took part, discussed, and questioned the analysis and results and their pre-understanding was taken into consideration throughout the research process. Going back and forth between the different parts of the analysis, and also recognizing the history and culture that the researchers brought with them, was important. The recorded interviews were transcribed verbatim and listened to several times with the purpose of reaching an understanding in accordance with hermeneutic understanding [23]. Quotations from the text were a way of ensuring that the participant's perspective was presented as distinctly as possible. Throughout the analysis, the researchers returned to the interviews in order to secure the analysis, and to confirm the findings and the interpretation of the findings in a hermeneutic spiral. Trustworthiness was also attained by letting Anna herself read the result of the study and decide if it followed her story.

Conclusion and Implications

Being a family member to someone in end-of-life care often involves a commitment to make the remaining time together as good as possible. We have in earlier studies seen that if this commitment cannot be accomplished, experiences of guilt and shame may arise. In Anna's story, it was obvious that these feelings did not have to appear because there was a sense of coherence in the situation, in which the professionals and the whole family worked together with a purpose to make the mother's final stage of life as good as possible. Of course you cannot generalize one case study but the findings in this study show the importance that professionals are involved in the family situation and have the courage to be sensitive towards the patient's and family members' requests in a situation where death is so apparent. Knowledge about the importance of a good quality of care and that the patient and the family members are being met with a trusting and supporting relationship, in a mutual involvement, a cooperation that can help the family choose how to be and act, which can reduce the risk of feelings of guilt and shame in end-of-life care.

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