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Endurance—integration of strength and vulnerability in relatives’ response to open heart surgery as a lived experience

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Abstract
Open-heart surgery is a threatening life event for patients and their relatives. The relatives’ situation is especially complex since at the same time they both support the patient and suffer themselves. The purpose of the present study was to describe relatives’ lived experiences of a family member’s open heart surgery in a lifeworld perspective. Nine relatives of patients who underwent coronary artery bypass and/or heart valve surgery were interviewed in depth using a phenomenological approach. Endurance was found to be the essential characteristic for this group and was derived from four constituents: unconditionality, uncertainty, mutuality and sadness. Unable to escape their changed lifeworld, they demonstrated endurance throughout the entire illness process, which implied a great sense of responsibility and the setting aside of their own needs and wishes. The endurance rendered them both strong and vulnerable, although the vulnerability was not immediately apparent. There is a risk that relatives in need for help to handle this threatening situation may be ignored by health care professionals because they seem so capable. A lifeworld perspective in health care including the entire family can prevent such a situation.

Key words: Endurance, lived experiences, lifeworld, open heart surgery, qualitative, relatives

Introduction
Open heart surgery is a life event that has a profound influence on both the individual and the family as a unit. Family members are mutually dependent and of equal importance in the interactive process between them (Artinian Trygar & Duggan Hillebrand, 1993; Runfors & Wrangsjö, 1986). Consequently, when a family member suddenly develops heart disease and requires open-heart surgery, it has an immediate impact on his/her relatives. The life situation of relatives has been described in terms of responsibility, stress, quality of life (Davies, 2000: Rankin & Monahan, 1991; Stolarik, Lindsay, Sherrard & Woodend, 2000) and burden of care. Montgomery, Stull and Bogatta (1985) first described burden as a product of interaction. This underlined the fact that illness and its inherent burden is something that the whole family has to deal with. Compared to the patients, relatives are exposed to the same or an even greater risk of developing psychological distress (Coyne, Ellard & Smith, 1990; Moore, 1994). In a sample of 56 spouses of patients who suffered a myocardial infarction, a third were evaluated as requiring psychological referral (Coyne et al., 1990). In an analyses of cross sectional data Coker (1998) noted that caregiver health and caregiver role strain had significant main effects associated with caregiver depression six months following surgery. A phenomenological study revealed that couples’ everyday life changed after a myocardial infarction. They showed mutual consideration in order to protect each other as well as having little verbal communication (Svedlund & Danielsson, 2004). Relatives are an important resource for the patient in his/her recovery (Rantanen, Kaunonen, Kurki & Tarkka, 2004). However, despite available findings, there is still a lack of awareness among health care professionals that relatives have needs that require attention (Bengtsson, Karlsson, Währborg, Hjalmarsön &
Herlitz, 1996; Moore, 1994; O’Farrell, Murray & Hotz, 2000). This circumstance may be attributed to that the health care system of tradition has an individualistic approach and focuses on the patient—as opposed to his/her family. This is of concern because relatives who experience emotional strain are found to be less supportive in their role as a caregiver (Kärner, Dahlgren & Bergdahl, 2004; O’Farrell et al., 2000), which will exert a negative effect on the patient, owing to the fact that they are mutually dependent.

The lifeworld is a central concept in phenomenological philosophy and means the unreflected everyday life, which is lived and taken for granted. There is no escape from it and it is constantly related to time and space. Present time also encompasses the past and the future. Humans live their lifeworld through their bodies and in relationship with others. Through sharing, we experience that which we have in common. Sharing is a primordial quality of the human world that also explains the deeper meaning of solitude; the absence of someone to be there for and with us. The lifeworld of each individual is unique but our senses and ability to communicate allow us access to the lifeworld of others. Illness disturbs this relationship, as it changes the lifeworld hence, the body language may no longer appear familiar and readable. The lifeworld is experienced at a deeper level by reflection (Dahlgren & Nyström, 2001). Lifeworld research can supply knowledge of the subjective experience of illness and intersubjective relations. Few previous studies describe relatives’ experiences of open heart surgery based on the lifeworld perspective. In this perspective, relatives are seen as an indivisible part of the patient’s lifeworld. A deepened understanding of how the lifeworld of relatives is affected by this threatening life event can lead to more adequate support from the health care professionals, thereby enhancing the patients’ recovery process. Thus, our purpose was to describe relatives’ lived experiences of a family member’s open heart surgery in a lifeworld perspective.

Method

The study was approved by the Research Ethic Committee Department of Medicine at Göteborg University, Göteborg, Sweden in 2001 (Ref. 408–01). The study had a qualitative, descriptive design with a phenomenological approach. Phenomenological interviews were used to describe the everyday life of relatives of patients who had undergone open heart surgery. The fundamental principle of phenomenology is to come close to a phenomenon, thus allowing it to reveal itself (Dahlberg et al., 2001).

Emergence of a phenomenon is a result of an interactional meeting between human beings. The researcher (A-KK) was given access to the informants’ lifeworld through talking with them and listening to their genuine stories. The researcher tried to approach the informants with an open mind and a sensitive attitude taking nothing for granted and seeking clarification by posing additional questions. Accordingly, the researcher learned about people’s subjective lifeworld by focusing on the informant and his/her story. However, the meeting also made the researcher a part of the studied lifeworld. It was important to keep this in mind and to bracket her pre-understanding of the phenomenon. In a phenomenological study, the aim is to allow the “things” to speak for themselves and to conceptualize them without distorting their meaning or attempting to interpret them (Bengtsson, 2001; Giorgi, 1997). In this study, the pre-understanding was based on the researcher’s professional experience as a social worker in medical and health care. Meeting patients with heart disease and their families has allowed the researcher to become familiar with their problems and their usual reactions to this threatening life event. The pre-understanding of this situation was dealt with by attempting to be open and adopting an uninformed attitude during the interviews. The researcher is a professional interviewer and uses conversational therapy in her daily work. This experience of interviewing was important since the researcher him/herself is the research instrument (Kvale, 2001). Although there are important purposely differences between conversational therapy and research interviews to be aware of, the fundamental principles for meeting human beings in openness and with sensitive curiosity are the same.

Participants

This study is a part of a larger, ongoing study involving patients who had undergone open heart surgery. Out of a study group of 100 patients, 14 (5 women and 9 men) were selected for in-depth interview. The selection was based on information from a questionnaire that had been filled out by all the patients, and concerned age, gender, civil status, financial situation, geographical location and heredity. The informants were selected in such a way that the studied phenomenon would be described as wide and varied as possible (Kvale, 2001). The patients were asked for permission to interview a relative selected by them and told that they could decline involving a relative if they so wished. The outcome was nine relatives (7 women and 2 men), all of whom were unknown to the researcher.
(A-KK), and were interviewed in depth during 2003. Eight were spouses and one was an adult child of patients who had undergone a coronary artery bypass and/or heart valve surgery. The main criterion for participation was the closeness of their relationship to the patient. No further questions about the family member were asked. The mean age of the patient group was 62.9 years (range: 53–74 years) and in the case of couples, the relatives were about the same age or as most 12 years younger. The adult child was approximately 40 years of age.

Data collection

Information about the study was sent to the patients together with inquiry for participation also concerning a relative. They were informed about the voluntary nature of participation, their right to withdraw at any time, and confidentiality was guaranteed. After receiving their informed consent, the researcher contacted the informants by telephone in order to confirm their agreement and to arrange a meeting. Interviews of relatives and patients took place on separate occasions six months after surgery. By that time, the rest of the data collection concerning the patients had been finished and it could not be influenced by the interviews with them. The fact that six months had passed since the operation was also deemed favourable for the interviews, as it allowed the informants an opportunity to reflect over their lifeworld. All the interviews took place in the researcher’s office at the hospital and lasted between 1.5 and 2 h. The hospital was familiar to the relatives, and the researcher could be certain of privacy and of being undisturbed. The interview questions were developed from a lifeworld perspective and the informants were asked to tell about their lived experiences of a family member’s open heart surgery treatment. The interviews were opened with an overall question about the informants’ experiences of their life situation at that moment. In the phenomenological thinking of time, the present time includes the past as well as the future. By that, the informants could tell their unique stories in the way they wanted and remembered things with help of open questions from the interviewer. Their expressions were followed up by further questions in order to clarify the content and illuminate the uniqueness of each interview (Dahlberg et al., 2001).

Analytical procedure

The interviews were audiotaped and later transcribed verbatim by the researcher (A-KK). The analysis followed Giorgi (1997). Initially each interview text was read several times by the researcher in order to become familiar with its overall substance. The text was then divided into meaning units. A meaning unit comprises one or more sentences fundamental to the purpose of the study. In the third step, the meaning units were transformed into language of the perspective. In this way, the material was raised to a more abstract level necessary for the scientific analytical process. The transformed meaning units were then sorted into constituents. Finally, reflection over the constituents in all their various forms using professional imagination led the researcher to the essence, i.e. the deeper meaning of the phenomenon. The essence and its structure were described and illustrated by quotations from the interview texts.

The three authors have different professions: social worker, physician and nurse. All have long experience of meeting patients with cardiac disease. During the analytical process, the findings were evaluated in the course of interdisciplinary discussions. The constituents were tested against each interview to confirm that they were fully representative. In order to ensure the trustworthiness of the study, the researcher’s supervisor (EL) acted as an independent judge. She read all the interviews and analysed some of them. When concordance was not achieved, the differences were discussed and the material further analysed until agreement was reached.

Results

Endurance is the essential characteristic for relatives in families in which someone has undergone open heart surgery and is derived from the following constituents: unconditionality, uncertainty, mutuality and sadness. Endurance is present in the entire period of illness and characterized by unconditional actions as well as of great uncertainty caused by the unknown life situation. Endurance is important as it promotes mutuality and a precautious hope in despite of feelings of sadness. Open heart surgery can have a major impact on relatives in that it has the power of changing their lifeworld. Relatives can feel obligated to face up to the situation since it cannot be escaped and their solution is endurance.

However, since endurance is an integrated reaction this renders them both strong and vulnerable, although the vulnerability is not immediately apparent. Imbalance between being a supportive carer and being in need of care oneself may cause a very difficult and lonely situation for the relatives due to their attitude of being capable. Increased conscious-ness of the double meaning of endurance can help health care professionals to support families in their struggle to achieve a new balance and avoid
increasing relatives’ burden of responsibility. A lifeworld perspective that includes relatives seems to be essential in understanding the problem.

Unconditionality

This focuses on the relatives’ immediate readiness to protect and encourage the patient and younger family members.

The informants showed immediate strength and readiness to act and to take care of their family member. They gave priority to the patient’s needs and were deeply involved in the ongoing process. They contacted health care staff in order to obtain information about his/her condition as well as encouraging and trying to make things easier for him/her. The informants also assumed responsibility for the family’s everyday life. As a result of their closeness they infused the patient with the will to live in order to protect their loved one from death. They kept their worries to themselves although feeling tired and vulnerable. The informants were also aware of their children’s reactions and feelings about having a parent with heart disease. They discussed the situation with their children, while at the same time taking care not to frighten them. Overall, being a relative was associated with strong feelings of love, kinship and responsibility.

Being a relative cannot be put into words. It is more of a deep feeling. You do things for them naturally without saying: this isn’t my concern. I really believe that I could do anything for a family member. (Wife)

Uncertainty

Uncertainty describes the relatives’ feelings of awkwardness and vulnerability when referring to the patient’s illness. It is also a description of reasons for reaching their own conclusions about the patient’s well-being and of the relatives’ hidden position in health care.

The informants described the early symptoms of their family member’s illness as being very diffuse. It was difficult to imagine that the patient was as seriously ill as the diagnosis indicated. Afterwards, they realized that they had noticed signs but had not associated them with heart disease. They had found explanations such as too much work, life changes and stress. Other reasons for reaching the wrong conclusion were their own problems or commitments in life that made them inattentive or the need to repress such a threatening possibility. When the heart disease became a fact, the informants felt unable to make the health care professionals pay full attention to their suffering family member. Primary care was criticized for not being sufficiently aware of the symptoms of heart disease, not providing clear enough information about it or for delayed referral to the hospital. The waiting period before surgery was a stressful period in their lives. To have a family member on a waiting list for heart surgery and understanding the severity of his/her condition was distressing and frightening. They felt the heavy burden of responsibility together with the feeling of powerlessness. Although the admission letter was a relief, their anxiety increased during surgery. Even those who shared this day with other family members witnessed a sense of extreme loneliness, which only ended with the telephone call from the surgeon informing them that everything was fine. The relatives often visited the patient at the hospital but seldom had contact with staff unless they themselves initiated it. They felt that they were not asked about their own feelings pertaining to the patient’s illness and that only on rare occasions were they invited, together with the patient, to talk to a staff member about their common situation. The informants expressed that they would have appreciated more attention from staff. There was frustration associated with the recovery process. There were unexpected setbacks after a couple of months as well as a lack of anticipated progress. The relatives worried when the patient went back to work, especially when his/her job was regarded as a contributory factor to the heart disease. Tacit communication was common in these families. Conclusions about the patient’s thoughts, feelings and strength were reached by means of observations of bodily and facial expressions as opposed to direct questions. This could be considered natural since they knew each other well, yet it was sometimes an expression of uncertainty in the relationship.

I didn’t feel well at that time. I didn’t know what was going on. My husband tried to inform me, but it was difficult to understand his explanations. I wished that a staff member would sit down and talk to us. They were always sweet but all contact had to be initiated by us, the family. (Wife)

Mutuality

Mutuality describes positive experiences of a deepened family relationship, sharing of thoughts and time, and the feeling of strength and freedom when life returned to normal.

The illness promoted tighter bonds and deepened mutuality between family members in various everyday situations. When the tempo slowed down, they shared more time together as well as thoughts and
feelings. They became more aware of their needs of contact with other people and their mutual willingness to share everyday experiences. Two kinds of support were provided by their informal network during the time of their family member’s illness: support directed to the informants themselves and support for the family in general. The female informants received support from close friends, colleagues and relatives, while the men were in contact with a close circle of relatives. The support given to the family in general, came from their circle of friends or from other family members and it was focused upon the patient. This perspective was not questioned by the informants. All support was of great importance. It was comforting and made them feel strengthened and more optimistic. The informants reflected over everyday life in the final phase of the recovery period. In many ways life reverted to normality to such a degree that they sometimes felt as if the operation had never taken place. The informants were pleased that their family member enjoyed life after surgery and they no longer worried to the same extent.

I felt his pain inside me when he had to cough. It was awful. He is my very best friend and I think that we became closer to each other during that time because he was willing to let me be a part of his life. (Wife)

Sadness

Finally, sadness describes the relatives’ vulnerability and painful feelings of loss and yearning due to their awareness of the shortness of life but also strength and a precautious hope for the future.

The relatives described life changes that had taken place after the patient’s illness. The heart surgery changed their lives permanently. It restricted their social lives and their ability to do things on their own. Some of the life changes offered very little hope for improvement in the future, such as the difference in age between married couples that had been irrelevant before and the change in the patient’s personality after the operation. The interviews clearly highlighted a connection between the experience of heart disease and thoughts about the shortness of life. This awareness made them reflect over what they really valued in life. The informants reported sharing more time with each other and being careful not to hurt their partner or quarrel unnecessarily. Although life went on, it would never be the same. For example, they no longer wanted to leave important things until the following day. All nine informants expressed one main wish for the future: that they and their family would share many more years together. While the desire to travel or obtain a new job was also mentioned, the main priority was good health.

We don’t talk about it much nowadays, but every day when he takes his medicines it reminds me, as does his scar. I think it will take years to get used to it. (Wife)

Discussion

The novel finding of this study was that the lives of relatives of patients who had undergone open heart surgery were characterized by endurance throughout the entire illness process. Endurance as a concept has not been used in other studies to describe the situation of relatives to patients treated with open heart surgery, but it has been identified as a stage of suffering occurring in response to a threat to integrity of self in patients after a trauma and in chronically ill patients (Morse & Carter, 1996). It was found that an enduring person reflexively suppressed his/her feelings in order to manage to go through a situation that could not be avoided. People around them perceived the person as being controlled and kept distance.

The other and divergent side of suffering was defined as emotional suffering in which emotions were released. Our findings are different as the relatives describe endurance as an integrated reaction. In the same way as the word endurance has the double meaning of toleration and sufferance (Waite, 2002), the relatives’ endurance integrated strength and vulnerability and which were of equal importance to recognize and to confirm. However, vulnerability was not immediately apparent. There was need for deepened questions to come close to the vulnerable side of their reaction. The relatives kept their own worry back in favour of the patient but they did not deny its existence and they were in contact with their feelings of hope and fear simultaneously. Overall, the relatives expressed that they had to be the stronger part in this situation, and at first, they felt that it was a betrayal against the patient, admitting that the situation also was burdensome to them. Although closely connected with the patients, the heart disease still did not directly threaten their own core of self and life. The indirect threat together with hope for improvements after surgery perhaps made them endeavour to show their strong and supportive side. However, they seemed to pay a rather high price for their endurance. Taking the role of the stronger part as their duty, the relatives deemed themselves to loneliness and they also contributed to preserve the traditional approach in which the patient is focused and cared for.
However, heart disease takes place in a family context and has consequences for all members. The informants’ everyday life changed, and they set aside own wishes and needs in order to devote themselves to the patient. Even when they felt anxious and frustrated, it seemed important to them not to fail in their supportive role. This is in concordance with an earlier study (Knoll, 2000), where relatives experienced feelings of stress, vulnerability and a need to put their own lives on hold in the recovery period after their family member’s cardiac surgery. When relatives are left in a situation in which they feel a heavy burden of responsibility, their own health and well-being are at risk to decrease. In 2000, 66% of a sample of 213 spouses met the criteria for distress and the most prevalent symptoms were feelings of tension, being easily hurt and sleeping disturbances (O’Farrell et al., 2000).

In another study including 120 cardiac patients, it was found that 30% of their caregivers had a health problem of their own to handle while caring for the patient (King & Koop, 1999). It is of great importance that health care professionals are conscious about the integrated meaning of endurance. When relatives are met with acceptance also when they feel vulnerable they will be strengthened and by reflection be able to find new ways to handle their changed everyday life. It would also help them allowing themselves to show their vulnerability and longing for attention. There is need for a lifeworld perspective in which relatives are seen both as a resource for the patients and as sufferers in their own right.

The informants experienced that it is impossible to have a relationship without being involved in and affected by each other’s lifeworld. This involvement was unconditionally governed by strong feelings of love and responsibility and was given with no demands for appreciation. Hence, this immediate, unreflected involvement made it difficult for relatives to draw up reasonable boundaries for their sharing. It was as if they had been asked to dance with previous studies (Ivarsson, Sjöberg & Larsson, 2005; Moser, Dracup & Marsden, 1993) they considered that the hospital staff did not give them the attention they needed as they rarely initiated contact. During the past decades, the situation of relatives of open heart surgery patients has been described, and a more active stance towards them on the part of health care professionals has been recommended (Coyne et al., 1990; Bengtsson et al., 1996; Davies, 2000; O’Farrell et al., 2000).

Our findings confirm the need to pay greater attention to relatives in order to decline their uncertainty and make them feel better. The tacit communication in these families was an expression of the relatives’ belief that they could “read” the patient’s mind and draw accurate conclusions about their thoughts and feelings. Communication is more than spoken words. However, taking their own interpretations for granted without clarifying them by means of questions implied a risk of misunderstanding. Failure to speak to each other can lead to a split and it is vital to offer such families professional assistance to help them communicate (Montgomery et al., 1985). According to the present and other studies, heart surgery has a definite effect on both marital and family life (Coyne et al., 1990; Svedlund & Danielsson, 2004; Van der Poel & Greeff, 2003).

In addition to the mutual sharing with the patient, it was important for the relatives’ well-being to feel the support and concern of their private network. The women had a variety of contacts while the men relied on the family. This gender difference in behaviour has also been observed among patients (King & Koop, 1999). Although in need of support the informants still were surprised when asked if someone in the family or professional network had shown concern for them in their role as a relative of an open heart surgery patient and, as such, a co-sufferer. To them, this seemed to be a new way of thinking. Support was defined as concern focused on...
the patient and it was taken for granted—especially in contacts with the health care professionals. Perhaps this reflected traditional thinking and expectations but a previous study suggested that relatives might find it easier to discuss the patient’s condition instead of their own needs (Rantanen et al., 2004).

The informants expressed that the experience of open heart surgery had changed their lives forever. They realized that life had reached a critical stage meant that things that had previously been important lost its meaning and fell like petals, leaving them defenceless, vulnerable and in sadness. As revealed in previous studies (Artinian Trygar & Duggan Hillebrand, 1993; Ivarsson et al., 2005), the informants feared losing their loved one. The severity of the illness and threat of death cast a shadow from the very beginning, irrespective of whether the patient had to go on a waiting list or if surgery took place immediately. This life event made them reflect on their life. They described changed values, a new awareness about the shortness of life and the urgency to make the best of it. In a way, their life horizons became more limited but with sharpened contours and deepened focus. The period of illness resulted in improved ability of family members to live in the present but decreased confidence in the future. The awareness of the fragility of life meant vulnerability and strength also in that sense that it brought the relatives closer to their own mortality as well as they learned about their ability to sustain.

Methodological considerations

The phenomenological method was chosen due to its strength in describing experiences without attempting to interpret them (Dahlberg & Drew, 1997). The in-depth interview was a suitable instrument for a researcher (A-KK) with extensive experience of conversational therapy. In this study, we had no direct influence over the choice of participants, since they were chosen by the patients. However, the patients were consciously selected which points towards a relevant selection in this study since all but one were spouses. It is regrettable that there were fewer relatives than there were patients, but if participation by a relative had been made a criterion for taking part in the study, patients without a relative would have had to be excluded. The interview questions were developed from a lifeworld perspective in order to reflect the studied phenomenon’s process “over time” in the phenomenological way of thinking, where present time always includes the past and the future. To conduct and later transcribe the interviews made the researcher deeply familiar with the content; this facilitated keeping an open mind while waiting for the phenomenon to show itself. Although it is not possible to fully bracket one’s pre-understanding, the researcher tried to avoid influence due to her pre-understanding. The study has been conscientiously validated. The supervisor (EL), who acted as an independent judge, is, like the rest of the group, familiar with the problems surrounding heart disease. The findings were evaluated by representatives of different professions and, although drawn from a specific context, should nevertheless have good transferability to groups experiencing similar situations in which there is a threat to close relatives’ life.

Conclusions

Open heart surgery had a major impact on the relatives in that it changed their lifeworld. Since they could not escape from their lifeworld, the relatives’ reaction on the stressful situation was to show endurance. Endurance was an integrated reaction of strength and vulnerability, although the vulnerability was not immediately apparent. It is important that health care professionals are conscious of the double meaning of endurance to avoid that relatives’ burden of responsibility increases because they are left alone with their own feelings and reactions. A lifeworld perspective that includes relatives is essential in understanding the problem. Further research to investigate health care professionals’ perceptions of the situation of this patient group and their relatives is needed.

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References


