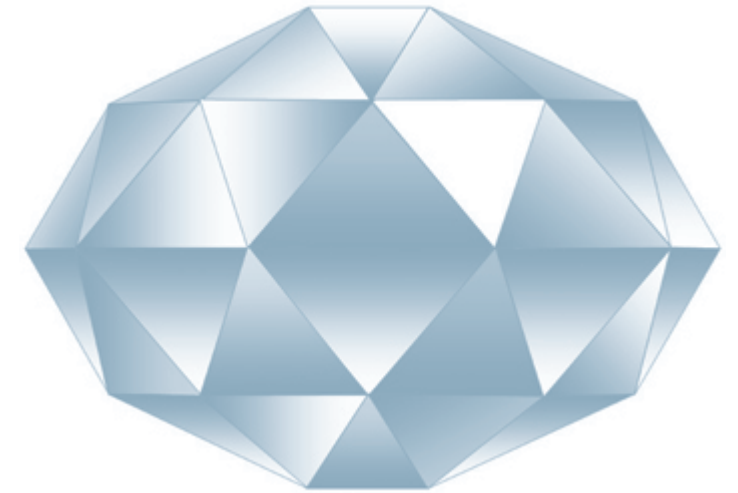


Open heart surgery and its consequences for well-being – the perspectives of patients, relatives and health care professionals



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“Having to face heart surgery means a great deal more than can be imagined and involves the realisation that you are the person you are. No mask can help or is even necessary.”

Male patient three years after open heart surgery

*To Folke and Kristian
and
in memory of my father, mother and brother*

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Abstract

Introduction: Adjustment to open heart surgery (OHS) is complex and necessitates multidimensional explanations. The surgery does not always provide the desired outcome, which can contribute to reduced well-being among patients and their relatives. Health care professionals (HCPs) play an important role in detecting signs of reduced well-being. However, such signs in both patients and their relatives can be difficult to discover, as the patients' stay in hospital after surgery is short and the HCPs' workload high.

Aim: The general aim of the thesis was to describe and explore OHS through patients' and relatives' experiences and HCPs' observations of its influence on well-being.

Methods: Phenomenological interviews were performed with patients and relatives and analysed in accordance with Giorgi. HCPs involved with patients undergoing OHS participated in focus group discussions and the data were analysed by means of content analysis. Finally, patients who had been examined five weeks and five months after OHS participated in a follow-up study 3 years later, the data for which were collected by means of questionnaires and telephone interviews and evaluated using statistics in addition to content analysis. Quantitative and qualitative data were analysed both separately and together.

Results: The essence of the patients' experience of OHS was "fragility", based on "distance", "uncertainty", "vulnerability", "reliance" and "gratitude". The characteristic of their relatives was "endurance" derived from the following constituents: "unconditionality", "uncertainty", "mutuality" and "sadness". HCPs' sensitivity to signs of reduced well-being in patients and relatives after OHS formed the theme "awareness of an exposed situation" based on the categories: "signs of vulnerability" and "signs of insecurity". Depressed mood occurred in 52 % of the patients during recovery or three years after OHS. The theme "transition", which was based on three categories: "adjusting oneself to

conditional health”, “positioning oneself in the surrounding world” and “making an inner journey”, emerged from the qualitative content analysis.

Conclusions: OHS was experienced as a great challenge, which changed the patients and made them fragile. Fragility remained in the life of all patients three years after OHS and was especially obvious in patients with depressed mood. This condition affected the majority of patients during recovery and also had an impact on their long-term well-being. OHS constituted a life transition for all patients, but those with depressed mood experienced disruptions while finishing their transitional process, which impeded reorientation. OHS had a major impact on the relatives, as it changed their lifeworld. The relatives’ reaction was to show endurance, which involves the integrations of strength and vulnerability. HCPs recognised signs of reduced well-being in patients and their relatives after OHS. However, those most often recognised concerned the patients, while the relatives’ well-being remained more or less unexplored.

Key words: Open heart surgery, depressed mood, well-being, qualitative methods.

Svensk sammanfattning

Introduktion: Anpassningen till livet efter öppen hjärtkirurgi är ett sammansatt förlopp och för att förstå skeendet behövs olika förklaringsmodeller. Att genomgå hjärtoperation leder inte alltid till önskat resultat; försämrat välbefinnande hos patienter och närstående kan också bli följden.

Sjukvårdspersonal har en viktig roll i att känna till och upptäcka tecken på försämrat välbefinnande. Sådana tecken kan emellertid vara svåra att upptäcka hos både patienter och närstående då vårdtiden efter operationen är kort och sjukvårdspersonalens arbetsbelastning är hög.

Syfte: Avhandlingens huvudsyfte var att utforska öppen hjärtkirurgi genom patienters och närståendes upplevelser samt sjukvårdspersonals iakttagelser av operationens påverkan på välbefinnandet.

Metoder: Fenomenologiska intervjuer av patienter och närstående genomfördes och analyserades enligt Giorgis modell. Sjukvårdspersonal som deltog i vården av patienter behandlade med öppen hjärtkirurgi medverkade i fokusgruppsdiskussioner. Data analyserades med hjälp av innehållsanalys. Vidare deltog patienter som undersökts fem veckor och fem månader efter operationen i en uppföljningsstudie tre år senare. Data insamlades med hjälp av frågeformulär och telefonintervjuer och analyserades med deskriptiv statistik och med innehållsanalys. Kvantitativa och kvalitativa data analyserades först var för sig och därefter tillsammans.

Resultat: Essensen av patienternas upplevelser av öppen hjärtkirurgi var ”skörhet”, baserade sig på begreppen ”distans”, ”osäkerhet”, ”sårbarhet”, ”tillit” och ”tacksamhet”. För närstående var ”uthållighet” det essentiella karaktärsdraget och härleddes ur kategorierna ”ovillkorlighet”, ”osäkerhet”, ”ömsesidighet” och ”vemod”. Sjukvårdspersonalens känslighet för tecken på minskat välbefinnande hos patienter och närstående efter hjärtkirurgi kom till uttryck i temat ”medvetenhet om en utsatt situation” baserat på kategorierna ”tecken på sårbarhet” och ”tecken på otrygghet”. Nedstämdhet förekom hos 52 % av patienterna under återhämtningsfasen eller tre år efter öppen hjärtkirurgi. Den kvalitativa innehållsanalysen utmynnade i temat ”övergång”, vilket byggde på de tre kategorierna ”anpassa sig till villkorad hälsa”, ”hitta sin plats i omvärlden” och ”att göra en inre resa”.

Slutsatser: Öppen hjärtkirurgi var en utmaning som förändrade patienterna och gjorde dem sköra. Skörheten fanns kvar hos alla patienter tre år efter hjärtoperationen, dock särskilt märkbar hos nedstämda patienter. Nedstämdhet påverkade majoriteten av patienterna under återhämtningsfasen, men också välbefinnandet över tid. Öppen hjärtkirurgi innebar en övergång i livet för alla patienter, men de personer som var nedstämda stördes mest i sin omorienteringsprocess. Öppen hjärtkirurgi hade stor påverkan på närstående vars livsvärld ändrades. De närstående reagerade med att visa uthållighet.

Uthålligheten var en integrerad reaktion av styrka och sårbarhet. Personalen kände igen tecken på nedsatt välbefinnande hos patienter och närstående efter öppen hjärtkirurgi. De flesta igenkända tecknen rörde patienterna emedan de närståendes välbefinnande förblev ganska outforskat.

Nyckelord: Öppen hjärtkirurgi, nedstämdhet, välbefinnande, kvalitativa metoder

Original papers

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Abbreviations

BDI Beck Depression Inventory

CABG Coronary bypass graft surgery

DG the depressed group

HCP Health care professional

HVR Heart valve replacement

MADRS-S the Montgomery Åsberg Depression Rating Scale, Self rating version

NDG the non-depressed group

OHS Open heart surgery

TDG the temporarily depressed group

Foreword

One day in the mid-1980s there was expectation in the air when I took part in the daily round at the medical ward. This was a historic day, as we were awaiting the arrival of the first patient to return from the regional hospital after undergoing open heart surgery (OHS) by means of coronary artery bypass graft surgery (CABG). All activity seemed to stop at the moment of his arrival and he was greeted like an honoured guest. The faces of the professionals around me - and no doubt mine as well - expressed wonder, curiosity and joy. This joy was reflected in the patient's smile but in his eyes I recognised fatigue and something more, which I have now learned to identify as vulnerability caused by the complexity of the experience. I cannot remember the presence of any relatives, although it is likely that they were there, but I am quite sure that the professional discussion did not touch on the question of their well-being. Recalling this memory twenty years later, I think that the patient was perceived and met in a way that every patient ought to be; as a unique person. The patient and the professionals were mutually dependent, as we were aware that we had much to learn from his experiences of OHS. Today, OHS is common in cardiac care and the arrival of a patient does not disturb routines. However, OHS still remains a unique and challenging event in the patient's life as well as that of his/her relatives, which must be neither forgotten nor minimized by health care professionals (HCPs). Furthermore, irrespective of HCPs' increased knowledge of OHS methods, the lived experiences of OHS can only be learned from the patients and relatives concerned. It is my sincere wish that their voices be heard beyond this thesis and touch the hearts of the readers.

As is the case with OHS, I want to believe that there has been an improvement in my own practice as a social worker in medical and health care. Applying a family perspective on health problems has come naturally to me from the beginning, as did the decision to engage in further education in family therapy, which I finished in the early 2000s. The more I invited patients to bring their close relatives to our meetings, the more I became aware of how important it was both to the families concerned and to myself for a deeper understanding of the complexity in their situation. One day I met a young woman who had undergone heart valve replacement (HVR). She brought her husband and their ten-year old daughter with her. The family exhibited obvious signs of a crisis, anxiety and depressed mood. In her description of everyday life, the little girl captured their situation in a clear and sensitive way. The husband both cried and shouted during the session. At last he said: "You are the only HCP who has asked about *my* well-being". In the silence following his statement, I almost felt the conception of this thesis, because in that moment I knew that it was time for me to take a further step. I felt that it was my duty to deepen my knowledge about the well-being of patients and relatives in connection with OHS and to

write about it in order to share my knowledge with practitioners and researchers both in hospital and primary health care.

Introduction

Both historically and today, the aim of OHS by means of CABG or HVR is the prolongation of life as well as the relief of symptoms such as angina and dyspnoea. This is reflected in the research literature, where for a long time the main focus has been on mortality and morbidity in relation to OHS. However, increased ability to prolong life has given rise to a variety of questions about quality of life including not only physical but also psychological and social dimensions [1]. Even if the surgery per se is successful, OHS does not always produce the desired outcome [2]. Adjustment to OHS is complex, and multidimensional explanations are required in order to understand it [1].

The importance of social support for the well-being of the patient [3-4] and his/her relatives [5-6] has been described. However, there are fewer descriptions of the consequences of OHS that view the patient and his/her relatives as a unit and thus an indivisible part of each other's lifeworld. Coyne et al. [7] described the maintenance of well-being after myocardial infarction as a dyadic process between patient and spouse. Moore [8] reported an association between spouse anxiety and patient depression as well as between spouse depression and patient anger. A recent study reported that couples experienced heart disease as affecting their life because it was a threat and the patient's body had suddenly become unreliable [9]. These examples demonstrate that a different kind of knowledge can be gained if questions about their relationship in connection with OHS are asked and patients and relatives perceived and cared for as an interactive unit.

HCPs play an important role in detecting signs of reduced well-being. However, such signs in both patients and their relatives can be difficult to discover, as the patients' stay in hospital after surgery is short and the HCPs' workload high. Depression, a risk factor for increased mortality after CABG [10], and other psychological signs are easily underestimated in a context where the focus is on physical signs [11-13]. Other reasons for underestimating depression in patients after OHS may be that the perceived symptoms are considered normal under the circumstances, the professionals may lack experience of identifying mental illness or find it too time-consuming to assess depression during a short hospital stay [14-16]. HCPs who endeavour to communicate with patients and relatives are important for the detection of decreased well-being [17]. Hence, findings such as those presented by Arnetz and colleagues [18], in which HCPs viewed time constraints and their own uncertainty as obstacles to patient involvement in the care after myocardial infarction should be a matter of major concern.

Background

Definitions

Open heart surgery (OHS)

OHS is a form of surgery where the heart is stopped and/or opened. The heart and lung functions are taken over by a heart-lung machine, which allows the surgeon to operate under safer circumstances and with less haste. The heart and other organs are chilled to protect them during the operation [19].

Lifeworld perspective

The lifeworld is a central concept in phenomenological philosophy and means unreflected everyday life that is taken for granted. It is related to time and space and there is no escape. The living horizon is constantly shifting as humans live both 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. The change in the lifeworld caused by illness disturbs this relationship and, consequently, the body language may no longer appear familiar and understandable. Reflection allows the lived lifeworld to be experienced at a deeper level [20-21].

Well-being

Well-being as defined by Naess et al. [22] includes the ability to be active, good interpersonal relationships, self-esteem as well as rich and intense aesthetic experiences. Being active means: having a zest for life, being involved in something outside one's own person and having control over one's actions. The meaning of good relationships is closeness, friendship and feelings of identity with a group. Self-esteem emphasizes the ability to cope and feeling satisfied with one's own efforts, while the aesthetic aspects are associated with being open and receptive, the absence of anxiety, restlessness and depression as well as a basic mood of happiness.

Depressed mood

Depressed mood is generally seen as distinct from a diagnosis of clinical depression, but may be considered a symptom of such depression if it lasts for at least two weeks and interferes with everyday life. It is situational and reactive and associated with grief, loss or a major social transition. Depressed mood can be reported by the patient as a symptom or observed by HCPs as a sign of reduced well-being [23].

Open heart surgery over time

The first successful OHS using a heart-lung machine was performed in Philadelphia, USA, in 1953 by MD John H Gibbon. Before this historical event, cardiac surgery was rare and, even after the introduction of the heart-lung machine, it remained risky and problematic. Dr Gibbon himself stopped performing OHS after losing two patients. However, his work was a breakthrough and followed up and further developed by others [24], e.g. Professor Clarence Crafoord in Stockholm, Sweden, who was the second to successfully perform OHS in 1954. By 1957 twenty-five patients had undergone OHS in Sweden but thirteen died in conjunction with the surgery [25]. OHS was first used for congenital heart disease in children and later for performing HVR in adult patients. Today, CABG is the most common operation in which a heart-lung machine is used [26]. The Swedish National Board of Health and Welfare reported that 25097 CABG operations were performed in Sweden in 2005 compared to 4592 in 1987, while the figure for HVR surgery increased from 647 to 1598 [27]. Nowadays the risks associated with OHS have decreased and depend on the severity of the patient's heart disease. Post operative bleeding occurs in about five per cent of patients. Other complications are wound infection, pneumonia, myocardial infarction, heart fibrillation, renal failure and stroke [26]. Such complications have a more or less direct impact on patient well-being, while the effect on their relatives is more indirect.

The existential meaning of heart disease and open heart surgery

Having a heart disease such as myocardial infarction is associated with feelings of fear and loss of control [28]. From the moment of the confirmation of the diagnosis, life changes in various ways. Crafoord [29] described it as a split between the infarction as a phenomenon and himself as a person. Although objective signs of the myocardial infarction were interpreted and treated by the HCPs, they did not enquire about his thoughts and feelings, which in Crawford's view are also important aspects of the illness. The sense of unreality seems to be connected with the experience of a suddenly changed body; a failing, untrustworthy and unfamiliar body [9, 30]. From a lifeworld perspective, life is lived through the body [20-21], thus the failing body pointing to its own end indicates that death is a part of everyday life and no longer a distant fact [9]. Awareness of the risk of a new cardiac event leading to death if immediate help cannot be obtained is a difficult situation to handle [30]. Such vulnerability can lead to feelings of powerlessness and undesired dependence on others [30-31] but also to a sense of spirituality and belief in a higher power [28, 32-33]. The chance to undergo OHS can be experienced as putting aside the inevitable death for some years, thus it becomes essential to derive maximum benefit from this "second chance to live" [28, 34]. However, experiencing OHS challenges a person's self-esteem as well as his/her ideas of the meaning of life. As no

guarantee of staying healthy can be given, the patient needs to find the courage to continue living [32].

The concept of well-being

The meaning of well-being has been explained as “the state of being comfortable, healthy or happy” [35]. This brief explanation indicates that well-being is complex and includes various aspects of human life. The concept of well-being has been discussed and defined from different perspectives. It has commonly been defined as both health and quality of life and also as an aspect of health [36]. In view of the difficulty involved in capturing its substantial content, the existence of the well-being concept in health care promotion has been questioned [37]. However, according to Sarvimäki [36], the concept of well-being may be perceived as both a unifying concept and characteristic of health and quality of life. In the same article, the author argued that, although well-being is a holistic concept, it can still be conceptualized in empirical research as e.g. physical, psychological, social and spiritual, but that it must be viewed as a whole on a philosophical level in order to achieve deeper understanding.

Naess et al. [22], whose definition of well-being has been applied in studies III and IV of this thesis, use the terms well-being and quality of life synonymously, both of which are linked to the experience of individuals. The definition is formulated as follows: “The quality of a person’s life rises in proportion to the degree that that person is active, has good interpersonal relationships, has self-esteem and has rich and intense aesthetic experiences” (p 16). These areas of well-being represent values which are good in themselves in contrast to resources, i.e. income, which is a means to achieve the good things in life. The four areas of well-being are of equal importance; they correlate strongly with each other and none should be assigned greater significance than the others. A person with the ability to be active is often happy, while self-esteem is necessary for good relationships with others. “A basic mood of happiness” means a feeling affecting the whole person over a long period.

Open heart surgery and patient well-being

Surgery is associated with hope and fear

Although OHS is a common and well-tested method today, physicians as well as patients have to weigh the risk involved in relation to the possible improvements in health. Several studies have presented results showing improved health status after surgery [38-39]. For patients aged 70 years or over, long-term survival and quality of life have been found to be comparable to an age-matched population [40-41]. Despite improved treatment methods, OHS implies a threat to the life of the patient and is associated with fear and anxiety [3, 28, 42]. A disease that necessitates OHS is an unwelcome interruption in a person’s life and the operation a major encroachment on one’s body and integrity [34]. In a sample of

30 patients, almost half experienced heart surgery as a huge personal shock and had difficulty adjusting to life afterwards [43].

Summary

OHS improves patients' health, prolongs life for some and increases quality of life. However, it also implies a threat to life and is associated with fear and anxiety as well as difficulty adjusting to life after surgery.

The patient and the inner self

Recovery is far more than survival, and a successful re-orientation seems to depend on various factors. One part of this process is the attempt to understand what caused the cardiac disease. It was recently reported that patients believed that risk factors in their own lives such as stress, smoking and high blood pressure had caused the illness. Patients with a higher socio-economic status more often attributed the heart disease to heredity and genetic factors [44]. Lichtenberger et al. [45] demonstrated that patients' perceptions of their physical capacity were more important to their body image (the way a person sees, thinks about, feels about and acts towards his/her body) than their actual physical capacity. Experiencing the capacity to influence and cope with the changed life situation is important for well-being, as are feelings of meaningfulness and satisfaction. It has been reported that patients with a strong sense of coherence experienced less loneliness, depressed mood, stress, anxiety and chest pain one year after CABG [46]. This is in accordance with a study describing that women with higher social role quality had higher levels of purpose in life, positive relationships and self-acceptance as well as lower levels of anxiety and depression after heart surgery [47].

Summary

The recovery phase is a difficult period, as patients are searching for the causes of their heart disease and trying to discover their own capacity. The experience of meaningfulness and coherence is favourable for patient well-being.

Mood and close relationships

Depression and anxiety have been studied in relation to OHS. Depression has been identified as a risk factor in cardiac morbidity and mortality [10, 15, 48-50] as well as having an adverse impact on quality of life following heart surgery [51]. Social support is important for well-being both before and after OHS. Koivula et al. [3] found that patients awaiting CABG surgery who received low emotional support from their social network experienced high levels of anxiety. It was recently established that low family support is associated with more symptoms of depression, anxiety and hopelessness six months after CABG

surgery. More depressive symptoms as well as chest pain were reported by patients living alone as well as those aged 65 and under [4].

Summary

Depression is a risk factor for cardiac morbidity and mortality after OHS and also has an adverse impact on quality of life. Low social support and living alone are associated with increased depressive symptoms and chest pain, especially in patients aged 65 and under.

Open heart surgery and well-being of relatives

The relatives' position in health care

OHS is a life event that has a profound influence on both the individual and the family unit. It is impossible to be linked to someone without being mutually dependent [7, 52-54]. Consequently, when a family member develops heart disease and requires OHS, it has an immediate impact on his/her relatives. Interest in the situation of relatives in the cardiovascular arena developed gradually in the 1980s [55]. According to Sales [55], such awareness demands a change from only focusing on the patient to a family centred perspective, which can be difficult for HCPs, as it challenges educational traditions. The relatives' role is complex and while their role as supporters and carers may be considered a resource [5, 56-58], other aspects are the personal [8, 53, 57, 59, 60- 63] and relational costs [7, 9, 64-69]. Including relatives as an indivisible part of the patient's life implies changes in professional support and communication [5-7, 9, 54, 67-75].

Summary

OHS influences both the individual and the family unit. Applying a family centred perspective on OHS shows that the relatives' role is complex, as it not only involves being the patient's supporter and carer but also a personal and relational cost.

The relative and his/her supportive role

Relatives, especially spouses, are the primary source of patient support [5], which includes different functions such as monitoring, suggesting lifestyle changes, solving problems, assuming responsibility for everyday life and comforting the patient [56-58]. Previous caregiving experience, role mastery and self-esteem are important for whether the care leads to feelings of growth or becomes a destructive burden [57, 76-77].

Summary

The supportive role includes a variety of practical tasks in addition to monitoring and comforting the patient. It can lead to personal growth or feelings of being burdened.

The relative and the burden of care

The short hospital stay after OHS means that a range of problems have to be solved at home by the patient and his/her relatives, which has a major impact on their everyday life [57]. Relatives have reported expressions of stress such as vulnerability, tension and sleep disturbances [53, 57, 59] and may also have to cope with health problems of their own while caring for the recovering patient [60]. Family caregivers have reported more depressive symptoms than patients both preoperatively and in the later stages of recovery [8, 61-63]. Apart from the long recovery process, a contributory factor may be a declining level of social support over time, as reported by Trygar Artinian [64]. A gradual decrease in social support increases the pressure on family relationships.

Summary

Relatives who are burdened by the caring situation develop various stress symptoms and depressed mood to a higher extent than the patients. In addition to the long recovery process, a contributory factor may be a decline in social support.

The burden of care and close relationships

In 1985 the burden of care was described for the first time as a product of interaction [65] and the study of Montgomery et al. was followed by others with the same focus [7-8]. Moore [8] reported that spouse anxiety was associated with patient depression and anger in the same way as spouse depression was related to patient anger. Such mutual interdependence between family members has also been described in later studies [9, 66-67]. Negative consequences can be increased burden and loneliness, resulting in overprotective behaviour [67] or a disruption in communication between the patient and his/her relatives [68-69]. On the other hand, well-functioning communication can bring family members closer together in a mutual striving to handle the changed life situation [9].

Summary

When the burden of care is viewed as a product of interaction and mutual dependence, associations between spouse depression and patient anger and vice versa become visible and can have a negative impact on family life. On the other hand, well-functioning communication promotes closeness and strengthens relationships.

Open heart surgery: patients' and relatives' relationship with the health care professionals

Undergoing OHS is a challenging experience [43, 78] and well functioning professional relationships are vital for well-being. The patient is vulnerable and dependent [31] and, in order to feel well prepared and have realistic expectations, he/she needs honest and adequate information about the heart disease and surgery [34, 78]. The patient wants to be seen as an individual, be the centre of the professionals' attention and feel confident that problems with e.g. pain, sleep and anxiety are carefully addressed [78-79]. Patients with a high level of fear and anxiety are in special need of individualised informational support [3, 80]. However, the effectiveness of the information is related to how well it matches the patient's coping style. Problem-focused patients wish to be prepared in detail beforehand, emotion-focused patients require more general and reassuring information while relationship-focused patients prefer interaction [81]. Overall, well-functioning communication between the patient and the professionals is important for stimulating the patient to play an active role in the recovery process and believe in his/her own ability to make lifestyle changes [44-45]. It was recently established that there is a connection between patients' satisfaction with their physicians and adherence to medical regimens and that depressed patients are less satisfied with the physicians directly involved in their care [82]. Much of the patient's existential and emotional suffering is tacit and will remain hidden unless HCPs meet the patient as a unique individual [32]. This implies a patient centred approach as well as communicating and acting with empathy [17, 32, 83-86].

Well-functioning communication between HCPs and relatives that provides information and invites dialogue is important, as it reduces uncertainty as well as anxiety and, as a result, depressive symptoms [5, 67, 70-71]. Several studies from the last fifteen years reveal deficiencies in this area and these unmet needs of the relatives are a matter of concern [5-6, 54, 71-74]. Relatives' expectations of receiving attention from HCPs seem to be modest. Their main wish is for understandable information and answers to their questions [54, 75]. Negative experiences of encounters between relatives and HCPs are neither forgotten nor moderated by subsequent well-functioning contact and can influence family life six months after discharge [7].

Summary

Undergoing OHS is a challenging experience and well functioning professional relationships are vital for well-being. The patient wants to be the focus of the professionals' attention and requires adequate information about heart disease and surgery. Well-functioning communication between the patient and the professionals promotes successful recovery, willingness to make lifestyle changes and adherence to medical regimens. Relatives want HCPs to provide understandable information as well as responses to their questions.

Good communication with HCPs is important for reducing uncertainty, anxiety and depressed mood in relatives. However, their needs often seem to remain unmet.

Open heart surgery: triangulation of perspectives

Human beings' dependence on each other, which is fundamental as opposed to chosen, makes us vulnerable due to the risk that our exposed needs will not be adequately met. A threat to life reduces the individual's influence on his/her situation, making his/her dependence on other people obvious. Awareness of the needs of others can be both negative and positive, depending on earlier experiences of the response to needs and how highly autonomy is valued. Caring for someone who exposes his/her vulnerability also constitutes a fundamental human condition, although the ability to care varies in accordance with emotional and cognitive resources. The relationship between the individual in need of care and the carer is asymmetric, which is desirable in the case of patient and professional carer [31]. However, an asymmetric relationship between family members may be problematic, as they are mutually dependent and have established roles in everyday life [52]. This thesis is built on the idea that the complexity of OHS implies the use of multiple perspectives in the exploration of the phenomenon. It was assumed that OHS and its influence on the well-being of patients and relatives would be described differently by patients, relatives and HCPs but that, when linked, the perspectives would constitute a meaningful whole, which is not only more than the sum of its parts but also qualitatively different [52].

Aims

The general aim of the thesis was to describe and explore open heart surgery through patients' and relatives' experiences and health care professionals' observations of its influence on well-being.

Specific aims

- To describe patients' experiences of OHS in a lifeworld perspective (study I).
- To describe relatives' lived experiences of a family member's OHS in a lifeworld perspective (study II).
- To explore how HCPs perceive the well-being of patients and relatives following OHS (study III).
- To explore the presence of depressed mood in patients during the recovery phase after OHS as well as depressed mood and well-being three years later (study IV).

Design, Material and methods

An overview of the research design and the methods applied in this thesis is presented below (Table 1).

Table 1 Overview over design and methods of the studies

Study	Design	Participants	Method and analysis
I	Qualitative, descriptive	14 patients	Phenomenological
II	Qualitative, descriptive	9 relatives	Phenomenological
III	Qualitative, observational	18 health care professionals	Focus groups Content analysis
IV	Quantitative and qualitative, observational	80 patients	Questionnaires and telephone interviews. Statistics and content analysis

Phenomenological approach and method

Phenomenology, which is both a philosophy and a method, was applied in studies I and II. The fundamental principle of phenomenology is to come close to a phenomenon, thus allowing it to reveal itself. Besides the concept of lifeworld (described above) there are two further concepts of crucial importance; intentionality and reduction. Intentionality alludes to a person's relationship with the experienced phenomenon. His/her consciousness is directed towards the phenomenon, which is experienced as something; it has a meaning. In phenomenological research you are interested in the way that consciousness grasps a phenomenon as something. Reduction is the researcher's conscious act of bracketing or "bridling" his/her pre-understanding of the phenomenon [20-21]. The emergence of a phenomenon is a result of an interactional meeting between human beings who have a mutual interest in a specific question, although the conditions of participation are not equal between the parties [20, 87]. Giorgi [88] emphasizes that the phenomenon of interest should be understood and described without addition or deletion. He states that interpretation is not description, as it adds a theoretical or other perspective that

may not be required for intuitive evidence. Instead, the researcher must strive to make the informant's description as detailed as possible from his/her professional perspective.

Content analysis method

Qualitative content analysis was applied in studies III and IV. This analysis method is used to examine social communication in the form of written documents or transcribed verbal communication [89]. Content can be both manifest and latent. The manifest content describes obvious and visible data while the latent content is an interpretation of the underlying meaning of the text [89-90]. Berg [89] recommends that both manifest and latent analysis are performed whenever possible. The creation of categories is central to qualitative content analysis. The categories should be derived from the data [89]. A category answers the question "what is happening here?" while a theme answers the "how" question and can be perceived as the expression of the latent content of the text [90].

Focus group method

A focus group is a group discussion with a clear and specific content led by a moderator [91]. The method is deemed to be applicable for capturing perceptions, attitudes and opinions in a context where many people co-operate [92]. According to Kitzinger [93], it is useful to work with pre-existing groups, as they provide a social context in which ideas are formed and decisions made. Aspects that should be taken into consideration are the risk of an existing group avoiding particular topics either because the opinions are taken for granted or to avoid conflict. However, such problems can be solved by means of conscious interventions on the part of the moderator. It is also important for the moderator to ensure that all participants are allowed time and space to express their standpoints [91]. The interaction between the participants distinguishes the focus group method from individual interviews and questionnaires, and the conversation between participants should be presented by means of quotations [93].

The MADRS-S instrument

The MADRS-S, a 9-item scale validated against the Beck Depression Inventory, BDI ($r=0.869$), is a self-assessment instrument for depression [94] and was used in Study IV. The items concern mood, anxiety, sleep, appetite, ability to concentrate, initiative, emotional involvement, pessimism and zest for life. Self-rated symptoms are evaluated on a scale ranging from no symptoms = 0 to severe symptoms = 6.

Study population

In the period between January 2002 and October 2003, 163 adult patients (≤ 75 years) were referred back to Varberg hospital, Sweden, for rehabilitation after OHS either at Sahlgrenska University Hospital Gothenburg, Sweden, or at the Scandinavian Heart Centre, Gothenburg, Sweden. Of these, 15 declined participation, 15 were excluded because of inability to speak Swedish and 35 because of atrial fibrillation which interfered with some of the planned analyses. One hundred patients (17 females and 83 males) were included in the study. The average age was 64 ± 9 years, ranging between 41 and 75 years. Ninety-four had undergone CABG, four had undergone CABG combined with HVR while two had only undergone HVR. Ninety-seven patients were examined five weeks after surgery, while three patients were not examined at all, as they dropped out of the study at an early stage. Three patients refused to attend the planned five-month visit, hence 94 patients underwent the two investigations on which all the studies described in this thesis are based (Figure 1).

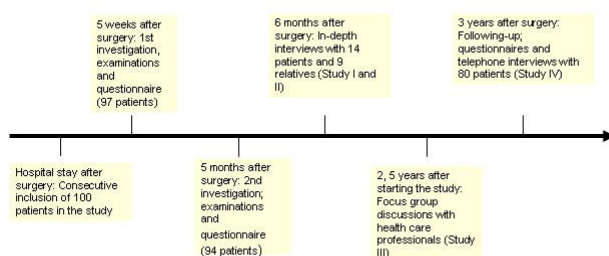


Figure 1 Flowchart for the studies

Participants

In Study I, nine men and five women who had undergone CABG and/or HVR surgery were interviewed in depth six months after the operation. The mean age of this group was 63 years, ranging between 53 and 74 years. Ten of the patients were married and five were working. In parallel with the patient interviews, nine of their relatives, seven women and two men, were interviewed in depth (Study II). Eight were spouses, while one was an adult child. They had been asked to participate by their ill family member. The patients could abstain from involving a relative if they so wished, which was the choice of three patients who lived alone. In two cases the relatives withdrew. As the main criterion for participation was the closeness of their relationship to the patient, no further demographic questions about the relatives were asked. In case of couples, the

relatives were about the same age or at most 12 years younger. The adult child was approximately 40 years of age.

In Study III, HCPs responsible for the care of patients undergoing OHS by means of CABG or HVR participated in focus group discussions. Six nurses and four assistant nurses (all female) took part in the study, together with four physicians (two male, two female), two physiotherapists and two social workers (all female). The number of years in the profession was as follows; nurses 1-27 years (median 10 years), assistant nurses 24-27 years (median 26 years), physicians 5-35 years (median 13 years), physiotherapists 18-20 years (median 19 years) and social workers 1-4 years (median 3 years).

Three years after OHS one patient had died. Hence, 93 patients who had undergone CABG and/or HVR and who were examined at five weeks and five months after OHS were asked about participation in a follow-up study (study IV) and 80 (67 male and 13 female) accepted. Their average age was 67 years (range 43-78 years). Eighty-two percent were married or co-habiting, while 18% lived alone. The majority, 70%, were retired or semi-retired, 34% worked full or part time, while 3% were on sick-leave. Ninety-eight percent underwent CABG, 5 % CABG combined with HVR and 3 % HVR.

Data collection

Studies I and II

Phenomenological interviews were conducted with patients and relatives on separate occasions. The researcher tried to approach the informants in an open and sensitive manner, took nothing for granted and sought clarification by posing additional questions. The interviews began with an overall question about the informants' experiences of their present life situation. In phenomenology, the present time includes both the past and the future, thus the informants could tell their unique stories in the way they wanted and remember things with the help of open-ended 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 for the researcher to keep this in mind and to bracket her pre-understanding of the phenomenon. In these studies 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 trained interviewer and uses conversational therapy in her daily work. This experience was important, since the researcher him/herself is the research instrument [87]. Although there are important differences between conversational therapy and research interviews,

the fundamental principles of meeting human beings with openness and sensitive curiosity are the same.

Study III

Data were collected by means of focus group discussions. Each profession was interviewed separately with the exception of the physiotherapists and the social workers, who together with the specialised rehabilitation nurse comprised a “rehabilitation group”. The focus group discussion started with open-ended questions such as: “How do you perceive patients’ well-being after OHS? How do you perceive their relatives’ well-being? What distinctive signs of well-being do you recognise?” The informants were encouraged to describe their observations in their own words and attempts were made to facilitate dialogue between them. Clarifications, additional explanations and examples were requested during the discussion, in order to deepen understanding and obtain rich and varying data.

Study IV

In this combined study, data were collected by means of questionnaires and telephone interviews. Data were also obtained from the medical records and demographic questions on a separate form included with the questionnaire. A questionnaire that assessed depressed mood by means of the Montgomery Åsberg Depression Self-rating Scale, MADRS-S [95], was employed and a telephone interview conducted to explore the participants’ well-being as expressed in their own words [96]. The opening question was: “How do you experience life three years after your heart operation?” and was followed up by further open-ended questions on physical and psychological health, personal relationships, social activities and existential values in accordance with the meaning of well-being as defined by Naess et al. [22]. Notes were taken during the interviews comprising keywords and short phrases, which were summarized and elaborated on immediately afterwards. The summary was sent to the participants for their signed approval.

Data analysis

Studies I and II

The analysis was carried out in accordance with Giorgi’s five steps [88]. Each interview text was read several times 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 the scientific language of the perspective. In this way the material was raised to a more abstract level necessary for the analytical process. The transformed meaning units were then sorted into constituents. Finally, reflection on the constituents in all their various

forms using professional imagination led the researcher to the essence, i.e. the deeper meaning of the phenomenon under study. The essence and its structure was described and illustrated by quotations from the interview texts.

Study III.

First the material was read through several times in order to become familiar with its content, after which meaning units relevant to the purpose of the study were marked in each interview, condensed and coded. The coded meaning units were sorted into clusters. Three categories, each with a number of subcategories, emerged from the clusters and were named. The findings were described and illustrated by means of quotes from the interviews. The latent content of the categories was interpreted as an overall theme [90].

Study IV

Depressed mood was defined as MADRS-S ≥ 7 and further classified as mild (MADRS-S 7-19), moderate (MADRS-S 20-34) and severe (MADRS-S ≥ 35) [97]. The data were labelled in a Microsoft Excel file, transferred to Stat View version 5.0 and analysed. The data were first evaluated as a whole and then divided into parts in accordance with changes in depressed mood over time [98] and analysed. Numerical distributions are presented by their mean \pm SD if not otherwise stated. Fischer's exact test and the Chi-Square test were used for group comparison of proportions, whereas McNemar's test was employed for paired comparisons of proportions. Analysis of variance (ANOVA) with Scheffe's post hoc analysis was used for group comparisons of continuous normally distributed data. For continuous data not normally distributed and ordered categorical data such as the MADRS-S score, the Kruskal Wallis and the Mann-Whitney tests were used for group comparisons. Student's t-test was employed for paired comparisons of normally distributed continuous data, while Wilcoxon's signed rank sum test was used for data not normally distributed and for ordered categorical data. Statistical significance was defined as $P < 0.05$.

In the first step, the telephone interviews were analysed by means of a qualitative content analysis method [90]. The interview summaries were read several times in order to obtain an overview of the whole. Meaning units relevant to the purpose of the study were marked in each summary, condensed and labelled in a Microsoft Access data base. The labelled material was then exported to a Microsoft Excel file and coded. The coded meaning units were grouped and three areas of well-being emerged. Each area was further scrutinised by means of discussion and adjustment by the first and the second author before being accepted as a category and named. The latent meaning in the interviews was interpreted as an overall theme. In the second step, the categorised material was divided and analysed on the basis of the three depressed mood groups from the quantitative analysis in order to search for characteristic patterns describing the well-being of these groups.

Ethical considerations

The Research Ethics Committee, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden, approved the studies in this thesis. The participants were informed about the voluntary nature of participation, their right to withdraw at any time and confidentiality was guaranteed. All participants gave their informed, written consent.

Main results

Fragility – the price of renewed life (Study I)

The essence of the experience of open heart surgery was fragility, which emerged from a general structure comprising distance, uncertainty, vulnerability, reliance and gratitude. At an early stage of the process, the patients felt distanced, both towards the illness and the people around them. The risky and unknown situation made them uncertain and vulnerable. Reliance on the hospital staff was necessary in order to carry them through the operation. They later expressed deep gratitude to health care, relatives, fate and life itself for renewed life. Their body and soul had experienced the fragility of life, thus they were aware of its limits and knew that they would never again take life for granted.

Endurance – integration of strength and vulnerability in relatives' response to open heart surgery as a lived experience (Study II)

Endurance is the essential characteristic of relatives of a person who has undergone OHS and is derived from the following constituents: unconditionality, uncertainty, mutuality and sadness. Endurance is present during the entire illness period and characterised by unconditional actions as well as great uncertainty caused by the unknown life situation. Endurance is important, as it promotes mutuality and cautious hope despite feelings of sadness. Open heart surgery can have a major impact on relatives in that it has the power to change their lifeworld. Relatives may feel obliged to face up to the situation since it cannot be escaped and they do so by means of endurance. However, as endurance is an integrated reaction, it renders them both strong and vulnerable, although their vulnerability is not immediately apparent. Imbalance between being a supportive carer and being in need of care oneself may lead to a very difficult and lonely situation for relatives due to their attitude of being capable. Increased consciousness of the double meaning of endurance can help HCPs to support families in their struggle to achieve a new balance and prevent an increased burden of responsibility. It seems essential to understand relatives from the perspective of their lifeworld.

Reduced well-being in patients and relatives after open heart surgery as seen by health care professionals (Study III)

The content analysis of the focus groups resulted in a theme “awareness of an exposed situation”, based on the categories: signs of vulnerability and signs of insecurity. These categories were supported by five sub-categories (Table 2). HCPs stated that they recognised signs of reduced well-being in patients and their relatives after OHS. However, the main focus was on the patients, while the relatives’ well-being remained more or less unexplored. As a multiprofessional unit, the recognition of the HCPs embraced all areas of well-being as defined by Naess et al. [22]. The findings showed that all areas are intertwined and form a whole, and thereby have an impact on all aspects of well-being.

Table 2 Description of the result

Meaning units/Quotations	Condensed meaning units	Codes	Sub categories	Categories	Theme
-Patients who are having a heart operation immediately after a myocardial infarction have a shock. -Suddenly they realise their own mortality. (Focus group 1)	Immediate surgery following a myocardial infarction realises the risk of dying	Threat	A jolty mind		
-They look burdened, stiff. -They drag their feet. -Their voices are weak and faint. (Focus group 1)	Burdened, stiff, weak and faint	Weakness	A burdened body	Signs of vulnerability	
-Younger patients’ behaviour borders on the aggressive, they are difficult to deal with as well as being very well informed. -They try to test our	Younger patients’ aggressive, questioning and well informed appearance	Hostility	Avoidance		Awareness of an exposed position

knowledge. - A wrong answer mars the rest of the patient's time in the ward.
(Focus group 3)

- People who are anxious and experience loneliness as difficult are reluctant to leave the hospital. - Some people have a tendency to worry more than others. (Focus group 2)	Anxious and lonely people are reluctant to leave the hospital	Anxious personality	Need for protection
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-The men don't bother about having a scar. - They want to show it. -The women are talking about it but they don't show it. (Focus group 4)	The men show the scar, women talk about it	Wish for attention differently expressed	Need for confirmation
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Signs of insecurity

Depressed mood over time after OHS impacts patient well-being (Study IV)

Mild to moderate depressed mood (MADRS-S 7-34) was reported by 52 % of the patients at some stage during the recovery phase or at the follow up three years after OHS, although none had severe depressive symptoms (Table 3).

Table 3 Depressed symptoms according to MADRS-S scores at 5 weeks, 5 months and 3 years after open heart surgery are displayed

	Depressed (n=28)	Temporarily depressed (n=28)	Non-depressed (n=24)	All Patients (n=80)
5 weeks after surgery				
MADRS-S (mean, range)	15 (8-30)	6 (0-16) **	2 (0-6) **§§	8 (0-30)
Mild depr (numbers, %)	22 (79)	10 (36)*	0 (0)**§§	32 (40)
Moderate depr (numbers, %)	6 (21)	0 (0)	0 (0)	6 (8)
5 months after surgery				
MADRS-S (mean, range)	13 (7-25)	9 (0-28) **	2 (0-6) **§§	8 (0-28)
Mild depr (numbers, %)	23 (82)	12 (43)*	0 (0)**§§	35 (44)
Moderate depr (numbers, %)	5 (18)	3 (11)	0 (0)	8 (10)
3 years after surgery				
MADRS-S (mean, range)	14 (7-28)	8 (0-20) **	2 (0-6) **§	8 (0-28)
Mild depr (numbers, %)	22 (79)	13 (46)*	0 (0)**§§	35 (44)
Moderate depr (numbers, %)	6 (21)	2 (7)	0 (0)*	8 (10)

Patients who reported at least mild depressive symptoms (MADRS-S score >6) on all three investigations were classified as depressed, whereas those who reported mild (MADRS-S 7-19) or moderate (MADRS-S >19) depressive symptoms at one or two investigations were classified as temporarily depressed. Patients with MADRS-S score 6 or lower at all investigations were classified as non-depressed.

Note: * or ** denotes a statistically significant difference versus the depressed group, $P < 0.05$ or 0.01 , respectively. § or §§ denotes a statistically significant difference versus the temporarily depressed group, $P < 0.05$ or 0.01 , respectively.

Depressed mood over time followed three main directions; one group of patients (35 %), labelled the depressed group (DG), reported depressed mood on all three

occasions. Some patients reported depressed mood on one or two occasions and were labelled the temporarily depressed group (TDG, 35 %). Finally, patients without depressive symptoms were labelled the non-depressed group (NDG, 30 %). No differences were observed between the groups in terms of gender, age, life situation, myocardial infarction, hypertension, BMI or surgical complications (Table 4).

Table 4 Characteristics of the compared groups of patients undergoing open heart surgery

	Depressed (n=28)	Temporarily depressed (n=28)	Non-depressed (n=24)
Age (years, mean \pm SD) ^{xx}	68 \pm 8	68 \pm 7	67 \pm 8
BMI [#] (kg/m ² mean \pm SD) ^x	27 \pm 3	26 \pm 4	26 \pm 3
Male gender (numbers, %) ^{xx}	23 (82)	23 (82)	20 (83)
<i>Living situation</i> ^{xx}			
Married/equiv. (numbers, %)	23 (82)	23 (82)	20 (83)
Working full/part (numbers, %)	7 (25)	12 (43)	9 (38)
Sick leave (numbers, %)	1 (4)	0 (0)	1 (4)
Retired full/part (numbers, %)	23 (82)	17 (61)	16 (67)
<i>Surgery</i> ^x			
CABG ^{###} numbers, (%)	27 (96)	27 (96)	24 (100)
Heart valve replacement numbers, (%)	4 (14)	1 (4)	1 (4)
Surgical complications ^{##} (numbers, %)	8 (29)	6 (21)	7 (29)
<i>History of</i> ^x			
Smoking (numbers, %)	4 (14)	5 (18)	2 (8)
Myocardial infarction (numbers, %)	14 (50)	14 (50)	12 (50)
Hypertension (numbers, %)	18 (64)	15 (54)	12 (50)
Diabetes (numbers, %)	5 (18)	5 (18)	1 (4)
Stroke (numbers, %)	2 (7)	3 (11)	0 (0)

Note: # denotes body mass index. ## atrial fibrillation, re-operation for bleeding, pneumonia or renal failure ### coronary artery bypass graft.

Patients who reported at least mild depressive symptoms (MADRS-S score >6) on all three investigations were classified as depressed, whereas those who reported mild (MADRS-S 7-19) or moderate (MADRS-S >19) depressive symptoms at one or two investigations were classified as temporarily depressed. Patients with MADRS-S score 6 or lower at all investigations were classified as non-depressed. ^x Refer to the examination at 5 months and ^{xx} 3 years after OHS.

The groups did not differ regarding medication and only a few patients were on antidepressants (Table 5).

Table 5 Medical treatment of patients 5 weeks and 5 months after open heart surgery

	Depressed (n=28)		Temporarily depressed (n=28)		Non-depressed (n=24)	
	5 weeks	5 months	5 weeks	5 months	5 weeks	5 months
<i>Cardiovascular drugs</i>						
Beta blockers	24 (86)	23 (82)	25 (89)	23 (82)	21 (88)	21 (88)
ACE-I [#]	7 (25)	8 (29)	4 (14)	8 (29)	4 (17)	6 (25)
ARB ^{# #}	2 (7)	2 (7)	1 (4)	3 (11)	1 (4)	1 (4)
Calcium blocker	3 (11)	3 (11)	3 (11)	4 (14)	1 (4)	4 (17)
Diuretics	11 (39)	6 (21)	10 (36)	10 (36)	4 (17)	2 (8)
Statins	23 (82)	24 (86)	26 (93)	26 (93)	21 (88)	22 (92)
Digitalis	3 (11)	1 (4)	0 (0)	0 (0)	0 (0)	0 (0)
Aspirin	22 (79)	24 (86)	25 (89)	25 (89)	21 (88)	23 (96)
<i>Psychotropic drugs</i>						
Benzodiazepines	3 (11)	3 (11)	1 (4)	1 (4)	0 (0)	1 (4)
Antidepressives	3 (11)	3 (11)	0 (0)	1 (4)	2 (8)	2 (8)

All values represent numbers (%)

Note: [#] denotes treatment with angiotensin converting enzyme inhibitors and ^{##} angiotensin receptor blocker, respectively

Patients who reported at least mild depressive symptoms (MADRS-S score >6) on all three investigations were classified as depressed, whereas those who reported mild (MADRS-S 7-19) or moderate (MADRS-S >19) depressive symptoms at one or two investigations were classified as temporarily depressed. Patients with MADRS-S score 6 or lower at all investigations were classified as non-depressed.

The content analysis of the interviews formed the theme “transition” supported by the categories: adjusting oneself to conditional health, positioning oneself in the surrounding world and making an inner journey (Figure 2). The qualitative data confirmed the quantitative findings, as the structure of the patients’ stories differentiated patients with depressed mood from those without such signs. The most obvious differences were between the DG and the NDG. The TDG was a mix of the other two, as these patients varied between being and not being depressive at the three investigations after OHS. OHS constituted a life

transition for all patients but those with depressed mood experienced difficulties finishing the transitional process, which impeded reorientation.

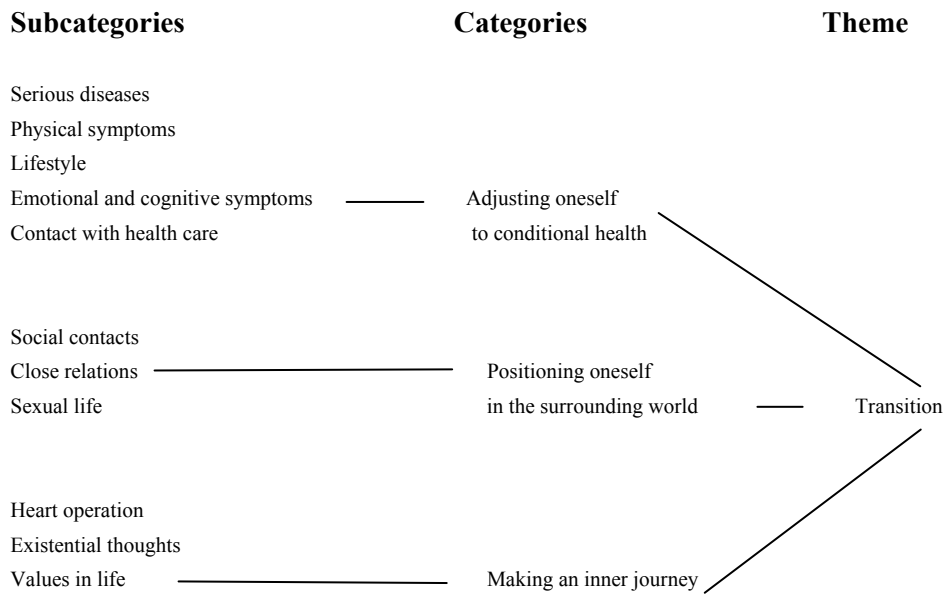


Figure 2 Exploration of the process following the experience of open heart surgery for all participants.

General discussion

The overall purpose of this thesis was to gain a comprehensive perspective on how OHS influences people's life both individually and in relation to others. Some aspects of the main findings and how they are interlinked will therefore be discussed, together with the reasons for the methods chosen.

Fragility after OHS

Fragility has not previously been used as a concept to describe patients' lingering tension after OHS. Fragility includes the experience of bodily betrayal, as health can no longer be taken for granted in the presence of remaining uncertainty about one's future life. The major themes in the study by Keaton and Pierce [28] have much in common with the constituents in study I. Both describe a process that starts with feelings of unreality and threat and concludes with re-orientation and gratitude for a second chance of life. However, the level where the constituents revealed the essence of fragility added an important

psychosomatic piece to the puzzle. In study I it was pondered if fragility is lifelong in terms of being a fundamental part of human life [31]. Even if this question cannot be answered adequately, we are at least aware that fragility was a part of the patients' life and influenced their well-being three years after OHS. Similar fragile tendencies have been reported among patients who survived different malignant diseases [99-100].

Endurance due to OHS

In common with fragility, endurance has not been previously used as a concept to describe the situation of the relatives of OHS treated patients, although it has been identified as a response to the threat to integrity of self in trauma and chronically ill patients [101]. Morse described endurance as a reflexive suppression of an exposed person's feelings in order to deal with an unavoidable situation, in contrast to suffering, in which emotions are released. Our findings differ, due to the fact that the relatives described endurance as an integrated reaction. In the same way as the term endurance has a dual meaning of toleration and sufferance [102], the relatives' endurance integrated strength and vulnerability, both of which were equally important to recognize and confirm. However, vulnerability was not immediately apparent, and deep questions were required in order to reveal it. The relatives concealed their own worries for the sake of the patient, but did not deny their existence and experienced hope and fear simultaneously. In general, the relatives expressed that they had to be the stronger one in the given situation and they initially felt that to admit that it was burdensome was to betray the patient. This dilemma of loyalty was also mentioned by Halm and colleagues [77].

The interplay between fragility and endurance

When viewed together, the concepts of fragility and endurance reveal an obvious and interesting interplay. The patient and his/her relatives are part of each other's lifeworld [20], which means mutual but not necessarily the same level of influence on each other's well-being. Heart disease is a serious life event that often leads to a crisis for patients and relatives [103], although not simultaneously. One example of this time difference between patients and relatives concerns their experiences of the threat to life associated with heart disease and OHS. Six months after OHS, this threat could be discerned in the patient's descriptions as they tried to focus on the future. The relatives, on the other hand, made clear that they were both emotionally affected and had reflected on the threat to and shortness of life for a long time. Reflections on the fragility of life occurred frequently in the patients' stories three years after surgery. Patients who are experiencing a threat to life perhaps invest their hope in OHS to such an extent that conscious reflections on their own death have to be suppressed during the acute phase of the illness. It could be assumed that HCPs also reinforce the idea of OHS as a hope and solution in their striving to

encourage the patient. This would explain the limited research literature on the existential perspective of OHS. However, the essence of fragility in study I tells us that the existential thoughts impact on both the patient and his/her relatives. Hence the more fragile the patient, the less likely it is that the relatives will show their vulnerability. Reactions which are suppressed or hidden can be manifested as over-protection of the patient or as inappropriate actions leading to family conflict [81]. A patient with a long-term need of a strong, enduring relative will leave only little space for the relative's own experiences of OHS. Thus, the latter's reactions may appear difficult to understand, both to him/herself and to other people, if they surface when things seem to have reverted to normal. Fragility and endurance may interact in "harmony" but are probably more often signs of decreased well-being in a strained family unit.

Professional awareness of signs of reduced well-being after OHS

Reduced well-being caused by illness is communicated by various signs; objective (produced or observed by the HCP) and subjective (experienced by the patient) [104]. According to Staiano [104], signs are contextual and cultural. A sign has a meaning and whether it is detected or remains hidden depends on the interpreter's, in this case the HCPs', ability to recognise, interpret and respond to it. The contextual connection of a sign can influence its chance of being recognised and interpreted correctly [13]. HCPs who participated in the focus groups in study III showed awareness of signs of decreased well-being, but with limitations that require consideration. The fragile patient was attended to, while the enduring relative with less expressed needs occupied a peripheral position in the HCPs' priorities. This confirms the relatives' expressed feelings of only being noticed by HCPs on rare occasions despite their wish for more attention (study II).

The fact that relatives' well-being was overlooked by HCPs may be explained by their patient centred perspective [17], lack of sufficient awareness of the family as an interactive unit striving to preserve its balance [52] and the importance of this interaction for patient well-being. Changing from a patient to a family centred perspective may be challenging for HCPs in view of professional traditions and practical training [55]. However, a family perspective on OHS is needed if the complex nature of endurance and the interplay between fragility and endurance are to be detected. Applying the lifeworld perspective would solve the problem, as the patient's lifeworld includes the relative and vice versa. Whether a HCP sees the patient or relative separately or together, the lifeworld perspective implies awareness and acknowledgement of the interactive family unit and its powerful impact [Figure 3].

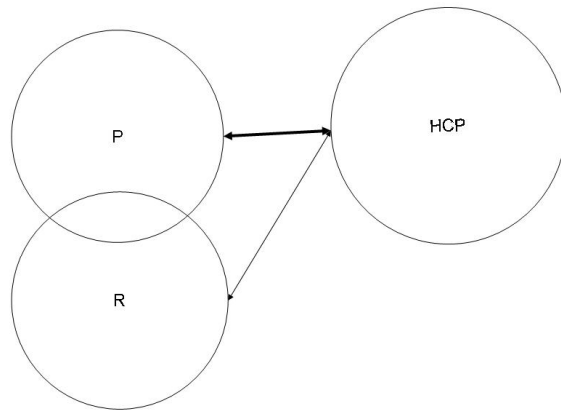


Figure 3 The relationship between a patient, a relative and a health care professional from a lifeworld perspective

Applying this perspective would mean that a HCP would never be in doubt about whether a relative is his/her responsibility, as relatives are essential for understanding problems connected with e.g. OHS. Furthermore, if detected endurance is to be responded to in a satisfactory way, HCPs must be open minded and aim to “care about” instead of just “caring for” [105]. HCPs who use the latter approach may see the relatives’ strength and ability but neglect their vulnerability because it is beneficial to do so in an already overburdened health care system [106]. A strong relative is a resource to whom responsibility for a weak patient can be shifted. HCPs who “care for” are at risk of being perceived as mechanical and technical by the families concerned and thus unable to help them emotionally [106].

The HCPs in study III highlighted the importance of informing patients and relatives. However, this task also needs a “caring about” approach. In order to be useful, information has to be individually adjusted according to content and timing [54]. Several studies, e.g. Dickerson [106], Davies [72] and McLean and Timmins [54], have reported insufficient or inadequate information from the perspective of patients and relatives. There may be many reasons for this, but it is important to note that patients and relatives in a crisis situation have reduced ability to assimilate information [107]. Sensitivity to signs is of great importance for early detection of decreased well-being in the form of depressed mood after OHS. Bodily [108-109] and emotional signs [12] are not always obvious, although they exist, alongside measurable symptoms, in the form of fears, anxiety, confused dreams and a varied ability to handle the relationships with relatives [29]. Hence, there is need for open minded and sensitive interpreters.

Depressed mood and well-being after OHS

Depressed mood is often associated with OHS [110] and needs to be detected, as it decreases patient well-being [16] and has also been identified as a risk factor for increased morbidity and mortality [10, 49]. In line with previous studies [14, 98], study IV underlined the difficulties associated with early identification of depressed mood after OHS. The majority of the patients who reported depressed mood five weeks after OHS had mild symptoms, which HCPs could easily have interpreted as normal under the circumstances. Symptoms of depressed mood were at the same level three years after surgery as at five months. Hence, the prevalence of depressed mood five months after surgery seems to be predictive of future well-being. By that stage the pain and physical weakness associated with the operation should have abated but, on the other hand, the time has come to continue with a life that has been put on hold. In a shorter time perspective, Mayou and colleagues [111] also reported unchanged levels of anxiety and depressed mood in patients three months and one year after myocardial infarction.

The interviews with the patients three years after OHS revealed that depressed mood had a definite influence on well-being. As in previous studies [112-113], the depressive patients in study IV described many and varied health problems compared to their non-depressive counterparts. Patients with depressed mood also reported changed relationships and decreased ability to participate in everyday life, while for their non-depressed counterparts, life continued more or less as usual. However, all patients were aware of the risk of heart problems in the future and thus the fragility of life. In line with other studies [2, 28] most patients stated that OHS had been a longer and more challenging process than anticipated and that the operation was their chance of life.

OHS and the lifeworld

As long as a person is healthy he/she takes health for granted. Illness disturbs the relationship with the world, each illness in its own particular way. An illness such as heart disease that constitutes a threat to life affects both present time and future plans [20]. The patients and relatives in this thesis confirmed a changed lifeworld after OHS. As the lifeworld is lived through the body, the heart disease made it obvious that the body could not be relied upon as before. This finding agrees with another phenomenological study [9].

The well-being diamond

Well-being can be described by means of a metaphor of a diamond, where each triangular facet represents a specific aspect of human well-being and is important for the experience of the diamond as a glittering whole (Figure 4). Some of the facets may glow from an inner strength, while others sparkle as a result of sharing with other people. Illness may lessen the shimmer of the diamond and even scratch its surface, but care from the social network and HCPs can restore it to new brightness.

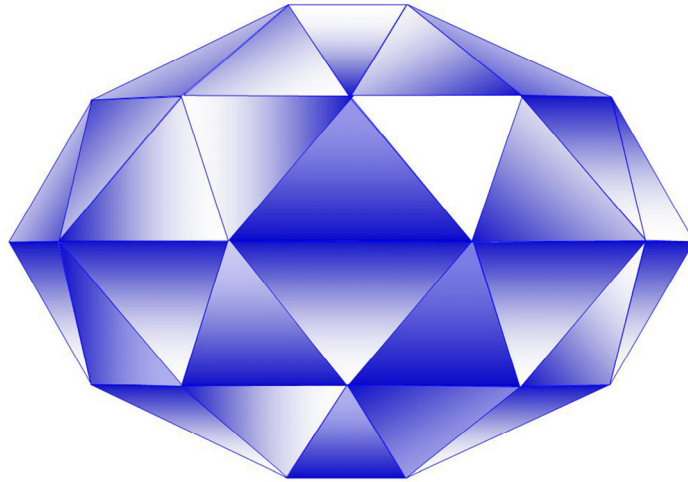


Figure 4 The well-being diamond

Summary of knowledge in this thesis

- OHS is a serious life event that places patients and relatives in an exposed position and changes their lifeworld.
- Fragility is the essence of the patients' experiences of OHS and a remaining characteristic over time.
- Endurance is the essential characteristic of relatives of a person who has undergone OHS and is an integrated reaction that renders them both strong and vulnerable.
- There is interplay between patient fragility and the relatives' endurance as the patient and his/her relatives are part of each other's lifeworld. Fragility and endurance may interact in "harmony" but are probably more often signs of decreased well-being in a strained family unit.
- HCPs are aware of patients' and relatives' exposed position due to OHS. However, the main focus is on the patients, while the relatives' well-being remains more or less unexplored.
- Depressed mood was reported by a majority of the patients at some stage during the recovery phase or at the follow-up three years after OHS, although none had severe depressive symptoms. The qualitative data confirms the quantitative findings, as the structure of the patients' stories differentiate patients with depressed mood from those without such signs.

Methodological considerations

Triangulation

The thesis describes the impact of OHS on depressed mood and well-being from three perspectives; those of patients, relatives and HCPs. Triangulation deepened the understanding of the complexity of OHS and highlighted the importance of interaction between the patient, his/her relatives and HCPs for well-being. The use of triangulation also made it possible to obtain mutual confirmation of some of the findings, as well as elucidating the time differences associated with the occurrence of reactions to OHS in patients and relatives. Both qualitative and quantitative methods were employed.

In-depth interviews

Phenomenological interviews were performed in studies I and II. This method was chosen due to its strength in describing a phenomenon from the perspective of a person's experiences in a given context, but without attempting to interpret them [114]. When applying a lifeworld perspective, the goal of the interview is to encourage the interviewee to reflect on the phenomenon of interest and come close to his/her experience of it [20]. According to Kvale [87], an interview should comprise interaction as well as participants who share an interest in the phenomenon, although the researcher and interviewee participate on different conditions. In line with the phenomenological method, the researcher tried to approach the informants in studies I and II with an open mind and a sensitive attitude, took nothing for granted and sought clarification by posing additional questions. She also remembered to bracket her pre-understanding of the phenomenon, although total bracketing is impossible. A limitation is that in study II we had no direct influence over the choice of participants, since they were chosen by the patients. However, the patients in study I were purposefully selected, which points towards a relevant selection in study II, since all but one were spouses. Trustworthiness was ensured by the fact that the supervisor acted as an independent judge and the findings were evaluated by representatives of different professions, all of whom were familiar with the problems surrounding heart disease. Both studies resulted in a general structure or essence, thus the findings, although drawn from a specific context, should have good transferability to groups experiencing similar situations in which there is a threat to one's own life or that of a close relative.

Focus groups

In study III, data were collected by means of focus group discussions. This method offered a unique opportunity both to collect the data emerging in an ongoing group discussion and to study the interaction process per se [91]. Homogeneous groups were chosen to facilitate discussions on equal conditions.

The research group discussed the issue that most of the participants knew the first author in her professional role as a social worker, but this was not deemed a problem, since the participants were professionals and thus not in a position of dependence. Instead, this knowledge seemed to promote a greater sense of security for some of the participants. It was also offset by the fact that the observer was not known to the participants. Likewise, the research group considered arguments for and against the use of pre-existing groups. The risk of hierarchies and sensitive topics that could have a negative impact on discussions was counterbalanced by the reassurance of knowing each other and being used to cooperating in everyday situations. The main researcher and the observer discussed every group interview immediately upon its conclusion, in addition to differences in the procedure, until agreement was reached. The reasonableness of the findings was evaluated by the interdisciplinary research group, while credibility was ensured by the inclusion of representative quotations from the focus groups.

The questionnaire

As patients who have just undergone OHS are weak and suffer from fatigue, it was important to choose a short questionnaire that was easy to complete. MADRS-S was suitable due to its brevity and as we wished to assess the presence of depressive symptoms as opposed to diagnosing depression. When compared to the BDI, MADRS-S has been found to be more sensitive in terms of discriminating between different degrees of depression [94]. The participants completed the questionnaires at home. The risk that the questionnaires were filled out by someone else is a limitation, but was counterbalanced by the fact that completing it in the home environment is less stressful, which was deemed favourable for the outcome. The instrument has been validated against the BDI and the scales were strongly intercorrelated ($r=0.869$).

Telephone interviews

Telephone interviews made it possible to interview all the participants, although such interviews have limitations compared to face-to-face interviews. A telephone interview can, for example, be influenced by whether a person likes talking on the phone and if he/she can talk in privacy. However, in common with previous studies [115-116] we found that telephone interviews produced rich data. The interviewer was responsible for ensuring that the dialogue was open and for being sensitive to the interviewee. Credibility was ensured by the fact that the patients read, commented on and approved the summaries of the interviews.

In study IV, quantitative and qualitative data collected by means of questionnaires and telephone interviews with open-ended questions provided rich and holistic descriptions of the patients' well-being. In quantitative terms the population was small, with low power to detect differences between the

groups. On the other hand, it was quite a large population to handle from a qualitative perspective. The qualitative findings are illustrated by means of a figure (Figure 2) however; the caption is unfortunately incorrect. The figure explores the content of the patients' well-being three years after OHS. The trustworthiness of the findings was subjected to an interdisciplinary examination, as the research group represented different professions.

Conclusions

This thesis reveals that patients in need of OHS went through a transitional process during the time of illness and recovery. OHS was experienced as a great challenge, and threat to life had changed them and made them fragile. The patients' fragility was not always obvious or easy to discover, as it could be hidden behind a smiling face. The question of whether the fragility is lifelong is impossible to answer, but it remained a part of all patients' lives three years after OHS and was especially noticeable in those with depressed mood. Depressive patients' descriptions of everyday life were complex and burdensome in character. Depressed mood not only affected the majority of patients at some stage during their recovery from OHS, but also influenced their long-term well-being. In addition, OHS had a major impact on the relatives, as it changed their lifeworld. Since they could not escape from it, their reaction to the stressful situation was to show endurance. Endurance was an integrated reaction of strength and vulnerability, although the latter was not immediately apparent. HCPs were aware that OHS is a life event that challenges patients' and relatives' well-being. They mainly focused on the reduced well-being of the patients, while that of the relatives remained more or less unexplored. Hence there was a lack of sufficient awareness of the family as an interactive unit and of the importance of this interaction for patient well-being after OHS.

Clinical and research Implications

OHS is a threatening and complex life event that affects individuals in various ways in that it changes their lifeworld and thus also impacts on the family as an interactive unit. The ability to recognise the characteristic signs of decreased well-being is important for reducing the negative effects of OHS on the patients and relatives concerned. Awareness of the dual meaning of endurance on the part of HCPs may prevent the relatives' burden of responsibility from increasing. No professional can be expected to singlehandedly detect and respond to all such signs, but all staff members are responsible for their attitude and openness to signs of reduced well-being in caring situations. Openness to signs must be continuously improved and refined through practice, reflection and supervision. According to each professions' unique knowledge, patients'

and relatives' exposed position following OHS may be understood differently. Therefore interdisciplinary teamwork and an increased exchange of knowledge should be encouraged, in combination with the implementation of a patient/family centred perspective in all professions. A perspective that clearly includes both the patient and his/her relatives should increase interest in the relatives' situation and position in cardiac care.

As exemplified in study IV, a combination of research methods can lead to new thinking and a deeper understanding of the topic of interest. In order to further explore OHS it would be of interest to study the interaction in the families concerned by means of interviewing couples or parents and children together. More research is needed on depressed mood over time in OHS patients as well as HCPs' experiences of applying a patient/family centred perspective in cardiac care. It would also be useful to investigate HCPs' experiences of working with patients with cardiac diseases.

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References

1. Hawkes AL, Nowak M, Bidstrup B, Speare R. Outcomes of coronary artery bypass graft surgery. *Vasc Health Risk Manag.* 2006; 2: 477-484.
2. Tolmie EP, Lindsay GM, Belcher PR. Coronary artery bypass graft operation: Patients' experience of health and well-being over time. *Eur J Cardiovasc Nurs* 2006; 5: 228-236.
3. Koivula M, Paunonen M, Tarkka M-T, Laippala P. Social support and its relation to fear and anxiety in patients awaiting coronary artery bypass grafting. *J Clin Nurs* 2002; 11: 622-633.
4. Okkonen E, Vanhanen H. Family support, living alone, and subjective health of a patient in connection with a coronary artery bypass surgery. *Heart Lung* 2006; 35: 234-244.
5. Rantanen A, Kaunonen M, Kurki-Åstedt P, Tarkka M-T. Coronary artery bypass grafting: social support for patients and their specific others. *J Clin Nurs* 2004; 13: 158-166.
6. Ivarsson B, Sjöberg T, Larsson S. Waiting for cardiac surgery – support experienced by next of kin. *Eur J Cardiovasc Nurs* 2005; 4: 145-152.
7. Coyne JC, Ellard JH, Smith DAF. Social support, interdependence and the dilemma of helping. In B R Sarason, I G Sarason, G R Pierce (Eds), *Social support: an interactional view* (pp. 129-149). New York, Wiley; 1990.
8. Moore SM. Psychologic distress of patients and their spouses after coronary artery bypass surgery. *AACN Clin Issues Crit Care Nurs* 1994; 5: 59-65.
9. Imhof-Mahrer R, Hoffmann A, Froelicher Sivarajan E. Impact of cardiac disease on couples' relationships. *J Adv Nurs* 2007; 57: 513-521.
10. Blumenthal JA, Lett HS, Babyak MA, White W, Smith PK, Mark D B, Jones R, Mathew JP, Newman MF. Depression as a risk factor for mortality after coronary artery bypass surgery. *Lancet* 2003; 362: 604-609.
11. Herrmann-Lingen C. The importance of depressive disorders in somatic medicine. *Z Psychosom Med Psychother* 2003; 49: 391-407.
12. Fraguas Junior R, Ramadan ZB, Pereira AN, Wajngarten M. Depression with irritability in patients undergoing coronary artery bypass graft surgery: the cardiologist's role. *Gen Hosp Psychiatry.* 2000; 22: 365-374.

13. McDonald DD, Frakes M, Apostolidis B, Armstrong B, Goldblatt S, Bernardo D. Effect of a psychiatric diagnosis on nursing care for nonpsychiatric problems. *Res Nurs Health* 2003; 26: 225-232.
14. Rumsfeld JS, Ho PM. Depression and cardiovascular disease. A call for recognition. *Circulation* 2005; 111: 250-253.
15. Rafanelli C, Roncuzzi R, Milaneschi Y. Minor depression as a cardiac risk factor after coronary artery bypass surgery. *Psychosomatics* 2006; 47: 289-295.
16. Ziegelstein RC, Kim SY, Kao D, Fauerbach A, Thombs BD, McCann U, Colburn J, Bush DE. Can doctors and nurses recognize depression in patients hospitalized with an acute myocardial infarction in the absence of formal screening? *Psychosom Med* 2005; 67: 393-397.
17. McCabe C. Nurse-patient communication: an exploration of patients' experiences. *J Clin Nurs* 2004; 13: 41-49.
18. Arnetz JE, Winblad U, Arnetz BB, Höglund AT. Physicians' and nurses' perceptions of patient involvement in myocardial infarction care. *Eur J Cardiovasc Nurs* 2007 (In press).
19. Persson J, Stagmo M. *Kardiologi – hjärtsjukdomar hos vuxna (Cardiology – heart diseases in adults)*. Lund, Sweden: Studentlitteratur; 2008.
20. Dahlberg K, Dahlberg H, Nyström M. *Reflective lifeworld research*. Lund, Sweden: Studentlitteratur AB; 2008.
21. Bengtsson J. *Sammanflätningar (Intertwinings)*. Göteborg, Sweden: Daidalos; 2001.
22. Naess S, Mastekaasa A, Moum T, Sörensen T. *Quality of life research: concepts, methods and applications*. Oslo, Norway: Institute of Applied Social Research; 1987.
23. <http://en.wikipedia.org/wiki/Depression> (mood)
24. Cohn LH. Fifty years of open heart surgery. *Circulation* 2003; 107: 2168-2170.
25. Radegran K. The early history of cardiac surgery in Stockholm. *J Card Surg* 2003; 18: 564-572.
26. Pettersson G, Stoltz-Löfgren M, Åström M. *Att hjärtopereras (Undergoing heart surgery)*. Västerås, Sweden: ICA bokförlag; 1999.
27. www.sos.se
28. Keaton KA, Pierce LL. Cardiac therapy for men with coronary artery disease. *J Holist Nurs* 2000; 18: 63-85.
29. Crafoord C. *Hjärtats oro (The anxiety of the heart)* Lund, Sweden: Natur och Kultur; 2004.
30. Johansson A, Dahlberg K, Ekerbergh M. Living with experiences following a myocardial infarction. *Eur J Cardiovasc Nurs* 2003; 2: 229-236.
31. Henriksen J-O, Vetlesen A J. *Etik i arbete med människor (Ethics in work with people)*. Lund, Sweden: Studentlitteratur; 2001.

32. Råholm M B, Lindholm L. Being in the world of the suffering patient: a challenge to nursing ethics. *Nurs Ethics* 1999; 6: 528-539.
33. Råholm M-B. Weaving the fabric of spirituality as experienced by patients who have undergone a coronary bypass surgery. *J Holist Nurs* 2002; 20: 21-47.
34. Lindsay GM, Smith LN, Hanlon P, Wheatley DJ. Coronary artery disease patients' perception of their health and expectations of benefit following coronary artery bypass grafting. *J Adv Nurs* 2000; 32: 1412-1421.
35. Pearsall J. (Ed) *The Concise Oxford Dictionary*. Tenth edition. New York: Oxford University Press; 1999.
36. Sarvimäki A. Well-being as being well – a Heideggerian look at well-being. *QHW* 2006; 1: 4-10.
37. Seedhouse D. Well-being; health promotion's red herring. *Health Promot Int* 1995; 10: 61-67.
38. Währborg P. Quality of life after coronary angioplasty or bypass surgery. 1-year follow-up in the coronary angioplasty versus bypass revascularization investigation (CABRI) trial. *Eur Heart J* 1999; 20: 635-636.
39. Penckofer S, Ferrans Estwing C, Fink N, Barrett ML, Holm K. Quality of life in women following coronary artery bypass graft surgery. *Nurs Sci Q* 2005; 18: 176-183.
40. Khan JH, Magnetti S, Davis E, Zhand J. Late outcomes of open heart surgery in patients 70 years or older. *Ann Thorac Surg* 2000; 69: 165-170.
41. Sjögren J, Thulin LI. Quality of life in the very elderly after cardiac surgery: A comparison of SF-36 between long-term survivors and an age-matched population. *Gerontology* 2004; 50: 407-410.
42. Keller C. Seeking normalcy: The experience of coronary artery bypass surgery. *Res Nurs Health* 1991; 14: 173-178.
43. Theobald K, McMurray A. Coronary artery bypass graft surgery: discharge planning for successful recovery. *J Adv Nurs* 2004; 47: 483-491.
44. Porras-Perkins L, Whitehead DL, Steptoe A. Patients' beliefs about the causes of heart disease: relationships with risk factors, sex and socio-economic status. *Eur J Cardiovasc Prev Rehabil* 2006; 13: 724-730.
45. Lichtenberger CM, Ginis Martin KA, MacKenzie CL, McCartney N. Body image and depressive symptoms as correlates of self-reported versus clinician-reported physiologic function. *J Cardiopulm Rehabil* 2003; 23: 53-59.
46. Karlsson I, Berglin E, Larsson PA. Sense of coherence: quality of life before and after coronary artery bypass surgery – a longitudinal study. *J Adv Nurs* 2000; 31: 1383-1392.

47. Plach SK, Heidrich SM. Social role quality, physical health and psychological well-being in women after heart surgery. *Res Nurs Health* 2002; 25: 189-202.
48. Connerney I, Shapiro PA, McLaughlin JS, Bagiella E, Sloan RP. Relation between depression after coronary artery bypass surgery and 12 month outcome: a prospective study. *Lancet* 2001; 358: 1766-1771.
49. Mallik S, Krumholz HM, Zhen QL, Kasl SV, Mattera JA, Roumain SA, Vaccarino V. Patients with depressive symptoms have lower health status benefits after coronary artery bypass surgery. *Circulation* 2005; 111: 271-277.
50. Doering LV, Moser DK, Lemankiewicz W, Luper C, Khan S. Depression, healing and recovery from coronary artery bypass surgery. *Am J Crit Care* 2005; 14: 316-324.
51. Goyal TM, Idler EL, Krause TJ, Contrada RJ. Quality of life following cardiac surgery: Impact of the severity and course of depressive symptoms. *Psychosom Med* 2005; 67: 759-765.
52. Runfors M, Wrangsjö B. *Familjemönster (Family patterns)*. Lund, Sweden: Natur och Kultur; 1986.
53. Artinian Trygar N, Duggan Hillebrand C. Patterns of concerns and demands experienced by spouses following coronary artery bypass surgery. *Clin Nurs Res* 1993; 2: 278-295.
54. McLean S, Timmins, F. An exploration of the information needs for spouse/partner following acute myocardial infarction using focus group methodology. *Nurs Crit Care* 2007; 12: 141-150.
55. Sales E. Family burden and quality of life. *Qual Life Res* 2003; 12 (Suppl.1): 33-41.
56. Kärner AM, Dahlgren Abrandt M, Bergdahl B. Rehabilitation after coronary heart disease: spouses' views of support. *J Adv Nurs* 2004; 46: 204-211.
57. Knoll SM, Johnson JL. Uncertainty and expectations: Taking care of a cardiac surgery patient at home. *J Cardiovasc Nurs* 2000; 14: 64-75.
58. Stolarik A, Lindsay P, Sherrard H, Woodend K. Determination of the burden of care in families of cardiac surgery patients. *Prog Cardiovasc Nurs* 2000; 15: 4-10.
59. O'Farrell P, Murray J, Hotz SB. Psychologic distress among spouses of patients undergoing cardiac rehabilitation. *Heart Lung* 2000; 29: 97-104.
60. King KM, Koop PM. The influence of the cardiac surgery patient's sex and age on care-giving received. *Soc Sci Med* 1999; 48: 1735-1742.
61. Coker LH. Caregiving activities for cardiac surgery patients and emotional outcomes for spousal caregivers. *Dissertations Abstracts*

- International: Section B. The Science and Engineering 1998; 59(5-B): 2452.
62. Lenz E, Perkins S. Coronary artery bypass graft surgery patients and their family member caregivers: Outcomes of a family-focused staged psychoeducational intervention. *Appl Nurs Res* 2000; 13: 142-150.
 63. Bengtsson A, Karlsson T, Währborg P, Hjalmarsson Å, Herlitz J. Cardiovascular and psychosomatic symptoms among relatives of patients waiting for possible coronary revascularization. *Heart Lung* 1996; 25: 438-443.
 64. Artinian Trygar N. Spouse adaptation to mate's CABG surgery: 1-year follow-up. *Am J Crit Care* 1992; 2: 36-42.
 65. Montgomery RV, Stull D, Bogatta E. Measurement and analysis of burden. *Res Aging* 1985; 71: 137-152.
 66. Ruiz JM, Matthews KA, Scheier MF, Schultz R. Does who you marry matter for your health? Influence of patients' and spouses' personality on their partners' psychological well-being following coronary artery bypass surgery. *J Pers Sol Psychol* 2006; 91: 255-267.
 67. Condon C, McCarthy G. Lifestyle changes following acute myocardial infarction: Patients' perspectives. *Eur J Cardiovasc Nurs* 2006; 5: 37-44.
 68. Goldsmith DJ, Lindholm KA, Bute JB. Dilemmas of talking about lifestyle changes among couples coping with a cardiac event. *Soc Sci Med* 2006; 63: 2079-2090.
 69. Van der Poel A, Greeff AP. The influence of coronary bypass graft surgery on the marital relationship and family functioning of the patient. *J Sex Marital Ther* 2003; 29: 61-77.
 70. Rankin SH, Monahan P. Great expectations: Perceived social support in couples experiencing cardiac surgery. *Fam Relat* 1991; 40: 297-302.
 71. Moser DK, Dracup K, Marsden C. Needs of recovering cardiac patients and their spouses: compared views. *Int J Nurs Stud* 1993; 30: 105-114.
 72. Davies N. Patients' and carers' perceptions of factors influencing recovery after cardiac surgery. *J Adv Nurs* 2000; 32: 318-326.
 73. Davies N. Carers' opinions and emotional responses following cardiac surgery: cardiac rehabilitation implications for critical care nurses. *Intensive Crit Care Nurs* 2000; 16: 66-75.
 74. Lukkarinen H, Kyngäs H. Experiences of the onset of coronary artery disease in a spouse. *Eur J Cardiovasc Nurs* 2003; 2: 189-194.
 75. Levine C. The good doctor: the carer's perspective. *Clin Med* 2004; 4: 244-245.
 76. Halm MA, Jacobson-Treat D, Lindquist R, Savik K. Correlates of caregiver burden after coronary artery bypass surgery. *Nurs Res* 2006; 55: 426-436.

77. Halm MA, Jacobson-Treat D, Lindquist R, Savik K. Caregiver burden and outcomes of caregiving of spouses of patients who undergo coronary artery bypass graft surgery. *Heart Lung* 2007; 36: 170-187.
78. Doering LV, McGuire AW, Rourke D. Recovering from cardiac surgery: what patients want you to know. *Am J Crit Care* 2002; 11: 333-343.
79. Watson-Watt J, Garfinkel P, Gallop R, Stevens B, Streiner D. The impact of nurses' empathic responses on patients' pain management in acute care. *Nurs Res* 2000; 49: 191-200.
80. Lie I, Arnesen H, Sandvik L, Hamilton G, Bunch EH. Effects of a home-based intervention program on anxiety and depression 6 months after coronary artery bypass grafting: A randomized controlled trial. *J Psychosom Res* 2007; 62: 411-418.
81. Stewart M, Davidson K, Meade D, Hirth A, Makrids L. Myocardial infarction: survivors' and spouses' stress, coping and support. *J Adv Nurs* 2000; 31: 1351-1360.
82. Spernak SM, Moore PJ, Hamm LF. Depression, constructive thinking and patient satisfaction in cardiac treatment adherence. *Psychol Health Med* 2007; 12: 172-189.
83. Kemper BJ. Therapeutic listening. *J Psychosoc Nurs* 1992; 30: 21-23.
84. Klein ER. Effective communication with patients. *Pa Nurse* 2005: 14-15.
85. Larson EB, Yao X. Clinical empathy as emotional labor in the patient-physician relationship. *JAMA* 2005; 293: 1100-1106.
86. Ciaramicoli AP, Ketcham K. *Empatins makt (The power of empathy)*. Stockholm, Sweden: Bokförlaget Forum; 2001.
87. Kvale S. *Den kvalitativa forskningsintervjun (The qualitative research interview)*. Lund, Sweden: Studentlitteratur; 2001.
88. Giorgi A. The theory, practice and evaluation of the phenomenological method as a qualitative research procedure. *J Phenomenol Psychol* 1997; 28: 235-260.
89. Berg BL. An introduction to content analysis. In *Qualitative research methods for the social sciences*. Fifth edition (pp 265-297) Boston: Pearson Education Inc; 2004.
90. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; 24: 105-112.
91. Wibeck W. *Fokusgrupper (Focus groups)*. Lund, Sweden: Studentlitteratur; 2000.
92. Malterud K. *Kvalitativa metoder i medicinsk forskning (Qualitative methods in medical research)*. Lund, Sweden: Studentlitteratur; 1998.
93. Kitzinger J. The methodology of focus groups: the importance of interaction between research participants. *Sociol Health Illn* 1994; 16: 103-121.

94. Svanborg P, Åsberg M. A comparison between the Beck Depression Inventory (BDI) and the self-rating version of the Montgomery Åsberg Depression Rating Scale (MADRS). *J Affect Disord* 2001; 64: 203-216.
95. Montgomery SA, Åsberg M. A new depression scale designed to be sensitive to change. *Br J Psychiatry* 1979; 134: 382-389.
96. Andersson G, Feleke E, Perski A. Patient-perceived quality of life after coronary bypass surgery. Experienced problems and reactions to supportive care one year after the operation. *Scand J Caring Sci* 1999; 13: 11-17.
97. Hermann N, Black SE, Lawrence J, Szekely C, Szalai JP. The Sunnybrook stroke study: A prospective study of depressive symptoms and functional outcome. *Stroke* 1998; 29: 618-624.
98. Scramer G, Cheok F, Hordackre A-L, Guiver N. Predictors of depression three months after cardiac hospitalization. *Psychosom Med* 2004; 66: 514-520.
99. Boehmke MM, Dickerson SS. The diagnosis of breast cancer: Transition from health to illness. *Oncol Nurs Forum* 2006; 33: 1121-1127.
100. Persson L, Hallberg IR. Lived experience of survivors of leukemia or malignant lymphoma. *Cancer Nurs* 2004; 27: 303-313.
101. Morse JM, Carter B. The essence of enduring and expressions of suffering: The reformulation of self. *Sc Inq Nurs Pract* 1996; 10: 43-60.
102. Waite M. (Ed) *Concise Oxford Thesaurus*. Second edition. New York: Oxford University Press; 2002.
103. Svedlund M, Danielsson E. Myocardial infarction: narrations by afflicted women and their partners of lived experiences in daily life following an acute myocardial infarction. *J Clin Nurs* 2004; 13: 438-446.
104. Staiano KV. *Interpreting signs of illness: a case study in medical semiotics*. Berlin, New York, Amsterdam: Mouton de Gruyter; 1986.
105. Gaut DA. Development of a theoretically adequate description of caring. *West J Nurs Res* 1983; 5: 312-324.
106. Dickerson Steffan S. Cardiac spouses' help seeking experiences. *Clin Nurs Res* 1998; 7: 6-28.
107. Hillgaard L, Keiser L, Ravn L. *Sorg och kris (Grief and crisis)*. Stockholm: Liber; 1987.
108. Mattsson B, Mattsson M. The concept of "psychosomatic" in general practice. Reflections on body language and a tentative model for understanding. *Scan J Prim Health Care* 2002; 20: 135-138.
109. Skott C, Eriksson A. Clinical caring – the diary of a nurse. *J Clin Nurs* 2005; 14: 916-921.

110. Gardner G, Elliott D, Gill J, Griffin M, Crawford M. Patient experiences following cardiothoracic surgery: an interview study. *Eur J Cardiovasc Nurs* 2005; 3: 242-250.
111. Mayou RA, Gill D, Thompson DR, Hicks N, Volmink J, Neil A. Depression and anxiety as predictors of outcome after myocardial infarction. *Psychosom Med* 2000; 62: 212-219.
112. Perski A, Osuchowski K, Andersson L, Sanden Å, Feleke E, Anderson G. Intensive rehabilitation of emotionally distressed patients after coronary by-pass grafting. *J Intern Med* 1999; 246: 253-263.
113. Herlitz J, Brandrup-Wognsen G, Caidahl K, Hartford M, Haglid M, Karlsson BW, Karlsson T, Sjöland H. Determinants for an impaired quality of life 10 years after coronary artery bypass surgery. *Int J Cardiol* 2005; 98: 447-452.
114. Dahlberg K, Drew N. A lifeworld paradigm for nursing research. *J Holist Nurs* 1997; 15: 303-317.
115. Chapple A. The use of telephone interviewing for qualitative research. *Nurse Res* 1999; 6: 85-93.
116. McCormick KM, McClement S, Naimark BJ. A qualitative analysis of the experience of uncertainty while awaiting coronary artery bypass surgery. *Can J Cardiovasc Nurs* 2005; 15:10-22.