THEORETICAL UNDERSTANDING OF THE COPING APPROACHES AND SOCIAL SUPPORT EXPERIENCES OF RELATIVES OF CRITICALLY ILL PATIENTS DURING THE INTENSIVE CARE UNIT STAY AND THE RECOVERY PERIOD AT HOME

Ingrid Johansson

Department of Medicine and Care, Division of Nursing Science, Faculty of Health Sciences, Linköping University, SE-581 85 Linköping, Sweden

School of Social and Health Sciences, Halmstad University SE 301 18 Halmstad, Sweden

Helsingborgs Lasarett

Intensive Care Clinic, Helsingborg Hospital SE 251 87 Helsingborg, Sweden

Linköping 2006
Linköping University Medical Dissertation  
No 944

THEORETICAL UNDERSTANDING OF THE COPING APPROACHES AND SOCIAL SUPPORT EXPERIENCES OF RELATIVES OF CRITICALLY ILL PATIENTS DURING THE INTENSIVE CARE UNIT STAY AND THE RECOVERY PERIOD AT HOME

Ingrid Johansson

ABSTRACT

Relatives may experience a difficult and demanding situation when the patient is critically ill. During the period in the intensive care unit (ICU), the relatives may be subject to strong emotions of an existential nature, and the situation may involve several stressors as a result of changed roles, responsibilities and routines. These emotional stress experiences may result in weakened mental and physical functioning on the part of the relatives. During the patient’s rehabilitation at home the relatives are expected to provide care-giving assistance, which may lead to a further deterioration in their already weakened mental and physical functioning.

The general aim of the thesis was to develop a theoretical understanding of coping approaches and social support experiences of relatives of critically ill patients, both in the ICU and at home. In order to gain an understanding of these areas it was deemed important to search for knowledge by means of qualitative methods, using grounded theory methodology, simultaneous concept analysis and qualitative content analysis. A total of 32 relatives of critical care patients participated in the studies.

The findings of study I revealed that relatives of critically ill patients coped with their situation by alleviating, recycling, mastering or excluding their feelings during the ICU stay. The critical factors behind their choice of coping approach were their social circumstances, previous experiences of care and/or caring and how they apprehended the situation. In study II, during the patients’ recovery period at home, the relatives coped with their situation by accepting, volunteering, sacrificing or modulating. The critical factors in this period were the physical and psychological state of the relatives, previous experiences of care and/or caring and the psychological condition of the patient. A coping model was developed in study III, based on the coping concepts generated in studies I and II. In this model, the characteristics of each coping approach were systematised into different determinants in order to highlight the inherent process. The analysis of the relationship between the various coping approaches revealed differences in adaptation to the stressful situation. In terms of coping effectiveness, adaptation was associated with social support and health outcome. In the extended
version of the coping model, with its dual perspective of the maladaptive-adaptive coping continuum and the weak-strong social support continuum, the degree of effectiveness of each coping approach was illustrated in relation to the others as well as to social support. In study IV and its Addition, a theoretical understanding of the phenomenon of what relatives experienced as supportive was developed. Support was perceived as empowerment by means of internal and external resources in the form of trusting oneself, encountering charity and encountering professionalism. The sense of empowerment permitted the relatives to experience their situation as safer and easier to control. The three support dimensions with their components and characteristics were illustrated in the empowerment model.

These four studies have developed knowledge that may provide healthcare professionals with an understanding of the coping approaches and social support experiences of relatives during the critically ill patient’s ICU stay and recovery period at home. The association revealed between coping effectiveness, social support and health outcomes may draw attention to the relatives’ situation as well as to the possibility of enabling relatives to endure the patient’s entire illness and recovery period by enhancing the factors that promote effective coping. The three models may together form the basis for the development of a support programme for relatives of critically ill patients that encompasses the whole course of illness and recovery, which means that both institutional and community-based care would be involved.

Keywords: coping, critical care, family, models, qualitative methods, social support
This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


Reprints have been made with kind permission from the publishers.
INTRODUCTION

BACKGROUND
The patient in critical care
From ordinary everyday life to being a relative of a critically ill patient
Coping with the demands of being a relative of a critically ill patient
The concept of coping
Coping approaches of relatives of a critically ill patient
Supportive transactions of relatives of critically ill patients
The concept of social support
Social support for a relative of a critically ill patient

AIMS OF THE THESIS

METHOD
Grounded theory methodology (Studies I, II, IV)
Origin in symbolic interactionism
Characteristic features and procedures
Inclusion criteria
Theoretical sampling
Interviews
Interview questions
Informants
Simultaneous concept analysis (Study III)
Usefulness of the method
Characteristic procedures
Qualitative content analysis (Addition)
Ethical considerations
FINDINGS
Coping approaches of relatives during the patient’s ICU stay (Study I)
Alleviating
Recycling
Mastering
Excluding
Coping approaches of relatives during the patient’s recovery at home (Study II)
Accepting
Volunteering
Sacrificing
Modulating
Model of relatives’ coping approaches during the patient’s ICU stay and recovery period at home (Study III)
The coping model
Theoretical foundations of the coping model
What is supportive for relatives during the trajectory of the patient’s illness and recovery (Study IV, Addition)
What is supportive for relatives during the patient’s ICU stay (Study IV)
What is supportive for relatives during the patient’s recovery at home (Addition)

DISCUSSION
Methodological aspects
Aspects of the findings
Implications

CONCLUSIONS

ACKNOWLEDGEMENTS

SUMMARY IN SWEDISH

REFERENCES
INTRODUCTION

When an accident-induced trauma occurs suddenly and unexpectedly, the relatives of the victim have no opportunity to prepare themselves emotionally and, as they usually have little or no experience of such situations, they are in a state of shock (Leske 1992a). The admittance of critically ill patients other than accident victims to an intensive care unit (ICU) can evoke similar reactions, although this does not hold true for all cases. A critically ill patient in an ICU is often associated with a high mortality risk and, whilst awaiting the diagnosis and prognosis, the relatives experience a sense of uncertainty and unreality (Engström & Söderberg 2004) and may feel as if they have been thrown into disequilibrium (Olsen 1970). The situation may include several stressors, such as fear of losing the patient (Hupcey & Penrod 2000), financial problems, change of roles, responsibilities and routines (Johnson et al. 1995, Hupcey & Penrod 2000, Van Horn & Tesh 2000) as well as possible emotional chaos during the patient's critical illness (Kleiber et al. 1994, Jamerson et al. 1996). These emotional stress experiences may result in weakened mental (Leske 1992a) and physical (Halm et al. 1993, Van Horn & Tesh 2000) functioning on the part of the relatives.

As soon as the need for life-sustaining treatment abates, the patient is transferred to a general ward for further treatment, but as the general tendency within the healthcare system today is to shorten the care period on the ward, the patient is discharged to the home for rehabilitation, most likely suffering from both mental and physical impairment resulting from the critical illness (Brooks et al. 1997, Lipsett et al. 2000, Gardner & Sibthorpe 2002, Granja et al. 2002, Chaboyer & Grace 2003). The relatives are expected to provide care-giving assistance at home (Johnson et al. 2001, Swoboda & Lipsett 2002, Foster & Chaboyer 2003) and this responsibility may further damage their already weakened mental (O’Farrell et al. 2000, Jones et al. 2004) and physical (Dew et al. 1998) functioning.

The knowledge that relatives may have to cope with major demands of both an emotional and physical character during the patient's period of illness and recovery makes it essential for healthcare professionals to support their ability to manage. The critical care nursing organisation with a ratio of one nurse to two patients (Fairley 2005) places nurses in a unique position to establish contact with the relatives. Thus, it is appropriate to commence long-term support while the patient is still in the ICU. The importance of supporting the relatives accentuates the need for a theoretical understanding of the coping approaches and social support experiences of the relatives during the critical care period as well as the recovery period at home. The literature related to the relatives of critically ill patients is limited (Hupcey 1999, Johnson et al. 2001), most especially in the areas of coping and support.
BACKGROUND

The patient in critical care

The purpose of critical care is to diagnose, monitor, treat and care for patients with acute life-threatening conditions. Indications for admittance to an ICU are impending or established failure of one or more organ systems and, in addition, the expectation of recovery if provided with appropriate support and therapy. Patients who are recognised as being at risk of acute life-threatening complications and in need of monitoring and observation are also candidates for ICU admission. In order to gain an overview of the critically ill patients’ sex, age and length of ICU stay, it may be interesting to reflect upon the demographic data for the year 2004 obtained from 50 of the 86 ICUs in Sweden (SIR 2004). The proportion of male and female patients was 57 and 43% respectively, the median age was 60 and 61 years, the mean length of ICU stay was 2.41 days. Those ICU patients with a stay of less than 3 days represent 82% of ICU admittances but only 32% of the total time spent on care. Postoperative, coronary and other forms of care explain 42% of ICU admittances, while thorax intensive care explains 4% and intensive care 54%. Most patients admitted to an ICU suffer from respiratory and/or circulatory instability and require treatment with assistant ventilation and vasoactive drugs, while in some complicated cases the patients need continuous renal replacement therapy (Kvåle & Flaatten 2002). Furthermore, in order to provide effective treatment during the initial and unstable phase of the patients’ critical illness, they have to be anaesthetised (Kvåle & Flaatten 2002). The initial treatment is provided on a 24-hour basis until stability is achieved in the vital organ systems. Against this background it is easy to understand that the five main stressors are considered by patients to be pain, impossibility to sleep, tubes in the nose and mouth, not being in control of oneself and being tied down by tubes (Novaes et al. 1997). When a patient is unable to meet his/her own basic needs, has difficulty communicating with staff and requires orientation knowledge, it is clear that he/she may feel vulnerable due to the extreme physical and emotional dependency on ICU staff (McKinley et al. 2002). The presence of a close relative at the bedside provides patients with a feeling of security and protection in their vulnerability (Bergbom & Askwall 2000).

ICU patients who recall unreal experiences are a well-known phenomenon (Schelling et al. 1998, Granberg et al. 1999, Jones et al. 2001, Rundshagen et al. 2002, Adamson et al. 2004, Samuelson et al. 2006). In the study by Rundshagen et al. (2002) about 21% of patients recalled dreams or dreamlike sensations, while some recalled nightmares and hallucinations 48-72 hours after discharge from an ICU. Of those patients who recalled hallucinations, some reported pleasant dreams and others very frightening ones, although both kinds were true-to-life delusions. Patients who recalled dreams needed a longer period of intensive care treatment and were also mechanically ventilated and anaesthetised for a longer time than those who did not recall any dreams (Rundshagen et al. 2002). It is acknowledged that posttraumatic stress disorder (PTSD) is a significant problem in the recovery phase after an ICU stay and that the frequency
of PTSD increases in line with the number of adverse events recalled, such as nightmares, anxiety and pain (Schelling et al. 1998). The frequency of PTSD also increases with the length of time on mechanical ventilation and, the younger the patient, the more often PTSD occurs (Cuthbertson et al. 2004).

The patients' mental and physical functioning after intensive care is an important factor both for themselves and their close relatives who may be involved in their subsequent care. The patients' functioning during the recovery phase can also be regarded as an important indicator of the treatment and quality of care. A study of health-related quality of life six months after discharge from an ICU revealed that 54% of the former patients reported feeling better and 29% feeling worse than six months before ICU admission (Granja et al. 2002). Chaboyer & Grace (2003) found that former patients still had problems one year after discharge. The patients reported the following problems: mobility (31%), some to total assistance required with the activities of daily living (58%), persistent problems with lack of energy and fatigue (16%), occasional to permanent sleep difficulties (19%), occasional to constant pain (32%), and occasional to continual perceptions of being depressed (35%). In another study, in which relatives of former critically ill patients were compared with a community group, health-related quality of life was investigated 16 months after the patients' discharge from an ICU (Brooks et al. 1997). At that phase of the recovery period, the former critically ill patients were more physical ill, were more dependent on others and more anxious and depressed compared to the community group, and 63% failed to achieve full health, were functionally impaired and perceived poorer quality of life than those who made a full recovery.
From ordinary everyday life to being a relative of a critically ill patient

A relative is defined as a close relative or friend and may best be described in the same way as family member, as outlined by Taylor (1994, p. 203), who states that family refers to “the sense of home we have within ourselves, which binds us to people with whom we have blood ties or special affinities”.

In the ordinary everyday existence of individuals, life usually goes by without them reflecting on its fragility or their relationships. Individuals in a close relationship are united with each other in a mutual dependency and share memories from the past, perceptions of the present and dreams and hopes for the future. When one of them suddenly becomes critically ill and thereby assumes the role of a critically ill patient while the other takes on the role of close relative, their normal life is changed into an extraordinary situation. This situation evokes the essence of the ordinariness in life; everything that is taken for granted in the ordinary everyday life of the relative and the patient is suddenly under threat (Walters 1995a). This essence of ordinariness (Taylor 1994) may best be described as a sense of homeliness that allows the relative to look at the patient and immediately experience the ties and bonds with him/her as well as in some cases causing the relative to experience fear and anxiety, both for the patient and for themselves (Walters 1995a). The relatives’ sense of homeliness is threatened, which evokes an awareness of the temporality of their togetherness (Walters 1995a). The relatives also become more aware of emotions, both their own and those of the patient, as well as a willingness to share their emotions with the patient.

In the light of this feeling of homeliness, the relatives’ experiences during the patient’s ICU stay are understandable. “Being-with” and “seeing” are themes that are based on those shared horizons experienced by relative and patient (Walters 1995a). “Being-with” involves the special physical and emotional connectedness experienced by the relative and represents concern for the patient’s well-being, while “seeing” the patient provides instant information about his/her progress, from the relatives’ perspective, as they compare the patient’s present state with his/her normal appearance. The repertoire of experiences will be complete when the themes “plain talk”, which deals with the importance of sensitive and timely communication, and “making sense”, focusing on the relatives’ understanding of the experience of the patient’s critical illness (Walters 1995b) are added. The importance of the close relationship with the patient is also apparent in the relatives’ experiences of “being present”, “putting oneself in second place” and “living in uncertainty” (Engström & Söderberg 2004). The theme “being present” encompasses the relatives’ experience of seeing the change in the critically ill patient, wishing to be near and showing respect. “Putting oneself in second place” describes how the whole family is influenced by the serious situation and how their everyday life is changed. The theme “living in uncertainty” emphasises the relatives’ feelings of being forced to wait for information and not knowing whether the patient will survive. Living with such uncertainty meant that the relatives alternated between hope and despair. Jamerson et al. (1996) described the course of relatives’
experiences during the ICU period as comprising four processes. “Hovering” is the initial process that describes the relatives’ experiences of confusion, stress and uncertainty, and the second process, “information”, helps them to move on from the hovering phase. In the third process the relatives “track” the patient’s care and prognosis, and finally their strategies are directed towards the process of “gathering resources” of what they perceive as their own needs or those of their family member.

The emotional responses of the relatives are described as deep emotional turmoil throughout the ICU stay (Kleiber et al. 1994). When the relatives received bad news about the patient and during the first 24 hours, the dominant emotions were fear, worry, anger and exhaustion, after which there was no evident pattern of emotional response as the stay progressed. The study of the change of roles within the family during an ICU stay also revealed a change of emotions, for example, uncertainty, hope, guilt, trying not to cry, the need to be strong, worry and concern, the need to protect the patient, withdrawal, isolation, sympathy, anger, irritability as well as calmness, extreme happiness, thankfulness, feeling positive and a desire to care for the patient (Johnson et al. 1995). The behavioural responses (Halm et al. 1993, Van Horn & Tesh 2000) as well as cognitive and emotional responses (Leske 1992a) of relatives of critically ill patients were investigated. The results indicate that, during the patient’s ICU stay, the health of family members may be at risk. Evaluation of stress-related symptoms in relatives revealed that about 33% of relatives had a moderate to major risk of developing post-traumatic stress symptoms at three months after the ICU experience (Azoulay et al. 2005). A high incidence of psychological distress was still evident in relatives six months post-ICU and correlated with the high level in patients (Jones et al. 2004). It should also be noted that the patient’s transfer from the ICU to a general ward was described as stressful and a source of anxiety by 20% of the relatives in the study by Leith (1999).

When relatives reflected on the recovery period at home, it was revealed that a vast majority of them devoted a substantial number of hours each week to taking care of the patient (Foster & Chaboyer 2003). More than half of the relatives provided a moderate to large amount of caregiving between one and nine months after the patient’s admittance to an ICU (Swoboda & Lipsett 2002). Almost half of the relatives quit work and some postponed further education and medical treatment, which reached a climax at 3 months post-ICU and paralleled the patient’s functional outcome. Johnson et al. (2001) confirm the association between caregivers’ experiences of burden and the patient’s physical and mental impairment. The relatives’ health status was examined during the year post-ICU and revealed that the health of 29% of the relatives had deteriorated (Dew et al. 1998).
Coping with the demands of being a relative of a critically ill patient

When a patient is admitted to an ICU, existential questions surface in the relatives, and as long the patient’s condition remains uncertain, the relatives will have to live with these questions. In addition, the strong feeling of threat affects the well-being of the relatives (Leske 1992a, Halm et al. 1993, Van Horn & Tesh 2000). When the patient improves and the initial danger has abated, his/her mental and physical impairments give rise to questions about the future. Finally, when the still physically and mentally impaired patient is discharged to the home, the relatives have to struggle with problems of both an emotional and practical nature (Johnson et al. 2001). The relatives thus have to endure the emotional crisis during the ICU stay as well as the emotional and practical problems at home, and in one or another way they are.

The concept of coping

The coping concept is concomitant with stress and is developed and defined from psychoanalytical theory, where defence mechanisms constitute a model (Lazarus 1993a). The hierarchical perspective presented by Menninger (1954), Haan (1969) and Vaillant (1977) developed the concept towards adaptive coping behaviour, characterised by flexible, purposeful and reality oriented behaviour, as distinct from defensive behaviour that is rigid, compelled, reality distorting and undifferentiated (Haan 1969). A further development took place in the 1970s, when the dominant research of the 1960s which linked specific coping styles to personality was overshadowed by the perspective of viewing coping as a process (Lazarus 1993a).

According to the coping process theory presented by Lazarus, coping changes over time and in relation to the circumstances and is considered a continuous transaction between the individual and his/her environment (Lazarus 1993a, Lazarus & Folkman 1984). The transaction between the individual and his/her environment underlines the fact that, from a phenomenological perspective, the individual is considered to have the ability to appraise the demands of the situation in relation to the available resources on a continual basis (Lazarus & Folkman 1984). Lazarus and Folkman (1984) distinguish between primary and secondary appraisal, but suggest that the two should be integrated and that primary does not precede secondary in chronological terms. Primary appraisal implies that individuals evaluate the potential threat, loss or challenge on the basis of what is important for their well-being. If the situation is appraised as stressful, the individuals consider, in a secondary appraisal, what could and can be done in order to deal with the situation. Continuous evaluation or reappraisals are made when a change in the transactions between the individual and the environment occurs. Lazarus & Folkman (1984, p. 141) define coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”. Lazarus emphasises that, in addition to feelings of stress, different emotions are experienced (Lazarus & Folkman 1984, Lazarus 1993b). Both stress and emotions are the result of cognitive appraisal processes.
when the individual experiences a threat or danger to personal values, commitments or goals (Lazarus & Folkman 1984). Stress appraisal and its attendant emotions influence the coping process, which in turn lead to other changes in the relationship between the person and his/her environment (Folkman & Lazarus 1988a,b). A reappraisal of this relationship leads to a change in emotional expression and, when viewed in this way, coping acts as a mediator of the emotional response to a stressful situation. In order to highlight the prominent position of emotions, Lazarus revised the model in the 1990s, and the coping process was renamed the emotion process (Lazarus 1993b). In line with the new position of emotions, the outcome of the appraisal of an overwhelming situation is labelled “the relational meaning” of an emotion, representing one of the 15 relational themes of emotions.

Two functions of coping are described in the literature (Menninger 1954, Mechanic 1978, Pearlin & Schooler 1978), and the clear distinction between them is apparent, one function being directed towards managing or altering the problem that causes the stress, while the second is directed towards regulating the emotional response to the problem (Lazarus & Folkman 1984). These two functions of coping are described as problem-focused and emotion-focused coping and have been defined by Lazarus and Folkman (1984). Problem-focused coping deals with the problem that causes the distress by acting on the environment or the individual him/herself for the purpose of changing the reality of the stressed person-environment relationship. Emotion-focused coping is directed towards regulating the emotional response to the problem without changing the realities of the stressful situation. Individuals use both problem- and emotion-focused coping when dealing with a stressful situation.

Coping approaches of relatives of a critically ill patient

The coping process of relatives during the initial three days of a patient's ICU stay has been described as comprising three periods (Leske 1992a): the notification, arrival and waiting period. The notification period is characterised by a feeling of numbness and non-functional thoughts. During the arrival period, the relatives experience fluctuating feelings and disorganised thoughts. Finally, during the waiting period the relatives feel powerless and their thoughts are characterised by a lack of control. During the whole ICU stay several different coping mechanisms can be clinically observed among relatives of critically ill patients: distracting oneself from the overwhelming situation, remaining close to the patient, maintaining hope, seeking information and turning to others for support (King & Gregor 1985), in addition to, for example, remaining in control, considering different ways of handling the situation and taking an objective view of the situation (Koller 1991). The most effective and frequently used coping approaches employed by relatives can be classified as: supportant, optimistic and confrontive (Koller 1991, Twibell 1998). The two approaches least used and deemed least effective by the relatives are labelled emotive and evasive (Twibell 1998). Relatives who are closely related to the patient cope less effectively with critical illness than those who are more distantly related, while older relatives use a greater variety of coping styles and cope more effectively than younger relatives (Twibell 1998). It is
interesting to note how relatives try to familiarise themselves with the ICU (Hupcey 1999) so that they can act in their own and the patient’s best interest. The relatives state that their role is supportive, but in reality, their main role is one of protecting or looking after the best interest of the patient. The relatives also describe how they endure the situation and remain vigilant while trying to find a niche in the ICU.

Unlike ICU patients in general, patients treated in coronary ICUs are conscious and lucid, a fact that influences the relatives’ coping approaches, which are mainly focused on maintaining emotional strength (Dhooper 1983) for the patient, family and self (Nyamathi 1987). The main strategy is to minimise the initial effects of the heart attack in order to maintain the family balance (Nyamathi 1987). The most effective and frequently used coping mechanisms by female relatives can be classified under the heading of supportant coping, while for male relatives, the most effective and frequently used approach can be classified as planful problem-solving coping (Yeh et al. 1994). A relationship exists between positive personality factors and problem-focused coping and between negative personality factors, emotion-focused coping and emotional and physical distress (Nyamathi et al. 1992).

The literature on the subject of relatives’ coping approaches during the patient’s ICU stay is limited. When reviewing the patient’s recovery period at home it was found that there were no studies dealing with critically ill patients in general, although some literature focusing on the relatives of former critically ill neurosurgical patients was identified (Sander et al. 1997). The study of relatives of patients who survived closed head injury revealed that the burden of caring for the patient, although decreasing, is still present more than 18 months after discharge from hospital (Sander et al. 1997), and moreover that there is a relationship between the burden of caring for the patient, psychological distress and emotion-focused coping.
Supportive transactions of relatives of critically ill patients

Social support is an integrated and natural part of human life (Vaux 1990) as well as readily available. In the world of relatives of critically ill patients, social support is considered an effective resource when coping with the situation (King & Gregor 1985, Koller 1991, Twibell 1998). In the stress and coping theory presented by Lazarus and Folkman (1984), social support is described as a critical part of the coping process when faced with overwhelming demands.

The concept of social support

The factors that facilitate social support are social network, social embeddedness and social climate (Langford et al. 1997). Social network is the convoy, the interactive process, through which social support is provided (Kahn 1979), while social embeddedness is the connectedness between individuals and represents the depth and strength of their relational ties (Barrera 1986). Walker et al. (1977, p. 35) defined interpersonal transactions within a social network as "... that set of personal contacts through which the person maintains his social identity, and receives emotional support, material aid services, information and new social contacts". Social climate is the essence of social support and is characterised by reciprocal readiness to help and protection (Langford et al. 1997) between individuals in a social network. A positive atmosphere provides opportunities for enhanced coping, emotional adjustment, self-esteem and mental well-being (Stewart 1993).

In the literature, the attributes of social support are described in different ways (Hutchison 1999), but there is a common typology with which most investigators are in agreement (Langford et al. 1997). These attributes are emotional, instrumental, informational and appraisal support, which House (1981) claims are a part of interpersonal transaction. Emotional support, which is powerful enough to provide empathy, love, trust and caring, is the most important of these attributes (House 1981). Cobb's (1976) definition of social support as communication that conveys the information that one is cared for, loved, esteemed, valued and a member of a network involving mutual obligations may well reflect emotional support. Instrumental support can be most clearly distinguished from emotional support and involves behaviours that directly help other individuals, for example taking care of them or doing cleaning or shopping for them (House 1981). Informational support implies providing an individual with information that can be used when coping (House 1981). Appraisal support can be defined as providing information in order to enable the receiver to evaluate himself/herself (House 1981) with reference to others' behaviour and abilities, which is important for an individual's self-concept and coping ability (Stewart 1993).

Social support is a multifaceted concept and has been defined in a number of ways in the literature (Hutchison 1999). The fact that no consensus has yet been established makes research complex and problematic when evaluating the outcomes of support interventions (Thoits 1982, Langford et al. 1997, Hutchison 1999). Nevertheless, a great deal of research points to a relationship between social support and
beneficial effects on mental and physical health-related variables (Cohen and Wills 1985, Krumholz et al. 1998, Preyde & Ardal 2003).

Social support for a relative of a critically ill patient

Several studies that describe the most important needs of relatives of a critically ill patient have been carried out in order to establish how best to support them. The reviews by Leske (1992b) and Robb (1998) indicate that the majority of the relatives’ needs are related to assurance, proximity and information, which is also confirmed by Al-Hassan and Hweidi (2004). What relatives describe as their most important needs accord with the meaning of what relatives claim are the most supportive interventions. These supportive interventions are, in order of importance, informational support (assurance and information), appraisal support (proximity), emotional support (care, empathy, concern) and instrumental support (providing goods and services) and are considered to have beneficial effects on families (De Jong & Beatty 2000). The provision of information and education as well as encouragement to express feelings is described as alleviating the relatives’ stress responses (Gardner & Stewart 1978, Thompson & Meddis 1990). A controlled intervention study with a needs-based education programme in an ICU described a significant reduction in the relatives’ anxiety level and an increased satisfaction score in the area of family needs (Chiu et al. 2004). Support group programs that provide educational-mutual support offer the relatives an opportunity to share feelings as well as coping skills (Halm 1990, Halm 1991, Harvey et al. 1995, Hildingh et al. 1995). The meetings with other relatives and professionals inspire hope in their anxious emotional state (Halm 1990, 1991). The review of the years 1999-2004 revealed that nurses’ caring behaviour and a family-centred approach to care has the potential to alter the stress responses of relatives of critically ill patients (Pryzby 2005). An opportunity to be involved in the care of the patient is emotionally beneficial for the well-being of these relatives (Azoulay et al. 2003, Hammond 1995). Support from the relatives’ own social network, in the form of information, advice and guidance (confiding support), was shown to reduce their physical symptoms of anxiety (Jones & Griffiths 1995).

The patient’s discharge from the ICU may be followed by a long recovery period at home, which means that the relatives experience both the burden of caring for the patient and the need for support. No literature dealing with the social support needs of relatives of former critically ill patients in general could be identified, although studies exist that focus on relatives of special groups of patients, such as those who suffered head injuries (Ergh et al. 2002).
AIMS OF THE THESIS

The summary of the current knowledge revealed that, during the patient's ICU stay and recovery at home, their relatives may experience great strain with negative consequences for their mental and physical functioning. This highlighted the importance of professional support for the relatives during these periods. As previous research on the subject of coping approaches and social support experiences of relatives was found to be limited, it was important to provide healthcare professionals with a theoretical platform of knowledge in these areas.

The general aim of the thesis was to develop a theoretical understanding of coping approaches and social support experiences of relatives of critically ill patients, both in the ICU and at home.

The specific aims were:
- to develop a theoretical understanding of relatives' coping approaches during the patients' ICU stay and subsequent recovery period at home.
- to develop a conceptual model of relatives' coping approaches during the patients' ICU stay and subsequent recovery period at home.
- to develop a theoretical understanding of what relatives experience as supportive during the patients' ICU stay and subsequent recovery period at home.

METHOD

As the aim of the thesis was to develop a theoretical understanding of the coping approaches and social support experiences of relatives of critically ill patients, it was considered important to search for knowledge in the areas of concern reported by the relatives themselves. The experiences described by individuals ascribe qualitative meaning to them as unique individuals, while in turn, meaning is formed in social interaction between individuals. These ontological and epistemological assumptions made it necessary to search for knowledge by means of qualitative methods.

This thesis includes four studies, three of which used grounded theory methodology (I, II, IV) and one simultaneous concept analysis (SCA) (III). An addition to study IV, with a qualitative content analysis, is also included in the thesis. The structural interconnection between the studies is illustrated in Fig. 1.
Figure 1  Structural interconnection between the studies in the thesis
Abbreviations: GT = grounded theory, QCA = qualitative content analysis and SCA = simultaneous concept analysis
Grounded theory methodology (Studies I, II, IV)

In order to provide healthcare professionals with a deep understanding of relatives' coping approaches (during the ICU and recovery period) and experiences of support (in the ICU) from a social context, grounded theory methodology was considered to be the most appropriate method. The structural interconnection between studies I, II and IV is presented in Fig. 1.

Origin in symbolic interactionism

The aim of grounded theory is to put a phenomenon into its social context. Grounded theory was developed from symbolic interactionism (Blumer 1969), a philosophical perspective that was suitable for studying relatives’ thoughts, actions and experiences when the patient was critically ill in an ICU and during the subsequent recovery period at home.

Since the 1920s, symbolic interactionism has been a research approach in the discipline of sociology. It is strongly based on Mead’s thoughts on human social nature (Blumer 1969). The human being has a self and this self is seen as a process, a part of which is the possibility for self-interaction. Self-interaction implies the ability to be aware of and have conceptions about oneself, to be able to communicate with and act towards oneself, in contrast to psychological science approaches, which view the self as an organic structure comprising psychological factors. Symbolic interactionism rests on the following three assumptions (Blumer 1969, p. 2): 1) “human beings act toward things on the basis of the meanings that the things have for them”, 2) “the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows”, 3) “these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters”. In other words, symbolic interactionism holds that human ability to create meaning is formed through social interaction with others and enables individuals to act in a typically human manner.

Characteristic features and procedures

Two kinds of theory, formal and substantive, can be generated from grounded theory methodology (Strauss & Corbin 1990, 1998). Formal theory describes a phenomenon on a conceptual level while substantive theory describes it within a narrow and specific area, such as in studies I, II and IV. However, both kinds of theories are developed from the same features and procedures that are characteristic of grounded theory methodology.

Grounded theory methodology is structured based on characteristic features, analytical cornerstones, that involve the whole realization of a study (Strauss & Corbin 1990, 1998). These are: concurrent gathering and analysis of data, constant comparison of analysis, theoretical sensitivity, theoretical sampling, theoretical saturation and memo writing. In addition to the analytical cornerstones of grounded theory methodology, a systematic set of analytical coding procedures is required in order to identify an
integrated grounded theory that is close to the data (Strauss & Corbin 1990, 1998). These coding procedures endow the research process with the systemic structure required to formulate a grounded theory and also facilitate the analysis by increasing the researchers’ sensitivity to the meanings in the data and reducing bias (Strauss & Corbin 1990, 1998). Familiarity with the field of study can enhance analytical sensitivity, but may block creativity if the researcher does not make efforts to minimise the risk (Strauss & Corbin 1990, 1998). The characteristic features and specific procedures involved in grounded theory methodology enable research studies to generate findings that reflect the reality of relatives of patients admitted to an ICU.

The analysis in the three grounded theory studies commenced with the first interview and as long a new data was needed for the generation of the theory, the concurrently gathering and analysis was proceeding. During the analysis, earlier and new data and the generated codes/categories were constantly compared. During this procedure, questions and comparisons emerged, which guided the continued search for new data. This procedure was a feature of the theoretical sampling, which continued until saturation was reached. By that stage of the analysis, the generated categories had been well established and validated. Theoretical sensitivity was characterised by the researchers’ familiarity with the data and their knowledge of what data to search for. This sensitivity increased in the course of the analysis process. The writing of memos was an important part of the analysis, as it increased theoretical sensitivity and guided subsequent theoretical sampling.

Three main types of coding were used, namely open, axial and selective coding (Strauss & Corbin 1990, 1998).

- In open coding the data were fractured in order to reveal the meanings contained therein. More concretely, in this step, data were broken down, examined in detail, compared for similarities and differences and finally conceptualised and categorised.
- In axial coding the categories were connected to their subcategories to provide an explanation of the phenomenon in the form of a causality schema, the so called paradigm model.
- In selective coding the major categories were integrated and refined into a larger theoretical schema, i.e. a theory.

Data were conceptualised by means of the coding procedures, and in order to ensure validity, data were constantly compared, which involved both inductive and deductive thinking (Strauss & Corbin 1990, 1998).
Inclusion criteria

The inclusion criterion in studies I, II and IV was being an adult (>18 years) relative of an adult (>18 years) patient admitted to an ICU due to a life-threatening illness, trauma, postoperative complication. In addition, the following criteria were also included:

- In study I (coping during the ICU stay) — the patient had to have been treated in the ICU for at least 3 days, with or without mechanical ventilation.
- In study II (coping during the recovery period at home) — the patients must have been on mechanical ventilation for at least 3 days and been cared for at home for at least 3 months following discharge from the ward or recovery clinic.
- In study IV (what is experienced as supportive during an ICU stay) — the patient must have been treated in an ICU for at least 3 days, with or without mechanical ventilation.

Relatives of dying or deceased patients were not invited to participate in the studies, and relatives who did not speak Swedish were also excluded.

Theoretical sampling

The data in studies I and II were collected directly from the field by means of theoretical sampling. Contact was established with the head nurse and the social worker of each clinic at the start of the research project, with a view to contacting the relatives of former patients. Before contacting them, the main researcher, in consultation with the head nurse and the social worker, selected those relatives who would be of most interest to the project. In studies I and II, saturation was reached after 16 and 12 interviews respectively, but a further two interviews in each study were coded and analysed, in order to ensure that the information provided by the relatives was complete.

The data in study IV were also collected by means of theoretical sampling but using studies I and II. Studies I and II provided rich data on the relatives’ experiences and their coping approaches during the respective periods. Study II concerned the patient’s recovery period at home but, as an introduction, the relatives were asked to describe their coping situation whilst the patient was in ICU. In all of the interviews in studies I and II, the discussion about the relatives’ coping approaches during the ICU stay also led to a dialogue about what they found supportive during this period. These data formed the basis for study IV. The accounts of what was supportive were either directly expressed by means of the word support or indirectly by relating positive or negative experiences that clearly indicated that the situation was easy or difficult to cope with. Saturation was achieved after 26 interviews. Had this not been the case, it might have proved necessary to search for additional primary data. An additional three interviews were coded, analysed and included in the study. This approach is similar to a study that starts with data collection in the field (Strauss & Corbin 1998). In other words, irrespective of whether the data were collected directly from the field or indirectly from an existing data bank, the same analytical grounded theory coding procedures and methodology were used.
Interviews

In studies I and II, a pilot interview was performed, and as the interview technique and questions were relevant to the aim of the studies, these interviews were included in the respective samples. The audio taped interviews in studies I and II took place in the informants’ homes, with the exception of interviews two and six, which were conducted at the hospital.

- The 18 interviews in study I were conducted between 7 days and 4 months after the patients’ discharge from the ICU and lasted between 30 and 75 minutes.
- The 14 interviews in study II were conducted between 3 and 15 months after discharge to the home and lasted between 32 and 82 minutes.

In study I, the wide variation in time between discharge from the ICU and the interview was a necessary strategy to avoid harming those relatives who were not yet psychologically ready. In study II the wide variation in time was designed to ensure that the relatives had experienced most of the patient’s recovery prior to the interview. However, in the search for valuable new data, some relatives were interviewed despite the fact that a longer period of time had elapsed. The interviews were all transcribed verbatim.

In study IV, 29 (18+11) interviews were deemed useful out of the 32 (18+14) from studies I and II, of which 18 were conducted in relation to the patient’s discharge from the ICU and 11 between 3 and 12 months after discharge.

Interview questions

The following four questions were asked in studies I and II:

1. Please describe the situation you have gone through, when having a next-of-kin in the ICU? (I) / Would you please describe what it is like to have a next-of-kin recovering at home following a critical illness? (II)
2. What did you do to cope with your situation? (I) / How did you cope with the situation? (II)
3. What do you think was the reason for your choice? (I) / Why did you choose that way of coping? (II)
4. What alternative ways of coping with the situation are there? (I) / What alternative ways are there of coping with the situation? (II)

These questions were used in order to open up the interview and encourage the relatives to discuss the issues as well as allow them to review their experiences. Specific questions were guided by the emerging analysis and aimed to obtain data that confirmed or rejected a hypothesis or shed light on an emerging hypothesis.

In study IV, the following three questions were put to the data:

1. What was supportive for the relatives during the patient’s ICU stay?
2. Why did the relatives find it supportive?
3. Are there alternative kinds of support in this situation?

Specific questions guided by the emerging analysis also formed part of this study.
Informants

The characteristics of the relatives in studies I, II and IV, such as age, sex, relationship to the patient, profession and the patient's illness, are described in Table 1. In study I, the patients were admitted to thoracic surgical, neurosurgical, coronary and general ICUs, in study II they were admitted to a general ICU, while in study IV they were admitted to thoracic surgical, neurosurgical, coronary and general ICUs, all of which are situated in southwest Sweden. The patients were mechanically ventilated during their ICU stay, with the exception of four patients from the coronary ICU in study I and study IV. Patient characteristics such as age, sex and length of caring period/s are briefly described in Table 1.
Table 1  Characteristics of the female (F) and male (M) informants in study I (N = 18), study II (N = 14) and study IV (N = 29). All patients were mechanically ventilated, with the exception of those with coronary disorders. Case numbers of the informants in study IV are in parenthesis beside those pertaining to studies I and II. The informants in the light-coloured lines were not included in study IV.

<table>
<thead>
<tr>
<th>Case (no.)</th>
<th>Age (years)</th>
<th>Sex</th>
<th>Relation</th>
<th>Profession</th>
<th>Patient disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I and IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (1)</td>
<td>72</td>
<td>F</td>
<td>Spouse</td>
<td>Housekeeper</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>2 (14)</td>
<td>70</td>
<td>M</td>
<td>Spouse</td>
<td>Plumber</td>
<td>Coronary</td>
</tr>
<tr>
<td>3 (4)</td>
<td>64</td>
<td>F</td>
<td>Spouse</td>
<td>Bookseller</td>
<td>Vascular</td>
</tr>
<tr>
<td>4 (5)</td>
<td>24</td>
<td>M</td>
<td>Partner</td>
<td>Factory worker</td>
<td>Neurological</td>
</tr>
<tr>
<td>5 (10)</td>
<td>37</td>
<td>F</td>
<td>Sister</td>
<td>Nursing assistant</td>
<td>Neurological</td>
</tr>
<tr>
<td>6 (19)</td>
<td>45</td>
<td>F</td>
<td>Spouse</td>
<td>Administrator</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>7 (15)</td>
<td>55</td>
<td>F</td>
<td>Partner</td>
<td>Secretary</td>
<td>Coronary</td>
</tr>
<tr>
<td>8 (13)</td>
<td>70</td>
<td>F</td>
<td>Spouse</td>
<td>Purchasing officer</td>
<td>Coronary</td>
</tr>
<tr>
<td>9 (18)</td>
<td>48</td>
<td>M</td>
<td>Father</td>
<td>Teacher</td>
<td>Vascular</td>
</tr>
<tr>
<td>10 (20)</td>
<td>64</td>
<td>F</td>
<td>Spouse</td>
<td>Nursing assistant</td>
<td>Neurological</td>
</tr>
<tr>
<td>11 (8)</td>
<td>35</td>
<td>F</td>
<td>Daughter</td>
<td>Writer</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>12 (12)</td>
<td>50</td>
<td>F</td>
<td>Daughter</td>
<td>Pre-school teacher</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>13 (11)</td>
<td>22</td>
<td>M</td>
<td>Friend</td>
<td>Nursing assistant</td>
<td>Neurological, orthopaedic</td>
</tr>
<tr>
<td>14 (3)</td>
<td>50</td>
<td>F</td>
<td>Mother</td>
<td>Assistant nurse</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>15 (2)</td>
<td>55</td>
<td>M</td>
<td>Father</td>
<td>Carpenter</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>16 (9)</td>
<td>60</td>
<td>M</td>
<td>Spouse</td>
<td>Chief officer of a local authority department</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>17 (16)</td>
<td>60</td>
<td>M</td>
<td>Spouse</td>
<td>Mechanic</td>
<td>Coronary</td>
</tr>
<tr>
<td>18 (17)</td>
<td>35</td>
<td>F</td>
<td>Daughter</td>
<td>Cleaner</td>
<td>Pulmonary, orthopaedic</td>
</tr>
<tr>
<td>Study II and IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (21)</td>
<td>76</td>
<td>F</td>
<td>Spouse</td>
<td>Storeman</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>2 (7)</td>
<td>65</td>
<td>F</td>
<td>Spouse</td>
<td>Shop-assistant</td>
<td>Gastrointestinal</td>
</tr>
<tr>
<td>3 (22)</td>
<td>79</td>
<td>F</td>
<td>Spouse</td>
<td>Assistant nurse</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>4 (23)</td>
<td>49</td>
<td>F</td>
<td>Mother</td>
<td>Nursing assistant</td>
<td>Otolaryngological</td>
</tr>
<tr>
<td>5</td>
<td>64</td>
<td>M</td>
<td>Spouse</td>
<td>Chief officer</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>6 (24)</td>
<td>39</td>
<td>F</td>
<td>Spouse</td>
<td>Dressmaker</td>
<td>Neurological</td>
</tr>
<tr>
<td>7</td>
<td>64</td>
<td>M</td>
<td>Spouse</td>
<td>Foreman</td>
<td>Vascular</td>
</tr>
<tr>
<td>8 (6)</td>
<td>51</td>
<td>F</td>
<td>Mother</td>
<td>Assistant nurse</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>9 (29)</td>
<td>53</td>
<td>M</td>
<td>Father</td>
<td>Carpenter</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>10 (25)</td>
<td>78</td>
<td>M</td>
<td>Spouse</td>
<td>Tradesman</td>
<td>Neurological</td>
</tr>
<tr>
<td>11</td>
<td>64</td>
<td>M</td>
<td>Spouse</td>
<td>Mechanic</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>12 (26)</td>
<td>47</td>
<td>M</td>
<td>Son</td>
<td>Carpenter</td>
<td>Vascular</td>
</tr>
<tr>
<td>13 (27)</td>
<td>61</td>
<td>F</td>
<td>Daughter</td>
<td>Children’s nurse</td>
<td>Pulmonary</td>
</tr>
<tr>
<td>14 (28)</td>
<td>58</td>
<td>F</td>
<td>Daughter</td>
<td>Children’s nurse</td>
<td>Pulmonary</td>
</tr>
</tbody>
</table>

The patients in study I: 8 female, 10 male, age 19-77 years, ICU stay 4-51 days.

The patients in study II: 9 female, 5 male, age 21-83 years, ICU stay 5-82 days, institutional care after ICU 3-278 days.
Simultaneous concept analysis (Study III)

When supporting the relatives, healthcare professionals would benefit by having access to knowledge that provides an understanding of the determinants of relatives’ coping approaches, such as the causes, facilitators, attributes and consequences, throughout both the critical care period and the recovery period at home. Increased knowledge would make it possible to predict and prevent problems that may arise for the relatives during the patient’s ICU stay and subsequent period of recovery at home. The SCA method was considered to have several advantages in this regard.

Usefulness of the method

Simultaneous concept analysis (SCA) was developed by Haase et al. (1992) and is an extension of Wilson’s (1969) individual concept clarification process. “Essentially it is an iterative process for examining multiple interrelated concepts simultaneously within a consensus group” (Haase et al. 1992, p. 142). Concepts that were selected for investigation by Haase et al. (1992) were spirituality, hope, acceptance and self-transcendence. These concepts were chosen for analysis and comparison due to the fact that they were deemed to be interrelated in nursing practice. Simultaneous concept analysis allowed identification of the distinguishing characteristics of each concept as well as the interrelationship between them, and provided mutually specific theoretical definitions. This kind of systematic concept clarification and differentiation was an important strategy for the advancement of nursing theory, the generation and testing of hypotheses, the development of measurement instruments as well as being vital for clear communication among nurse theorists and practitioners (Haase et al. 1992).

The aim of study III was to develop a model of the coping approaches employed by relatives during the patients’ ICU stay and recovery at home in order to increase understanding of these approaches. For this purpose, the SCA method was considered to have several advantages in terms of the aim of the study. It was decided to use the concepts generated in two earlier grounded theory studies (I, II), which describe the coping approaches of critically ill patients’ relatives, both during the patients’ ICU stay (I) and the subsequent recovery at home (II). The coping concepts associated with each period were interrelated by means of the grounded theory procedures, and for that reason it was deemed possible analyse them simultaneously. However, the research group also considered the possibility of including the coping concepts of both periods in the same simultaneous analysis, as all concepts were associated with the coping approaches of relatives of critically ill patients. An SCA clarification process will result in a coping model in which all concepts are clarified and interrelated, thus implying that the concepts have been agreed on as well as grouped and abstracted in an identical way.
Characteristic procedures

A consensus group was formed at the start of the study. Apart from the main researcher, the group was composed of four experts in the field of critical care nursing, coping research and qualitative methods. One of the experts was not experienced in the area of critical care nursing, but instead contributed knowledge from the field of health promotion. As mentioned above, the consensus group decided to use coping approach concepts that had been generated in two earlier empirical studies (I, II) (Fig. 2, 3). However, only those concepts that represented the coping approaches of patients who had been on mechanical ventilation were included in the study, as a result of which the concept “excluding feelings” was omitted.

The SCA method can broadly be described as having two main features: 1) clarification of each concept (Wilson 1969) and 2) simultaneous reconsideration of all concepts (Haase et al. 1992). However, a comprehensive stepwise description of the SCA method provides more detailed knowledge about these features:

1. Clarification of individual concepts. The researchers started by performing independent and critical examinations of the coping concepts from the two empirical studies, and all background data were read through at this point. Then, in the course of ordinary group meetings, each coping concept was clarified with the aid of a structured matrix, which included the critical attributes as well the antecedents and outcomes of these attributes. In accordance with Haase et al. (2000), the consensus group also identified enablers of the attributes. The matrix of each concept was discussed and continually reformulated until consensus was reached.

2. Development of validity matrices. In order to compare the attributes of the coping concepts for similarities and differences, their attributes were placed in a single validity matrix (Fig. 4). The antecedents, enablers and outcomes were placed in individual validity matrices. The comparison enabled the research group to identify factors that were common across concepts. Overall, the development of validity matrices facilitated the study of each element in comparison to the others. The main content of the validity matrices was continually discussed and reformulated.

3. Validation against the empirical data. After having re-evaluated the identified antecedents, enablers, attributes and outcomes for similarities and differences across concepts, the refined concepts were validated against the empirical data on which the study was based.

4. Validation against the literature and the formulation of definitions. A search was made of the coping literature in collaboration with a qualified librarian, after which each author in the consensus group was assigned one or several concepts for further examination in terms of meaning. The author had to consider the existing empirical data concurrently with the literature. These examinations were critically evaluated in the course of the group meetings. The terminology used when expressing the concepts was considered an essential part of the refinement of the concepts, and therefore an English dictionary was consulted (Bullon et al. 2003). When the concept was deemed to have been sufficiently refined, a concise definition was formulated. The simultaneous analysis procedure thus led to the decision to
collapse the concept of “mastering feelings” (coping approach during the ICU period) with “modulating the situation” (coping approach during the recovery period at home) under the label “mastering” due to the fact that the concepts were almost identical. The concept of “accepting the situation” was renamed “acquiescing”, because accepting “bore false witness” when the empirical data were compared with the literature, in which the term “accepting” had a positive connotation, which failed to reflect the meaning of the generated concept.

5. Developing and summarising the model. A model was developed by placing the completed validity matrices of antecedents, enablers, attributes and outcomes in a single model (Fig. 4). In the course of the analysis procedure, it was deemed possible to include coping concepts of two different periods in a single model. As the model was designed to enable new insight into each concept as well as into the relationship between them, the consensus group examined the consistency and pattern among them while at the same time including the new concepts that appeared in the model (Haase et al. 2000). This model served as an analytical tool and a precursor of theory (Haase et al. 2000).

6. Defining and illustrating the theoretical foundation of the coping model. Having examined the completed model, it was apparent that some coping approaches were more successful than others. This fact inspired the consensus group to perform additional analyses. Finally, a hypothesis was developed that took account of the effectiveness of the different coping approaches. Definitions and relational statements were developed, which endowed the hypothesis with a basic theoretical foundation. An extended version of the model was developed to illustrate the effectiveness of each coping approach.

7. Submission of the preliminary model to peers for critical comment. The consensus group consulted two seminar groups of nurse researchers and doctoral students in order to validate the findings. The consensus group had renamed the concept of “recycling feelings” “chewing”, because recycling had a positive connotation, which did not reflect the findings in this study. However, as a result of the first seminar, the concept of chewing was finally labelled “preoccupying” as the former label failed to fully cover the meaning of the concept.
Qualitative content analysis (Addition)

The Addition to study IV was developed for the purpose of the thesis and aimed at describing what relatives experienced as supportive during the patient’s recovery at home. Together with study IV, the Addition made it possible to present a description of what relatives considered supportive during the entire trajectory of the patient’s illness and recovery. In the Addition, qualitative content analysis in line with the steps proposed by Graneheim and Lundman (2004) was used to reveal the manifest content. However, the method required the use of the existing databank employed in study II (coping during recovery), as well as the application of the concepts generated in study IV (what is experienced as supportive during ICU stay) as a theoretical frame. Thus, the Addition was a secondary analysis with a deductive design. The databank from study II contained dialogues on the subject of the relatives’ coping during the patient’s recovery at home, which led to discussions about “what was experienced as supportive during the recovery at home?” These experiences were either directly expressed using the word “support” or indirectly by the mention of positive or negative experiences that clearly indicated whether the situation was easy or difficult. The 14 informants were those who participated in study II.

Questions to be answered during the analysis:
1. Can the supportive dimensions pertaining to the ICU stay and generated in study IV be used for the recovery period?
2. Is it possible to use some of the components that are included in these dimensions or is it necessary to make omissions or additions?

The following steps were used in the analysis.
1. The interviews were read through to obtain a sense of the whole.
2. The text about “what is supportive for relatives during the patient’s recovery at home” was extracted and combined into one text, which constituted the unit of analysis.
3. The text was divided into meaning units, which were then condensed.
4. The condensed meaning units were “passed through” or compared to the theoretical frame.
   The procedure revealed that all condensed meaning units were covered by all of the supportive dimensions generated in study IV.
   It was also revealed that only some of the condensed meaning units were covered by existing dimension components.
5. Further analysis was required for the condensed meaning units that were not specifically covered by any existing dimension component. These condensed meaning units were abstracted and labelled with a code. The various codes were compared in terms of differences and similarities and grouped into “component of the dimension” (status = category) and “characteristics of the component” (status = sub-category) and finally placed under one of the existing dimensions.
**Ethical considerations**

The studies presented in this thesis were performed in accordance with the Helsinki declaration and approved by the head physicians of the hospitals involved and the Ethics Committee of the Medical Faculty, Lund University, Sweden (LU 109-99, LU 274-01).

The relatives of the critically ill patients were contacted and given information about the aim of the study, the procedures and ethical issues involved. If the relatives agreed to take part in the study, they were provided with an information sheet that restated the aim of the study, the right to abstain or to withdraw during the interview without the need to give a reason. The prospective respondents were also informed that the interview would be audio taped and that the collected data would be treated confidentially. After some days — at least four days after the patients’ discharge from the ICU in study I and three months after discharge to the home in study II — the relatives were contacted by the main researcher and asked if they still wished to take part in the study. At this stage the relatives were informed about the personal and emotional nature of the interview and once again informed about their right to withdraw at any time without giving a reason. However, before asking them if they would be willing to participate in the study, the main researcher spoke to the relatives and enquired how they were getting on. If the researcher was of the opinion that they were too emotionally unstable to take part in the interview at that stage, she instead asked them about the possibility of contacting them again in several weeks time. At the time of the interview, all information was repeated, and after ensuring that the relatives understood it, the main researcher obtained their informed and written consent. During an interview, memories and feelings about the patient’s life-threatening situation may resurface. In such a situation it would be important to slow the interview down, talk gently, listen and wait, or perhaps gradually bring the interview to a close. Contact with the social worker from the respective clinical departments was established at the beginning of the research project in order to offer emotional and social support if necessary.
FINDINGS

Coping approaches of relatives during the patient’s ICU stay (Study I)

A theoretical model describing the main characteristics and components of the relatives’ coping approaches during the ICU period was developed. The findings underline the fact that the relatives tried to make their situation more bearable but that their ways of coping differed with regard to the individual’s internal and external resources. Four coping approaches with different characteristics were generated: the relatives were alleviating, recycling, mastering or excluding their feelings. Those relatives who alleviated or recycled feelings coped with their situation in an emotional way, while those who mastered or excluded feelings coped in an intellectual way. Factors such as social circumstances, previous experiences of care and/or caring and how the situation was apprehended predicted their chosen method of coping. Fig. 2 shows the interrelationships between the different coping approaches, as well as how the distance between their different characteristics can vary, depending on the position of the relatives in the quadrant.

**Figure 2.** Interrelationships between the coping approaches of relatives during the patient’s ICU stay.
Alleviating

The relatives who adopted this coping approach found it easier to deal with the situation by alleviating their overwhelming feelings. This approach was modulated as the patient gradually recovered. The characteristics of this coping approach were the relatives’ use of distraction, communication and verbalisation. Among the components of distraction was the refusal to face the seriousness of the patient’s illness as well as isolation and suppression of their own feelings in order to avoid collapse. Other components of this approach were the relatives’ desire to find activities that diverted their minds or helped them to regain their composure. Communication with family, friends, nurses and God eased the relatives’ feelings and introduced new perspectives. When they verbalised their own thoughts and sorrows, they could hear themselves describing their circumstances, which helped them see their situation more clearly. The relatives who adopted this coping approach were embedded in a solid family relationship and had a strong social network of family and friends who supported them, and this sense of community provided them with solace, security and confirmation.

Recycling

The characteristics of this coping approach were that the relatives were occupied by continuously pondering over their situation and feelings, which they claimed helped them to come to terms with the situation. In order to cope, the relatives put themselves in the patient’s place. Their feelings were strengthened by memories of previous social tragedies. In their present situation, the relatives particularly experienced aggressive and depressive moods. The relatives who adopted this coping approach had no strong social environment on which they could rely, and they also lacked the experience of family security and social support. Because of the overwhelming feelings that surfaced when talking about their situation, the relatives rejected this kind of support from friends and professionals, for fear of draining themselves of energy. As a substitute for communication with others, the relatives talked to themselves about their situation.

Mastering

This coping approach was characterised by relatives who were conscious of their experiences and emotional reactions, capacity and needs. In order to have sufficient strength to manage the whole trajectory of illness and recovery, these relatives planned how to combine work, hospital visits, relaxation and stimulation. The relatives who adopted this coping approach had solid family relationships and a strong social network and had experienced care in critical situations before, either as a relative or a professional in an ICU care team.
Excluding

The relatives representing this coping approach were those of patients who were cared for in the coronary ICU and who were conscious and lucid during the ICU stay. As soon as the patient arrived at the hospital, the relatives became confident that he/she would recover. This feeling was partly due to the patient’s ability to deal with the situation. These relatives reported that they felt and acted calmly, were realistic about the situation and stated that they usually excluded emotions. However, they later revealed that it was difficult to grasp the seriousness of the situation. Their everyday life was almost normal during the patient’s coronary care; in a way they were merely witnessing what was happening. The relatives who adopted this coping approach had no need for social support, although they informed family and friends about the situation as a matter of course.
Coping approaches of relatives during the patient’s recovery at home (Study II)

A theoretical model describing the main characteristics of the relatives’ coping approaches during the patient’s recovery period at home was developed. The findings indicate that the relatives considered their personal circumstances as well those of the patient when coping with their situation, although their approaches differed in accordance with the individual’s personal situation as well as that of the patient. Four coping approaches showing different characteristics were generated: accepting, volunteering, sacrificing and modulating. Those relatives who employed accepting or volunteering coped with their situation by being directed towards the patient, while those who adopted sacrificing or modulating coped with their situation by being directed towards themselves, that is wishing to pay more attention to their own needs instead of those of the patient. Factors such as the physical and psychological status of the relatives, previous experiences of care and/or caring and the psychological status of the patient were predictors of the chosen way of coping. The relatives who participated cared for patients who suffered to a greater or lesser degree from a functional impairment due to the after-effects of critical illness, and as a result, the everyday care provided by the relatives differed according to the patient’s needs. Fig. 3 shows the interrelationships between the different coping approaches of the relatives, as well as how the distance between the characteristics varied, depending on their position in the quadrant.
### Figure 3.

Interrelationships between coping approaches of the relatives during the former critically ill patient’s recovery at home.

<table>
<thead>
<tr>
<th>CHARACTERISTICS OF THE RELATIVES</th>
<th>CHARACTERISTICS OF THE COPING SITUATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directed towards the patient</td>
<td>The patient was dependent on the relative</td>
</tr>
<tr>
<td>Directed towards oneself</td>
<td>Accepting the situation</td>
</tr>
<tr>
<td></td>
<td>Sacrificing oneself for the situation</td>
</tr>
</tbody>
</table>

#### Accepting

This coping approach was characterised by patients who were emotionally dependent on the relative’s constant presence during the recovery period at home. The patients’ mental health had suffered to a greater or lesser degree due to the critical illness and ICU stay, and they exhibited psychological states of vulnerability, regression and acute confusion. The relatives accepted the burden of the caring situation, despite their awareness of what the situation meant in terms of less time for relaxation or recreational activities. These relatives did not hesitate, as they felt responsible for the well-being of the patient and reasoned that the situation would improve over time. The main aspect of caring was to provide the patient with security and support. However, everyday caring duties were also involved, unless these tasks had been left to the community care. For their own part, the relatives received sporadic support of an emotional and/or practical kind from family, relatives and/or friends. The relatives who adopted this coping approach exhausted their physical and mental reserves, due to the fact that they experienced the situation as extremely trying.
Volunteering

The relatives who adopted the volunteering approach found it natural and a matter of course that they should take part in caring for the patient. They did not take their own needs or physical and mental well-being into account. The relatives’ approach was based on the belief that the patient would regain a normal level of functioning. The commitment to the patient was, however, limited by their socio-economic situation. The relatives’ coping approaches were further characterised by a patient who was not emotionally dependent on being cared for by a particular relative. Volunteering was represented by two different caring situations: in the first the patient resided in the same house as the relative and, in the second, he/she lived alone. In the case where the patient lived together with the relative, the latter took full responsibility for the care during the day and at night. If the patient was functionally impaired, caring entailed a huge amount of physical effort, but also a mental strain in the form of worry and anxiety, as they had no previous experience of such a situation. These relatives received sporadic support of an emotional and/or practical nature from their relatives and/or friends. In the latter case, where the patient lived alone, the community took direct responsibility for the care, but the relatives assumed overall responsibility in order to be in control. The relatives’ commitment included observing and supporting the patient, as well as organising the care. These relatives received a great deal of emotional and practical support from their family and relatives, but due to the fact that they lived some distance from the patient, they had little control over the situation. The mental strain resulted in psychosomatic symptoms.

Sacrificing

The characteristics of the relatives who adopted this coping approach were their need and wish to participate in recreational activities in order to maintain their own mental and physical well-being. This coping approach was characterised by the patient being emotionally dependent on the relative’s constant presence during the recovery period at home. The mental health of the patient had been damaged to a greater or lesser degree due to the critical illness and the ICU stay, resulting in a psychological state of vulnerability, regression, acute confusion and anxiety/psychosis. Despite the relatives’ need for relaxation and time of their own, they chose to sacrifice themselves, as they really wanted to help the patient and felt responsible for his/her well-being. The main caring efforts of the relatives involved being available for a greater or lesser part of every 24-h period in order to provide the patient with security, support and the opportunity to talk about his/her critical illness and memories of the ICU. These relatives were also involved in the patient’s everyday care unless these tasks had been handed over to the community care. The relatives received sporadic support of an emotional and/or practical nature from family and relatives. The relatives who adopted this coping approach perceived their situation as a great strain, mainly due to having undergone intense physical and mental suffering during the patient’s ICU stay. The relatives were physically and emotionally exhausted and, as a consequence, exhibited a
depressed psychological state as well as aggressive moods. In reality, the relatives themselves were in need of relaxation in order to regain their strength.

**Modulating**

The relatives who employed modulation acknowledged their own need for recreational activity in order to regain sufficient strength to meet the patient’s care needs after their experience of reduced physical and mental strength as a result of the patient’s ICU stay. They had a genuine desire to help the patient and did so to a great extent, although they limited their own participation and handed over some of the responsibility to the community care. These relatives could go to work or take a break in order to relax or engage in recreational activities, secure in the knowledge that the community was providing the necessary care. This coping approach was further characterised by patients who were not emotionally dependent on being cared for by a particular relative. The relatives received emotional and/or practical support from family, relatives and friends. A key aspect of this approach was that the relatives had previous experience of care in critical situations, either as a relative or a professional team member in an ICU or were currently experiencing ongoing, long-term ICU care of the patient, which made them realise the importance of acknowledging their own limitations.

**Model of relatives’ coping approaches during the patient’s ICU stay and recovery period at home (Study III)**

**The coping model**

Study III developed a model of the coping approaches used by relatives of mechanically ventilated patients during the ICU stay (I) and recovery at home (II) (Fig. 4). The model is a matrix structure that includes all coping approaches and their distinguishing characteristics in the form of antecedents, enablers, attributes and outcomes, as well as their underlying factors. This model provides an overall perspective of the similarities and differences between the different coping approaches. Each refined coping concept was also given a summarising definition based on the knowledge obtained through the SCA method (see paper III). The coping model leads to a structured understanding of the characteristics of each coping approach adopted by the relatives during the critical care period and the recovery period at home.
ANTECEDENTS

M = Mental state of the relative
P = Patient's condition

ENABLERS

E = External resources
I = Internal resources

ATTRIBUTES

C = Cognition
Em = Emotion

OUTCOMES

Ph = Physical condition
Ps = Psychological condition

Mastering

Assertiveness (C)
Economising on resources (C)
Flexibility (C)
Planning (C)

Control (Ps)
Confidence (Ps)
Maturity (Ps)

Alleviating

Distraction (Em)
Communication (C)
Verbalisation (C)
Creation of hope (C)

Physical weariness (Ph)
Mental weariness (Ps)
Confirmation (Ps)
Security (Ps)
Solace (Ps)
Maturation (Ps)

Volunteering

Willingness (Em)
Offering (Em)
Unawareness (Em)

Varying well-being
Worries (Ps)
Overlooking own needs (Ps)
Costly satisfaction (Ps)
Figure 4. The coping model describing the characteristics of each coping concept adopted by the relatives of critically ill patients. Commonalities across concepts are in the form of factors (shown in italics).
Theoretical foundations of the coping model

When analysing the relationship between the various coping approaches, differences in adaptation to the stressful situation of being the relative of a patient during the ICU stay and the recovery period at home were revealed. The more the relatives adapted to the situation, the more they experienced a balanced state of mind and well-being. The effectiveness of coping in terms of adaptation was defined in the following way:

- Coping is adaptive when the individual’s way of managing the situation is effective — that is, when the coping approach brings relief to the individual.
- Coping is maladaptive when the individual’s way of managing the situation is ineffective — that is, when the coping approach makes the individual’s situation even more difficult.

In the analysis, specific factors determined the effectiveness of the relatives’ coping approaches. Highly effective coping and less effective coping were defined as follows:

- Highly effective coping was associated with a strong experience of social support, buffering caring/care experiences and the use of other available internal and external resources.
- Less effective coping was associated with a weak experience of social support, lack of buffering experiences, lack of physical/mental strength and lack of other internal and external resources.

Relatives considered that emotional support was the most appropriate form of social support during the patient’s stay in the ICU, and that emotional and practical support were desirable during the patient’s recovery period at home.

These findings are presented in the extended version of the coping model, which shows the different coping approaches in graphic form (Fig. 5). In the model, the horizontal axis shows maladaptive to adaptive coping (involving the use of both internal and external resources), while the vertical axis shows the experience of social support from weak to strong. This dual dimension shows the relationship between the different coping approaches and the experienced social support, as well as visualising the effectiveness of each coping approach in relation to the others via their relative position in the model. The coping approach of mastering involves a high degree of mature coping and represents adaptive coping and strong social support. The coping approach of preoccupying is on the opposite point of the horizontal axis and involves immature and maladaptive coping as well as weak social support. The relatives’ coping approaches of alleviating, volunteering, acquiescing and sacrificing are situated between mastering and preoccupying and represent a decreasing degree of a balanced state of mind and well-being.
Figure 5. The extended version of the coping model describing the effectiveness of the coping approaches used by relatives of critically ill patients.
What is supportive for relatives during the trajectory of the patient’s illness and recovery (Study IV, Addition)

What is supportive for relatives during the patient’s ICU stay (Study IV)

A theoretical understanding of the phenomenon of what relatives experience as supportive was developed. Support was experienced as empowerment by means of internal and external resources in the form of: trusting oneself, encountering charity and encountering professionalism. The sense of empowerment permitted the relatives to experience their situation as safer and easier to control. The three support dimensions with their components and characteristics are illustrated in the empowerment model (Fig. 6). The model also includes the additional recovery component “encountering far-sighted care” under the dimension of encountering professionalism. This additional component was found in the Addition pertaining to the recovery period, the findings of which will be presented under the next heading.

- The dimension of trusting oneself includes the component “acknowledging own coping ability”. This dimension revealed how the relatives found it supportive to trust in their own coping ability when dealing with a situation. They selected their coping approach in the hope of being better able to handle the situation and considered their way of coping beneficial and the only alternative.

- The dimension encountering charity includes the components “being accepted as I am” and “meeting people who care about me” and revealed how the relatives valued being accepted by others as they were, receiving understanding and acknowledgement for the way in which they coped with the situation, as well as meeting others who cared about them and who exhibited a caring attitude and sometimes also an interest in discussing their experiences with them.

- The dimension encountering professionalism includes the components “being given an opportunity to participate”, “encountering security” and “being given an opportunity for emotional and social guidance”. This dimension revealed how the relatives found it supportive when ICU staff allowed them to build up a sense of control over their situation. The component “being given an opportunity to participate” includes the characteristics “being invited to be with the patient” and “being invited to share information and thoughts about the patient’s condition”. Encountering a genuine invitation to be present at the patient’s bedside — having the possibility to be with the patient in order to provide support and personally witness the care and treatment — and encouraged to share information and thoughts about the patient’s condition were described as extremely supportive and provided the relatives with a feeling of participation, especially if it also was the general policy of the ICU. The component “encountering security” includes the characteristics “experiencing responsibility for the care of the patient”, “experiencing commitment to the care of the patient”, “experiencing the best possible care” and “experiencing high quality care”. This dimension revealed how the relatives found it supportive when the healthcare professionals provided high quality care and exhibited their commitment to and responsibility for the patient. They also found it supportive when the professionals expressed that the patient was receiving the best possible care. The component “being
given an opportunity for emotional and social guidance” was described as supportive when such guidance was given spontaneously and as a natural part of ICU care, and emotional guidance was especially supportive when provided at a time considered appropriate by the relatives themselves.

What is supportive for relatives during the patient’s recovery at home (Addition)

The dimensions generated in study IV — trusting oneself, encountering charity and encountering professionalism representing what is supportive during the patient’s ICU stay — were revealed by the Addition as suitable for the recovery period at home. The components included in the various dimensions did not completely cover what was revealed to be supportive during the recovery period; components/characteristics that were not typical of the recovery period had to be omitted and newly identified component/characteristics of the recovery period added. The components “being accepted as I am” and “being given an opportunity to participate” were not relevant to the recovery period. However, as it proved possible to develop a model highlighting what is supportive for relatives during the whole course of the patient’s illness and recovery, such omissions were unnecessary, and additions were only required for the presentation of the model.

The additional component to those generated in study IV was: “encountering far-sighted care” — which was included under the dimension encountering professionalism. This component, in turn, includes the following characteristics: “experiencing planning for transitions in the caring process, taking account of the needs of both patient and relative”, “experiencing a co-operative attitude to the patient’s care”, “experiencing a holistic view of the needs of the patient”, “experiencing that professionals can understand the need for support when the situation has calmed down, even during the recovery period”, “being given an opportunity to get to know the healthcare professionals” and “encountering an accessible care system, such as access to healthcare professionals during the patient’s recovery period”. The additional component revealed that it was supportive for the relatives to experience an unbroken chain of care and care planning encompassing the whole course of the patient’s illness and recovery. This means that the healthcare professionals in charge of the patient’s care should be responsible for the whole caring process; a component that touches upon the need for experiencing security in the care of the patient, which in turn may reduce the burden on the relatives. The relatives also found it supportive to experience that professionals understood that emotional guidance may be necessary after a long period of caring for the patient in the home.

Thus, the additional component together with the dimensions, components and characteristics generated in study IV revealed what the relatives experienced as supportive during the entire course of the patient’s illness and recovery, all of which are presented in the empowerment model (Fig. 6). It should be noted that this model only represents relatives of critically ill patients who received mechanical ventilation due to the fact that the Addition only encompasses relatives of mechanically ventilated patients.
<table>
<thead>
<tr>
<th>Trusting oneself</th>
<th>Encountering charity</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Acknowledging own coping ability</td>
<td>• Being accepted as I am</td>
</tr>
<tr>
<td></td>
<td>• Meeting people who care about me</td>
</tr>
</tbody>
</table>

**Encountering professionalism**

- **Being given an opportunity to participate:**
  - Being invited to be with the patient; in order to provide support and personally witness the care and treatment
  - Being invited to share information and thoughts about the patient’s condition
- **Encountering security:**
  - Experiencing responsibility for the care of the patient
  - Experiencing commitment to the care of the patient
  - Experiencing the best possible care
  - Experiencing high quality care
- **Being given an opportunity for emotional and social guidance:**
  - Experiencing the guidance provided as a natural and maintaining part of the care
- **Encountering far-sighted care**
  - Experiencing planning for transitions in the caring process; taking account of the needs of both patient and relative
  - Experiencing a co-operative attitude to the patient’s care
  - Experiencing a holistic view of the needs of the patient
  - Experiencing that professionals can understand the need for support when the situation has calmed down, even during the recovery period
  - Being given an opportunity to get to know the healthcare professionals
  - Encountering an accessible care system, such as access to healthcare professionals during the patient’s recovery period

**Figure 6.** The empowerment model describing what relatives of critically ill patients experience as supportive during the ICU stay and recovery period at home.
DISCUSSION

Methodological aspects

The qualitative approach employed in studies I and II made it possible to enter into the world of a relative of a critically ill ICU patient who is subsequently cared for in the home. The relatives related their own personal experiences of these two periods. They were able to describe their vulnerable state of mind without embellishing their narratives, which indicates that the interviews contained rich and realistic descriptions of their situation. Studies I and II, which were carried out first, formed the basis for the rest of the studies; study III developed both the coping model and the extended version of the coping model from the generated coping concepts, while in study IV and its Addition, the empowerment model describing what is supportive during the patient’s ICU stay and recovery period at home was developed from the original empirical data. Despite a total of only 32 interviews, there was no need to search for additional data when conducting study IV and its Addition, as the original interviews were sufficient. However, one cannot state that there are no new data left to find. These secondary analyses of existing data/findings could be considered an effective way of performing such studies, as well as showing respect for what the relatives contributed in the original interviews. The secondary analysis approach has not been widely used in relation to qualitative data, but limited opportunities for conducting primary research and the cost of qualitative work have prompted researchers to consider maximising the use of available data (Heaton 1998).

The grounded theories generated in studies I, II and IV were developed with a level of abstraction that was neither too broad nor too narrow, i.e. one that is applicable in clinical practice. In social science, such theories are known as substantive theories because of their function, which is to describe human beings in specific situations (Glaser & Strauss 1967, Strauss & Corbin 1998). Substantive theories can be more or less general in nature, that is, they can express human situations in more or less general terms (Glaser & Strauss 1967). As the theories in the present studies were generated from a small number of relatives residing in the southwest of Sweden, they are only representative of the population from which they were derived. However, the aim of the theories generated in these studies is to explain the phenomena of interest, rather than to describe relatives in general terms (Strauss & Corbin 1998). In future research it may be possible to “build in the variation or include the broad propositions of a more general theory” (Strauss & Corbin 1998, p. 267), and as long as the findings are not contradicted by new studies, the grounded theory will be alive (Strauss & Corbin 1998).

In Study III, the aim of which was to develop supportive interventions for relatives based on the coping concepts generated in studies I and II and taking the whole period of the patient’s illness and recovery into account, it was important to have the coping concepts of both periods clarified simultaneously by means of concept analysis and placed in a combined model, the coping model. The intention was not to change the level of abstraction of the concepts, but to combine them into the same model; a model
which categorises and describes the antecedents, enablers, attributes and outcomes. As a result of the clarification process, some coping concept labels were changed to more appropriate ones after due consideration of the content, and characteristic elements that were verified in the empirical data were also added. The new labels could have been determined in studies I and II, which is a weakness. The concepts were improved thanks to the experience and knowledge of the consensus group and the procedures advocated by the SCA method. The coping model developed in study III includes several concepts, some pertaining to the ICU period and others to the recovery period at home, while the mastering concept covers both the ICU and the recovery period. When in a position of supporting relatives, it would be valuable to have access to coping concepts that describe the relatives’ coping approaches during the whole course of the patient’s illness and recovery. However, if this were to become reality, it is highly likely that the coping concepts generated would produce too abstract a description of the phenomenon to be useful in clinical practice, due to the fact that all variations in the experiences of the patients and relatives must be considered.

When discussing the trustworthiness of these studies, the findings may be biased due to pre-understanding resulting from the researchers’ experience of critical care as well from their knowledge of Lazarus’ stress and coping theory (Lazarus & Folkman 1984). However, the researchers maintained an awareness of the risks in order to minimise bias in the findings. At the same time, the researchers consider their experience as beneficial for their theoretical sensitivity to the area under study, both when conducting the interviews and analysing the data (Strauss & Corbin 1990, 1998). These two aspects relate to trustworthiness, which in this case refers to the concordance between the experiences of the relatives and the findings (Fridlund & Hildingh 2000). The researchers’ experience of qualitative methods and the accuracy inherent in them are also important aspects of trustworthiness (Fridlund & Hildingh 2000). In the three grounded theory studies (I, II, IV) and in the SCA study (III), these aspects were deemed to be adequately addressed. With regard to the rigour of the grounded theory method, it should be emphasised that Glaser and Strauss developed this method after which their collaboration ceased (Glaser & Strauss 1967). The grounded theory methodology of Strauss and Corbin (1990, 1998) was used in studies I, II and IV, which methodology has been criticised for its theory generation procedures. Glaser holds that the paradigm model in the axial coding presented by Strauss and Corbin forces the data into a theory, which means that the researchers’ own prejudices are incorporated (Glaser 1992). However, Strauss and Corbin (1998, p. 13) argue that “these procedures were designed not to be followed dogmatically but rather to be used creatively and flexibly by researchers as they deem appropriate”. The procedures are thus considered as a guide for researchers in order to endow the process with some standardisation and rigour. It is not an easy task to reproduce the findings of these grounded theory studies (Strauss & Corbin 1998). The original social circumstances must be included, as well the experience and personality of the researchers. Thus, given the same conditions, other researchers would reproduce a theoretical explanation that is very similar to the original (Strauss & Corbin 1998).
Aspects of the findings

The findings revealed eight different coping approaches used by relatives of critically ill patients. Four coping approaches represent the relatives’ strategies during the patients’ ICU period, while the other four are associated with the patients’ recovery period at home. During the ICU period, the relatives coped with strong emotions as a result of the patient’s life-threatening situation, while during the recovery period at home the relatives had to cope with caring for the patient. When comparing the determinants of the different coping approaches by means of the coping model, it was revealed that the degree of adaptation differed for each coping approach. It was proposed that the coping approaches are situated along a maladaptive-adaptive coping continuum, which represents a low to high degree of effectiveness in the relatives’ way of coping with their situation. The findings are illustrated in the extended version of the coping model.

The relatives’ way of apprehending the situation determined their perception of the ICU period. All relatives of mechanically ventilated patients found their situation overwhelming, but relatives of coronary care patients where no mechanical ventilation was required reported that they did not experience strong emotions when the patient was safe in hospital, due to the fact that the coronary patients were conscious, communicable and could deal with the situation, thus the coping approach of these relatives was that of excluding feelings. As a result, it was decided to only include relatives of mechanically ventilated patients in studies II and III.

Social circumstances were found to be critical for the relatives’ way of coping with their situation during the ICU period. Those relatives with favourable social circumstances and continuity of supportive relationships used an effective way of coping, which took the form of moderating. This group included relatives who alleviated their feelings, using distraction as a means of coping with the situation. Others in the same group mastered their feelings, using the most effective (adaptive) way of coping, which took the form of balancing their own capacity and needs against the demands of the situation, something they had learned from previous caring/care experiences. However, relatives who had unfavourable social circumstances and had experienced discontinuity of supportive relationships as well as previous traumatic social experiences had difficulty adapting to the situation. These relatives employed a less effective (maladaptive) way of coping; they recycled their feelings (renamed preoccupying in study III), which means that they were preoccupied with constantly reflecting on their situation. The recycling and mastering coping approaches represent the respective end-points of the maladaptive-adaptive coping continuum, extreme approaches that are similar to the opposite poles of victim or victor described by White (1995).

The relatives encountered a more concrete and comprehensible situation during the patient’s recovery period at home. The psychological condition of the patient was a predictor of the approach used by the relatives. Relatives of patients who were not emotionally dependent on their constant presence were able to use an effective way of coping. Some used the modulating approach (renamed mastering in study III), which was very similar to the approach of mastering feelings adopted during the ICU period.
Other relatives in this group adopted the volunteering approach and willingly participated in the care without considering their own needs or well-being. On the other hand, relatives of a patient who was emotionally dependent on their constant presence experienced a great burden, which resulted in ineffective coping. In this group, some relatives adopted the approach of accepting (renamed acquiescing in study III), which means that, due to social obligations, they did not hesitate to accept their situation, in spite of the fact that they experienced it as inescapable and were aware that they had to put their own mental and physical well-being at risk in order to care for the patient. Other relatives in this group adopted the approach of sacrificing themselves. These relatives had undergone great suffering during the ICU period and subsequently experienced a conflict of interest between their own need for relaxation and the patient’s need of care and attention during the recovery period. The coping approach of sacrificing has a poorer effectiveness than that of accepting the situation. Caring for a physically impaired patient appears to be an easier situation to cope with than emotional dependency. These findings are in agreement with Kausar and Powell (1996), who revealed that a patient’s psychological problems such as behavioural and emotional disturbances contributed to a greater burden for caregivers than physical problems.

As shown above, social circumstances were a critical factor for the relatives’ choice of coping approach during the ICU period and made the difference between effective and ineffective coping. During the recovery period, the critical factor for effective or ineffective coping was the patient’s psychological state at discharge. However, when comparing the effectiveness of the coping approaches adopted during both the ICU period and the recovery period, an association was found between coping effectiveness, social support and health outcome. The association between coping effectiveness and social support is illustrated in the extended version of the coping model. The association between coping and support is in line with Cobb (1976), who suggested that social support facilitates coping in crisis situations and that moderating the impact of the crisis should lead to a positive outcome. Moreover, the research literature provides evidence of the relationship between social support and beneficial effects on mental and physical health-related variables (Cohen and Wills 1985, Krumholz et al. 1998, Preyde & Ardal 2003).

The need to support relatives in their difficult situation was reported by the relatives themselves, who recognised the importance of empowerment as a means of acknowledging their own coping ability and regaining trust in themselves as well as control over their situation. Empowerment is a concept that originates in community psychology and that has evolved from client organisations and self help groups (Rappaport 1981). It is viewed as a process in which individuals strive to gain mastery over their lives, although to date, there is no consensus with regard to a definition of the concept (Hansson & Björkmann 2005). Having reviewed several approaches to empowerment, Hansson and Björkmann (2005) suggest that the concept can be defined by the following: 1) the psychological dimension that is related to self-esteem, self-trust and self-efficacy; 2) the social action-oriented dimension related to power, involvement and control over one’s own situation. Empowerment is the concept that emphasises the phenomenon of what relatives experience as supportive during the ICU period and
subsequent recovery at home, which is in strong agreement with the conclusions of Hansson and Björkman (2005). The empowerment model included in the thesis reveals that it is empowering to have both internal and external support, in the form of trusting oneself and encountering charity and professionalism. Trusting in oneself and encountering charity enhance the sense of control, and the same can be said for encountering professionalism. The latter implies being encouraged to participate in the caring process, encountering a sense of security, being given an opportunity for emotional and social guidance, and not least experiencing an unbroken chain of care and care planning that encompasses the whole course of the patient’s illness and recovery. The importance of external support is confirmed by the nursing research literature (Zazpe et al. 1997, Leith 1999, De Jong & Beatty 2000, Van Horn & Tesh 2000, Johnson et al. 2001).

The relatives received considerably more support when the patient was in a life-threatening situation in the ICU than during the recovery period at home. Perhaps the relatives and the patients prefer to manage the situation at home by themselves or perhaps friends and family members believe that once the danger has “blown over”, there is no need for further support. Whatever the reason, it is most important that healthcare professionals explain about and convince relatives of the continued need for support during the recovery period at home, as it is during this time that their strength may be further depleted and health damaged (Dew et al. 1998, O’Farrell et al. 2000, Jones et al. 2004). It is especially important to establish good and long-term support for those relatives who recycle their feelings during the ICU period, who have unfavourable social circumstances and poor social support, as they lack the strength to establish a network that provides sufficient security for them to accept social support. People who are socially competent are more likely to develop strong support networks and remain healthy by coping effectively with stressful situations (Cohen & Wills 1985, Stewart 1993, Langford et al. 1997).

The studies have contributed knowledge that provides healthcare professionals with an enhanced understanding of the coping approaches and social support experiences of relatives during the patient’s critical illness and recovery. The association revealed between coping effectiveness, social support and health outcomes may open the eyes of healthcare professionals to the relatives’ situation as well as to the possibility of enabling relatives to endure the patient’s entire illness and recovery period by enhancing the factors that promote effective coping.
Implications

Deeper knowledge has been gained about relatives’ coping approaches and social support experiences during the patient’s periods of illness and recovery. The main contribution of this knowledge is the association between the effectiveness of coping, social support and health outcomes, which indicates the need to support the coping approaches of relatives. The developed models and their usefulness in terms of supporting relatives of critically ill patients are described in the following.

A. The coping model (III) provides healthcare professionals with an understanding of the distinctive features and outcomes of the coping approaches of relatives of critically ill patients, thus making it possible to identify and predict which approach a relative has adopted or will use in the future. This will facilitate the prediction of health outcomes and the planning of support interventions (Fig. 4).

B. The extended version of the coping model (III) provides healthcare professionals with a model that visualises and compares the effectiveness of the different coping approaches in relation to social support (Fig. 5).

C. The empowerment model (IV, Addition) provides healthcare professionals with an understanding of what relatives experienced as supportive during the ICU stay and recovery period at home, thus making it possible to identify the type of support that would empower the relatives to cope with the situation (Fig. 6).

In the future, these three models may form the basis for the development of a support programme for relatives of critically ill patients. The fact that they encompass the whole course of the patient’s illness and recovery implies that input from both institutional and community based care is necessary. The process will include several steps and should begin with an educational programme in which healthcare professionals discuss the background, content and possibilities of the models and how to use them to support relatives of critically ill patients.
CONCLUSIONS

- During the patients' ICU stay, the relatives coped with their situation by alleviating, recycling, mastering or excluding feelings. Social circumstances, previous caring/care experience and how the situation was apprehended determined the choice of coping approach.
- During the patients' recovery at home, the relatives coped with their situation by accepting, volunteering, sacrificing or modulating. The physical and psychological status of the relatives, previous caring/care experience and the psychological status of the patient determined the choice of coping approach.
- Coping approaches of relatives, during both the ICU and the recovery period revealed different degrees of effectiveness, from maladaptive to adaptive, in terms of coping.
- A highly effective coping approach indicates strong social support, buffering caring/care experiences and the use of other internal and external resources.
- A less effective coping approach indicates weak social support, lack of buffering experiences, lack of physical/mental strength and a paucity of other internal and external resources.
- Empowerment was found to be the best means of supporting relatives of critically ill patients. Empowerment involves both internal and external resources and is characterised by three dimensions: trusting oneself, encountering charity and encountering professionalism.
ACKNOWLEDGEMENTS

I wish to express my warm and sincere gratitude to all those who have contributed to this thesis, without your great efforts, it would not have been completed. Special thanks to:

* All the relatives of the critically ill patients, who kindly participated in the studies and shared their experiences with me.
* Bengt Fridlund, Växjö University, and Cathrine Hildingh, Halmstad University, my supervisors, for your interest in critical care research and your outstanding scientific knowledge, careful guidance, for always being available and for your great kindness and encouragement. You are great!
* Gerd Ahlström, co-author, for sharing your great knowledge of coping and not least for making it possible for me to get a main thread into my studies. Many thanks for the creative and inspiring meetings with the consensus group in Örebro and Varberg.
* Stig Wenneberg, co-author, for your encouraging and future-oriented support and not least your resourcefulness in the consensus group.
* Anna-Christina Ek, Professor, for inviting me to your department and for sharing your deep scientific knowledge during seminars.
* Ole Olsson, Head of department, Halmstad University, for making it possible for me to begin my career as a doctoral student.
* Evy Lidell, for your enthusiastic introduction into the world of coping and support.
* Birgitta Neyman-Thulin, the Area Manager at my workplace in the Intensive Care Clinic, Helsingborg Hospital, for your great interest and enthusiasm in the care of relatives and for giving me the opportunity to combine my work with research.
* Eva Sarvell and Göte Karlsson, the social workers at Helsingborg Hospital, and Anna Brita Berling, Viktoria Kawesa and Anna Jakobsson, the social workers at the University Hospital of Lund, for your careful selection of informants for the studies. I would also like to express my thanks to Christina Simberg, head nurse at Helsingborg Hospital, and Anna Marie Lundgren, Cecilia Jerenäs, Gunilla Hillerström, Anki Ekman and Britt-Marie Körling, head nurses, at the University Hospital of Lund.
* Margareta Alm, Gerd Almquist Tangen, Kärtin Bolse, Inger Flemme, Ingalill Koinberg, Inger Wieslander and Kristina Ziegert for your great friendship and support during my years in the seminar group at the University of Halmstad, Lillemor Hallberg for valuable discussions and Åsa Axelsson for your great enthusiasm.
* All the helpful and friendly doctoral students and lecturers at the Division of Nursing Science, Linköping University, for sharing knowledge and interesting discussions as well as for your great interest and helpful comments during seminars.
* The nurse researchers and doctoral students at the University of Örebro, for your great interest and helpful comments during seminars.
* Anetth Granberg Axéll and Karin Samuelson, my friends and colleagues, for sharing your interest in critical care research, and Margereth Björklund, my friend, who introduced me to further studies at Halmstad University.
*Ann-Britt Fritiofson, secretary at Halmstad University, Eva Borg and Erika Lindén, former and present secretaries at Linköping University, for your kindness and helpfulness.
*The librarians at Helsingborg Hospital for skilful assistance over the years.
*Gullvi Nilsson and Monique Federsel, for your skilful revision of the language in my manuscripts and in this thesis.
*Bodil Ivarsson, my research friend, for your critical encouragement and faithful friendship.
*Rolf, my beloved husband and companion.
*My mother Wivi and in memory of my father Sven.

The studies were supported by grants from The Swedish Society of Nursing, the Florence Nightingale Foundation, Skane County Council’s Research and Development Foundation and the Department of Health Sciences, University of Örebro.
SUMMARY IN SWEDISH

Anhöriga kan uppleva en svår och krävande situation när en närstående blir kritiskt sjuk. Under tiden på intensivvårdsavdelning (IVA) kan anhöriga uppleva starka känslor av existentiell natur och situationen kan innebära förändringar i roller, ansvarstaganden och rutiner i vardagen som kan vara stressande. Denna upplevelse av emotionell stress kan resultera i en försvagad mental och fysisk funktion hos de anhöriga. Under patientens rehabilitering i hemmet förtvivlade anhöriga bidrag med vårdande uppgifter som praktisk assistans, övervakning och uppmuntran, ett ansvarstagande som ytterligare kan försvaga deras redan försvagade funktion.

Det övergripande syftet med avhandlingen var att utveckla en teoretisk förståelse av anhörigas sätt att hantera sin situation och av deras upplevelser av socialt stöd, både när deras närstående ligger på IVA och är i hemmet för rehabilitering. För att få fram en förståelse av dessa områden var det viktigt att söka kunskap med hjälp av kvalitativa metoder. De metoder som användes var grundad teori, simultan begreppsanalys och innehållsanalys. Totalt 32 anhöriga deltog i de fyra studierna.

Resultatet i studie I visade att anhöriga ”gav lättnad åt”, ”var fullt upptagna med”, ”mästrade” och ”exkluderade” sin känslostämning för att hantera sin situation medan deras närstående vårdades på IVA. Avgörande faktorer för deras val av sätt att hantera sin situation var socialt förhållande, tidigare erfarenhet av vårdande situation och hur man uppfattade sin situation. Studie II visade att anhöriga ”accepterade”, ”gav sig frivilligt in i”, ”offrade sig för” och ”modulerade” sin situation när patienten var i hemmet för rehabilitering. Faktorer som var avgörande för de anhörigas val var: deras fysiska och psykologiska status, tidigare erfarenhet av vårdande situation och patientens mentala status.

I studie III utvecklades en copingmodell (coping = hantering av sin situation) med hjälp av de copingbegrepp som tidigare utvecklats i studie I och II. Copingmodellen omfattar således både perioden på IVA och rehabiliteringen i hemmet. I denna copingmodell systematiserades det karakteristiska för varje copingbegrepp till olika determinanter i avsikt att belysa den inneboende processen i varje copingbegrepp. När copingbegreppen jämfördes med avseende på deras determinanter upptäcktes skillnader i anpassning till den stressande situationen. Anpassningen, uttryckt i effektivitet, var associerat till det upplevda sociala stödets och hälsokonsekvens. I den utvidgade versionen av copingmodellen illustreras effektivitetsgraden för varje copingbegrepp, både i relation till varandra och till upplevda socialt stöd.

I studie IV med Tillägg utvecklades en teoretisk förståelse av fenomenet av vad anhöriga upplevde vara stödjande under patientens vårdtid på IVA och rehabilitering i hemmet. Resultatet visade att anhöriga upplevde det som stödjande att ”bli bemyndigade” både i fråga om inre och yttre resurser att hantera sin situation. För att nå känslan av att ”bli bemyndigad” beskrev anhöriga behovet av ”att lita på sig själv”, ”att möta vänlighet” och ”att möta professionalitet”. På detta sätt upplevde de anhöriga sin situation som lättare, tryggare och med större kontroll. De tre stöddimensionerna med sina karakteristika är illustrerade i en modell för ”empowerment”. 
Dessa fyra studier har genererat kunskap som tillsammans kan ge hälso- och sjukvårdspersonal en förståelse av anhörigas sätt att hantera sin situation och av deras upplevelser av socialt stöd under patientens kritiska sjukdomstid på IVA och rehabilitering i hemmet. Associationen som visade sig mellan effektiviteten på anhörigas coping, socialt stöd och konsekvenserna för hälsan kan öppna upp ögonen för anhörigas situation, men även för möjligheterna att stödja dem genom att initiera förändringar i deras förutsättningar för att kunna klara av situationen. De tre modellerna som utvecklades kan tillsammans utgöra basen för framtagande av ett framtida stödprogram för anhöriga till kritiskt sjuka, omfattande hela patientens sjukdomsperiod och rehabilitering i hemmet, vilket skulle innebära att både den institutionella och kommunbaserade vården måste bli involverade.
REFERENCES


Kausar R. & Powell G.E. (1996) Subjective burden on carers of patients with neurological problems as a consequence of precise objective symptoms (objective burden). *Clinical Rehabilitation* 10(2), 159-165.


