

Memories and Health Related Quality of Life

-in patients with trauma cared for in the Intensive Care Unit

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To my family

ABSTRACT

Patients' experiences of hallucinations and nightmares during an intensive care unit stay (ICU) are well-known, but it is less known how these delusional memories (DM) affect patients after discharge from hospital following trauma. The overall aim of this thesis was therefore to acquire a comprehensive understanding of patient memories from the ICU-stay and their putative effects on outcome after physical trauma from a long and short-term perspective.

Both quantitative and qualitative methods have been used. In a multicenter study including five hospitals in the western part of Sweden, patients with the diagnosis of trauma admitted to the ICU during one year were included. In the first quantitative study, 239 adult patients answered a questionnaire about memories from the ICU and self-estimated health 0.5-1.5 years after the trauma. Patients of the same cohort (n=153) participated in a follow-up study after four years. Clinical data were obtained from medical records. Eighteen participants from the first study were included in a qualitative study and interviewed 2-3 years after the trauma. Questions about memories from the injury, hospital and ICU-stay and life after discharge from hospital were asked and analyzed by means of phenomenological hermeneutical analysis.

The results of the studies indicate that memories from the trauma and ICU-stay often were fragmentary and one out of four patients had DM. These patients were younger, more seriously injured, had more complications, were more often mechanically ventilated and sedated. They also remembered more feelings of pain, panic and fear and described more unexplained feelings of panic after discharge from the ICU. These patients also experienced lower health related quality of life (HRQoL) both from a long and short-term perspective after the trauma and ICU care compared to those of a reference sample. Patients who reported DM experienced lower HRQoL and also higher levels of anxiety and depression 0.5-1.5 years after trauma compared to patients without such memories. Four years after the first measurement, patients with DM still experienced anxiety and depression to a greater extent than patients without such memories. When comparing HRQoL over time, all patients had improved in half of the eight health domains. Patients with DM still differed from the other patients in all HRQoL domains, except for general health. About five years after injury, 75% of all patients had returned to work (RTW). Despite a poorer HRQoL, patients with DM had a comparable level of RTW. From the interviews emerged both good memories of care and gratitude for life and bad memories from a surrealistic world and an injured body. When these memories balance out, there are more possibilities to move on despite an uncertain future following the injury. Memories of being cared for and a gratitude for life seemed to make it easier to go on with life and meet this uncertain future.

The findings provide new insights regarding the impact of patients' memories after a physical trauma and ICU care on HRQoL, including the psychological well-being from both a long and a short-term perspective.

Keywords; trauma, injury, intensive care unit, delusional memories, health related quality of life, intensive care, anxiety, depression, return to work.

ORIGINAL PAPERS

This thesis is based on the following papers, referenced in the text by their roman numerals I - IV

- I. Ringdal M, Johansson L, Lundberg D, Bergbom I. Delusional memories from the intensive care unit – Experienced by patients with physical trauma *Intensive and Crit Care Nurs* 2006;22(6):346-354
- II. Ringdal M, Johansson L, Lundberg D, Plos K, Bergbom I. Outcome After Injury – Memories, Health-Related Quality of Life, Anxiety and Symptoms of Depression After Intensive Care *J Trauma* 2008 (*in press*)
- III. Ringdal M, Plos K, Bergbom I. Memories of being injured and patients' care trajectory after physical trauma *BMC Nursing* 2008, 7:8
- IV. Ringdal M, Plos K, Örténwall P, Bergbom I. Memories and health related quality of life, after intensive care – a follow-up study (*submitted*)

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ABBREVIATIONS

APACHE II	Acute physiological and chronic health evaluation
CAM-ICU	Confusion assessment method for the intensive care unit
DSM IV	Diagnostic and statistical manual of mental disorders
DM	Delusional memories
HAD	Hospital anxiety and depression scale
HRQoL	Health related quality of life
ICU	Intensive care unit
ICUM tool	Intensive care unit memory tool
KVITTRA	The Swedish trauma registry (Kvalitet i trauma)
PTSD	Post traumatic stress disorder
RTW	Return to work
SF-36	Short form 36
SOFA	Sequential organ failure assessment
SRSA	Swedish rescue service agency
ISS	Injury severity score
QoL	Quality of life
WHO	World health organization

INTRODUCTION

The focus of this thesis is patient memories and health related quality of life (HRQoL) after a trauma and care in the intensive care unit (ICU). A trauma which requires intensive care is often severe and the patient can have confusing and delusional memories (DM) from the ICU-stay or even experience amnesia (Gjengedal 1994; Jones, et al 2000a; Löf et al. 2006; Mendelson & Foley 1956). The overall goal for the care in the ICU, as well as in other health care settings, is that the patients should regain their health and their wellbeing and a satisfactory life with quality. It is also important for the individual to be a part of the social society and return to work (RTW) after the trauma. These goals are unfortunately not always achieved. Patients with trauma are noted to have a poorer HRQoL than other patients after an ICU-stay for the first year after the trauma (Ridley et al. 1997; Ridley & Wallace 1990). It is important to have both a long and short -term perspective regarding the effect of memories experienced by the patients while they are cared for in ICU, as these memories may affect HRQoL after the ICU-stay (Granja et al. 2005; Schelling et al. 1998). This perspective is necessary in order to improve the intensive care and thus being able to carry out optimal caring actions. Caring for these patients involves listening to, understanding and meeting patients who are living with the effects of critical illness, something which a part from the physical aspect also often includes a mental dimension due to different memories.

The impact of the critical condition can be apparent in the patients' lives post-discharge even if there is a lack of memories from the trauma or the critical illness (Adamson et al. 2004). The process of finding meaning in what has happened, and of understanding and living with fragmentary memories, is often a tough challenge for patients who suffer from a trauma. Case studies report that under these circumstances, life can be forever changed for the patients (Davidhizar 1997). After a trauma, people can have memories of losing control of the situation, feeling pain and being dependent on assistance of others which can be extremely stressful (Fredriksen & Ringsberg 2007). Patients who are cared for in the ICU may also have experiences from a life-threatening situation (Almerud et al. 2007).

From a philosophical point of view, memories are a person's history of life. They bring meaning to events and has influence on a person's present and future life (Gadamer 1989). When something happens that makes the individuals forget parts of their own history or leave them with memories that are bizarre or unbelievable, it may affect their every day life. This was also found by Storli et al. (2007) who describes how critical illness and critical care leaves the person with lingering memories. According to Richmond et al. (2000) memories in connection to a trauma are divided in two parts, before and after the injury. In this thesis the memories after the trauma were studied. Some patients have amnesia or fragmentary memories from the trauma and the time in the ICU, while others have DM (Gjengedal 1994). According to Jones et al (2000a; 2000b),

DM that occur during the ICU stay, are memories from paranoid experiences, hallucinations, nightmares or vivid dreams. A delusion is real to the patients and can have as a result in a precarious existence while the patient is in the ICU. In a case study the patient described, this as a feeling of being trapped in a twilight zone and existing in a dream-world (Bowers 2004). However, all of the patient's memories from injury event and the care in hospital are not necessarily negative. Memories from the relatives' presence are often positive (Granberg et al. 1999). Discomforting memories of being confused, not being able to differ between real and non-real events, as well as difficulties to remember, might be frightening and influence daily life. A relevant question is: Can positive experiences and memories from care events or activities counteract discomforting memories and promote the patients' health? According to McKinley et al. (2002) the care should focus on creating good memories of personalized care which takes the patients' individual needs into consideration. It should also be family centered. The whole family are often affected when a loved one is cared for in the ICU (Engström & Söderberg, 2004). Normal family relationships can also be disrupted. In a study with 198 patients in a Swedish ICU, as many as 25% of the patients have no visitor at all in the ICU (Eriksson & Bergbom 2007).

In order to improve care and promote health, it is important to elucidate memories when patients are being cared for after a trauma. However, there are no present strategies for nursing care or nursing care actions that focus on creating good and avoiding disturbing memories. Previous research of care for patients with trauma in the emergency unit shows that patients expected a somewhat higher quality of care than they received (Franzén et al. 2008). Hov et al. (2007) claim that good nursing care in the ICU depends on the ability of the nurse to understand each patient's situation.

The care and treatment that are provided in the ICU is often associated with suffering from multiple causes; the injuries, vital organ failure, treatment with invasive methods, mechanical ventilation and loss of normal routines and security (Almerud et al. 2008; Hupcey 2000). All of these factors cause pain, disturbed consciousness, confusion, anxiety and vulnerability (Magarey & McCutcheon 2005; McKinley et al. 2002). It has in recent years become important to evaluate the intensive, high-technological and costly care in relation to the outcome from the patients' perspective (Bowers 2004; Chaboyer & Elliott 2000; Dowdy et al. 2005). There is also a lack of knowledge of what effect memories during the ICU-stay have on patients' health from a long-term as well as from a short-term perspective. Therefore, this research will focus on the patients' outcome in relation to their memories from the event of injury and the following intensive care.

BACKGROUND

Perspectives on memories

The concept of memory is complex and has several definitions. In the World Encyclopaedia memories are described as “*the power of the mind to think of a past that no longer exists*” (Oxford University Press, 2005). In the philosophical perspective, memories and forgetting and recalling belong to the historical constitution of the individual and are a part of his/her history, the being of man (Gadamer 1989). In the psychological perspective memories are described as a function of preserving, involving, encoding, storing, and retrieving information. Humans have a declarative memory for factual information about the world and a procedural memory for information concerning how to do things. There is also the long-term memory for information stored for more than a few seconds, the short-term memory for temporary storage of information for briefer periods and the sensory memory for very brief storage of visual and possibly other sensory information. Finally, there is a division into the episodic memory for events and experiences and semantic memory for information about the world, although the perceptual memory may not fall into any of these categories (Colman 2006; Tulving 2002; Tulving & Craik 2000). The biological definition of memory is that of information being stored in the brain. The exact mechanism of processing and storing information is not fully known but is thought to involve the construction of circuits of neurons (Baddeley 2004; Martin & Hine 2004).

DM or delusions are in this thesis a comprehensive term for hallucinations, dreams, nightmares and paranoia. These memories may also be called unreal experiences but are, despite the name, very real to the patient when experienced. Unreal experiences also refer more to positive or neutral experiences and not only frightening or discomforting memories that have been experienced, but they are memories that afterwards may be questioned by the patient as to how real they are. The word, ‘experiences’ is also more of present time ‘here and now’ in contrast to memories which allows us to think of a past that not longer exists. For a human being who mentally can travel back in time (Tulving & Craik, 2000) these unreal experiences during ICU-stay become DM.

In order to give an example of DM the following quotation from a participant in one of the studies of this thesis, illustrates and describes the content and character of such memories:

“Before the surgery an auction was held on me. The surgeon that paid the least was allowed to buy me. After the surgery I was kept in the backyard at a road tavern. The nurse was also a treasurer lady and refused to give me painkiller.”

The above description is based on the memories of a 59-year-old man on mechanical ventilation who spent a total of six days in the ICU after a fall from a high roof. His DM are typical of the memories that patients often describe after care in the ICU. This example of terrifying hallucinations and paranoia of being kidnapped together with the staff treating them badly and plotting against them are common themes in these frightening memories. According to Löf et al. (2008) although patients in the first place thought that the experiences were real, the majority of them realized afterwards that it had never taken place. Not knowing if the memories are DM or real, may cause the patient problems after the ICU-stay. Such experiences might result in a feeling of uncertainty and a decrease of self-confidence.

The term delusion was earlier only used in psychiatry to describe psychiatric dysfunction and it implies that the delusion is a result of a process of illness in the brain or a pathological condition. Delusions have been found to occur in many, both physical and mental pathological states. Most psychological and psychiatric definitions of delusions go back to Karl Jaspers (1883-1961) and his three criteria; subjective certainty, incorrigibility and impossibility of content (Spitzer 1990). Even if these criteria were often used to define delusion, they served only as clinical hints. Many delusions are in fact possible, so impossibility was changed to falsity and the content of the delusion could be true. *"A delusion is a delusion not because it is a false statement, but because it is a statement made in an inappropriate context and most importantly with inappropriate justification"* (Spitzer 1995 p 98).

There are other definitions of delusions. According to the Medical Dictionary a delusion is defined as;

"A belief that is held with unshakable conviction, cannot be altered by rational argument, and is outside the person's normal cultural or subcultural belief system. The belief is usually wrong, but can occasionally be true. The abnormal pathology lies in the irrational way in which the person comes to the belief. In mental illness it may be a false belief that the individual is persecuted by others, is very powerful, is guilty of something they have not actually done, is poor, or is a victim of physical disease. Delusions may be a symptom of schizophrenia, mania, or an organic psychosis." (Martin 2007).

This definition implies that delusions are a symptom closely connected to a psychiatric disease which generally is not the case for patients in the ICUs and participants in this research.

DM experienced by patients during their ICU-stay are difficult to define. However, an operational definition has been developed by a research-team in the UK (Jones et al. 2000a; Skirrow 2002) who studied patients' memories in the ICU and it is the one used as a definition in this thesis;

“A dream, nightmare, or hallucination experienced by the patient during their ICU-stay. A belief or memory of ICU that has been rejected as false by the patient. A belief or memory of events in ICU that is not shared by medical staff or family members present during the patients’ stay” (Skirrow 2002 p 28-29).

It is also important to add that the patient is not sure whether the content of the dreams or nightmares is real. The definition may serve as a clinical hint to describe these patients’ experiences in the ICU rather than a definition and should not be mistaken for a psychiatric definition of madness.

In this thesis DM are seen as a symptom, not a disease in itself. DM as a symptom are closely related to ICU delirium and Post Traumatic Stress Disorder (PTSD). To distinguish between DM and ICU delirium or PTSD, DM can be seen as a symptom experienced and pronounced by the patient, while ICU delirium and PTSD are regarded as syndromes that is diagnosed and monitored by others such as medical staff according to defined criteria set by the American Psychiatric Association in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV) (2000). DM such as hallucinations and nightmares which are symptoms that are included in both ICU delirium and PTSD.

In a literature review by Granberg et al. (1996) consisting of 20 different studies between 1954-1990, the ICU delirium consists of interactions between many factors and it has also contains individual patterns developed by patients during their ICU-stay. Hallucination, illusion, delusion and paranoid experiences are mentioned as clinical symptoms of ICU delirium in 8 of 20 of these studies. However several modifications in the definition of delirium have been done. Delirium is described with an acute onset, fluctuating course, altered level of consciousness, disorganized thinking, disorientation, memory impairment, agitation, inappropriate speech or mood, sleep disturbance and perceptual disturbance, i.e. hallucinations or delusions (American Psychiatric Association 2000; Morandi et al. 2008). According to these criteria, delusional memories is one of several symptoms of the ICU delirium. The onset of delirium is often on the third day (Ely et al. 2001a) and most patients experience the delirium while they still are in the ICU. However, the time for the onset of ICU delirium is still under investigation and there is no consensus among the researchers. The Confusing Assessment Method for the Intensive Care Unit (CAM-ICU) (Ely et al. 2001b; Ely et al. 2001c) is an instrument used by the staff in some ICUs to assess ICU delirium.

DM may also be associated with PTSD (Corrigan et al. 2007; Jones et al. 2001). The characteristic symptoms of PTSD include re-experiencing of the traumatic event, for examples nightmares, hyperarousal symptoms and avoidance of stimuli associated with the trauma. These symptoms must be present for more than 1 month (American Psychiatric Association 2000). According to Jones et al. (2001), PTSD symptoms correlate with DM but are less likely in patients with factual memories. Patients with DM without

factual memories from the ICU had more psychological symptoms 8 weeks after discharge. This study suffers from a small sample with only 9 of 45 patients who experienced delusional but no factual memories. In this study, there were only 7 patients with trauma and 6 of them had amnesia. In a more recent study with 226 patients in the ICU, the feeling of extreme fear rather than DM seems to have developed symptoms of PTSD (Samuelson et al 2007). However, for ICU patients in general, DM may cause psychological problems in the rehabilitation process (Jones et al. 2007).

To summarize, in this thesis memories are important in each person's history of life. They bring meaning to events, can be shared with others and have an influence on life (Gadamer 1989). DM also become a part of a person's history of life from an often dramatic period when this person is in a very critical situation. In this thesis, the concept of DM during intensive care can be one of several symptoms of the ICU delirium.

Perspectives on health

Health is one of four consensus concepts which direct nursing and nursing science. The concept and phenomenon is very abstract and can be seen from many different perspectives. From a hermeneutical point of view health can be seen as a matter of course and not before the good health disappears you fully realize the importance of it. When health returns, so does the normal state again and thereby you forget that you are healthy (Gadamer 1996) It is important for the human existence to care for our own health. Health is constituted by the rhythm of life, the breathing, digesting and sleeping which helps to produce vitality, refreshment and to restore energy. This is a process in which equilibrium re-establishes itself (Gadamer 1996). The World Health Organisation (WHO) has adopted a positive definition of health and specified that "*Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity*" (WHO, 1948). This original concept of health has been revised by WHO to be more of a resource in everyday life than a goal in itself "*Good health is a major resource for social, economic and personal development and an important dimension of quality of life*" (WHO, 1986). This also shows also a more holistic view on health.

From a caring science perspective on an ontological level, health is multidimensional and relative and always in a motion. Health is both subjective and objective, reflecting both physical as well as mental well-being. Eriksson's (1984) definition of health implies that health is an integrated state of healthiness, freshness and well-being but not necessarily an absence of disease.

Health status and HRQoL are only part of an overall quality of life (QoL). QoL is defined by the World Health Organisation Quality of Life group (WHOQOL) as "*individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*" (WHO, 1998 p 551). QoL and HRQoL are more comprehensive than health status and include a

more global evaluation of health (Bowling 2005). In general terms, a person's QoL can be what is good or bad for the individual and what is experienced as a good life (Brülde 2003). Research shows that most people define their QoL in terms of having a good psychological outlook and emotional well-being and the physical ability to do the things they want to do. It is also important to have a good relationship with friends and family and to participate in social activities, live safely and have enough money (Bowling 1995). In this thesis, the term HRQoL is used as outcome after trauma to evaluate different factors' influence on HRQoL. For this purpose a definition of HRQoL is proposed where HRQoL encompasses;

"Those attributes valued by patients, including: their resultant comfort or sense of well-being; the extent to which they were able to maintain reasonable physical, emotional and intellectual function; and the degree to which they retain their ability to participate in valued activities within the family, in the workplace, and in the community." (Wenger & Furberg 1990)

Dimensions that should be included in research in order to assert HRQoL as a minimum are; physical, psychological, social functioning and role activities and overall life satisfaction and perception on health status. Physical functioning is defined as a person's ability to perform daily life activities. Social functioning refers to individuals' ability to interact with family, friends and community. Psychological functioning is emotional well-being and refers to people's experiences of anxiety, depression and worry. It is also a positive aspect of joy and hopefulness for the future. Overall life satisfaction represents individuals' total well-being for a defined time. Overall health in the past months needs to be distinguished from actual health and the dimension of general health status. Pain is another commonly assessed dimension of HRQoL and it may include degree of pain and how pain affects daily life (Naughton & Shumaker 2003). HRQoL is an important concept in health care because it shifts the focus from medical diagnosis and mortality rate to a holistic view on individuals' lives. It also focuses on the individual as a person (Rustøen & Wentz-Edgardh 1993). There are different methods to study HRQoL and there are several instruments to measure it. However, the question remains; is health measurable? Probably not in a comprehensive way, but with issues concerning physical activity, lack of pain, mental state, social activity and relations, some dimensions of health are made visible by measurements.

Mental health

Treatment in an intensive care unit can be stressful for patients in general in the ICU (Scragg et al. 2001). In this thesis self-estimated anxiety and symptoms of depression is seen as part of a broader mental health. To have good mental health regarding freedom of anxiety can be to feel secure from any threat or danger and be surrounded by a familiar and understandable world (Gadamer 1996). This can also refer to feelings of mental well-being which is an important component in regaining health after critical illness. Post-trauma depression has been found to be associated with poorer outcome for

patients after trauma (Holbrook et al. 1999). Also a psychiatric problems prior to the trauma has frequently been found among individuals with minor injury (Richmond et al. 2007).

The symptom of anxiety is a highly personal experience that may be affected by past feelings and situations. The level of anxiety is variable and the reaction can range from mild anxiety with worry and fear to panic and terror. Anxiety can be described as *"vague, uneasy and unpleasant feelings of potential harm or distress. These feelings are accompanied by an arousal that is due to real or perceived threats to ones physical or mental well-being"* (Gobel 1993 p 580). The variability of level of anxiety is accounted for by three major factors: medical, psychological and social factors. The medical factors are illness such as symptoms of pain, psychological factors are coping and ability to modify life plans, and finally social factors are such as support from family and friends (Gobel 1993). Anxiety is not always a symptom of illness or deleterious. It can be the cause of illness, or an effect of illness. Anxiety can be a response to a perceived threat in contrast to depression which can be a response to a perceived loss or harm. Depression is in this thesis regarded as a symptom, meaning different degree of dispiritedness. Depression as a mood state includes a broad spectrum of moods such as a feeling of gloom, emptiness, lack of feelings or despair (Munch & Barsevick 1993).

According to Schnyder et al. (2000) psychological problems after trauma are not always correlated with the severity of injury but rather with the patients' subjective appraisal of the severity and threat of the accident and their general attitude toward life. Jones et al. (1994) discuss that psychological symptoms can be delayed for patients with trauma and not to appear until six months after injury.

Return to work

The ability to work and to RTW after a trauma is for most individuals highly desired for financial and social reasons. The possibility to RTW after a trauma depends on several factors such as the individual health, the working place and the work task. The individual work ability is the relationship between the individual resources relative to the work. The individual resources are health (physical, mental and social), education, values, attitudes and motivation. These resources relate to working demands, organisation, environment and employers. The outcome of the interaction of the individual and the surrounding factors constitutes the individual work ability. The concept is multidimensional and can change over time. One ambition can be to adjust work to people's conditions and one aspect is the possibilities to modify task and conditions at the workplace in order to facilitate for individuals with disabilities (Hogstedt et al. 2004). A trauma may cause work disability (Brenneman et al. 1997). Medical factors such as physical or mental disabilities are a matter of great but not vital importance for the ability to work (Ydreborg et al. 2007). The work capacity normally

varies from person to person and can presumably be influenced after a trauma. In this thesis, the participants' own answers of RTW full or part-time has been assessed.

Intensive care context

The ICUs are highly specialized units which have developed from postoperative treatment care and they became medical sub-specialities of anaesthesiology during the 1950's in Sweden. Intensive care is more of a level of care than a particular place and it is defined as advanced surveillance diagnostics or treatment of patients with failure of vital organs (SIR 2007). There are units of different size (number of beds), but the environment is always highly technical including plenty of technical equipment surrounding the beds and connected to the patients as well as a large number of staff. This usually makes the ICU environment seem unfamiliar to patients and their families. Moreover, when in intensive care patients are never left alone. They are monitored and supported and have access to acute intervention day and night. Patients treated for trauma in the ICU are always admitted unexpectedly and they are not prepared for the ICU care as are the elective admitted patients. If it is possible the patient is cared for in a single room, but often there are two to four patients in the same room. The nursing care involves, in most cases, one specially trained registered nurse and one enrolled nurse at the bed side. Registered nurses are often responsible for two patients during their working shifts (Bergbom 2007; Cedergren 2005).

State of knowledge

Intensive nursing care

Physical trauma and critical illness involve the whole person and engages the entire family (Bowers 2004; Engström & Söderberg 2004). Chaboyer (2006) discusses that when a person is critically ill both the person and the family had experiences that are foreign to them. The private zone and the personal integrity shrink as the patients are too ill to take care of themselves. Most patients are thus totally dependent on caring staff for satisfying their basic human needs. Wallis (2005) discusses the 'lack of control' that the patient and family members feel when a catastrophic injury or illness has occurred. Therefore, nursing care actions such as creating a trustful relationship in order to protect the patients' dignity and making them feel safe and secure are vital in the first phase together with taking control. However, when the patient gets better the caring nurse allows the patient and family more choice and thereby also more control.

Wilkins (2003) argues that caring work in the ICU from a nursing perspective includes the nurses' feelings as a motivators for nursing actions; feelings concerning patients' comfort, showing that they care with 'touch', empathy and respect for the patients' dignity. The caring work also includes the nurses' knowledge about technology (Wikström et al. 2007), knowing the patient, taking care of relatives (Söderström et al.

2006), prioritizing care and managing critical situations. Finally, caring in the ICU involves the nurses' skills in terms of interactions with the patient providing physical care and mental support.

The nursing care in intensive care units is characterized by an advanced focus on and attention paid to reactions and behaviour in order to prevent a deterioration of patients' conditions, as patients are usually balancing between life and death. Hence vigilance is crucial (Fridh & Bergbom 2006). Caring for patients involves closeness to the patient, giving spiritual care, provide hope of recovery to the patient and family and act in advocacy of the vulnerable patient. It is also to be responsible for a totally dependent patient and give technical support and nursing care at the bedside (Beeby 2000b). Cronqvist et al. (2004) state that the obligation to care for patients in the ICU can be seen as 'caring about' and 'caring for' the patients, where 'caring about', implies that there is a genuine concern for the patient and 'caring for' stands for more task-oriented nursing care. The view on humans is central to all caring. In the ICU, patients are totally dependent on those who are caring for them. Holland et al. (1997 p 132) has pronounced caring in the ICU by citing a patient's personal view of critical illness as "*The single most important person in the critically ill person's day is the nurse. The most important attribute is whether they care*".

Patients often needed sedation and analgesia to manage the treatment as this type of medication allows them to relax and rest, but it also makes the patients drowsy (Samuelson et al. 2003). Sleeping is also disrupted due to the constant care and so is also the patient's consciousness (McKinley et al. 2002). The overall situation for the patient treated in an ICU can be very stressful (Novaes et al. 1997). Apart from being seriously ill, they have no control over their own situation and as they do not know what is happening around them, they have to rely on others to cope with their situation.

The nurse works in partnership with the patients and their families and an important nursing care action is to facilitate for the family and other significant people to visit the patients in order to preserve and maintain the connection to their own social context, meaningful values and beliefs. The close family and friends are often free to visit their loved ones at any time. This is very important as the family often provides a lifeline and an important link to reality for patients who suddenly find themselves in a situation which can be hard to understand and control (Bergbom & Askwall 2000). Social support from family is often extremely important to patients in the ICU but quality rather than quantity should be in focus (Hupcey 2001).

To summarize, nursing care focuses on four main issues; maintaining a trustful relationship, take care of all bodily functions, monitor and take actions when changes in vital functions appear and finally to take care of and to cooperate with the patient's family. The nurses' attention toward the patients is a vital condition for the patients' care and treatment and indirectly influences the possibilities of survival. In the present thesis, the term care represents the intensive nursing care and it involves a genuine

caring for the patients and their families in the ICU. This involves founding and establishing a caring relationship, protecting and preserving the patients' dignity and integrity and alleviating suffering.

Physical trauma

Injuries are the most common causes of death before the age of 45 and approximately 100 000 patients are in hospital care in Sweden every year due to injury. There has been no change regarding the number of patients during the past ten years. However, there have been changes in health care policy, and organisation and the time spent in hospital has been shortened. The trend since the 1970 is that deaths after injury have decreased but in the late 1990 the number of deaths started to increase again. According to statistics provided by the Swedish Rescue Service Agency (Räddningsverket/SRSA) injuries accounted for almost five percent of all deaths in Sweden during 2004. Almost two thirds of those were male. Fatal injuries among adults are just the tip of the iceberg and out of one death of injury there are additionally up to 30 with "severe injuries" and 200 with "slight injuries" (Nationellt centrum för lärande från olyckor 2007).

Trauma is defined as *"any injury or physical damage caused by some external event such as an accident or assault"* (Oxford University Press 2005). This definition implies that an injury can be intentional or unintentional. Unintentional injuries include motor vehicle crashes, falls, poisoning, drowning, and burns while suicide, homicide and assault are defined as intentional injuries. The term trauma is used both for physical and psychological trauma and therefore the term injury can be more appropriate to use when describing the consequences of the trauma. Injury is defined by SRSA as;

"a bodily lesion at the organic level resulting from acute exposure to energy (which can be mechanical, thermal, electrical, chemical or radiant) interacting with the body in amounts or rates that exceed the threshold of physiological tolerance". (Statens räddningsverk & Nationellt centrum för lärande från olyckor 2005).

Patients with trauma requiring ICU admission constitute a special group of patients in the ICU. They are often younger and with better previous health than most other critical care patients.

Memories from the intensive care unit

Patients' experiences from the ICU-stay have been studied since the late 1950 when Mendelson et al. (1956) described nine patients treated after poliomyelitis. These patients had delusions and were disorientated while they were treated in a tank-respirator, and after their recovery they remembered the 'dreams' with extreme vividness. Since the middle of the 1980's the research of patients' experiences from the ICU has escalated in the Nordic countries. Bergbom et al. (1988, 1989) described patients' recollection from the ICU-stay. They found that more than half of the patients did recall the mechanical ventilation. Patients who suffered from surgical, medical

illness or trauma were studied and showed that patients with trauma had poorer recall than other patients in the ICU. Nearly half of the patients had felt anxiety and/or fear during the treatment and they had suffered from communication problems and isolation in the ICU. In the nineties Gjengedal (1994) described patients' experiences from the ICU using a phenomenological method. Patients narrated their experiences of loss of voice, anxiety, insecurity, time disorientation and changed body image which revealed limited recalls of good memories.

During the 2000s Granberg et al. (2001) found that many patients had problems with not remembering what had happened to them which was experienced by the patients as violations of their personal integrity. Later Löf et al. (2006) found that patients' memories from ICU over time showed very little variation. Samuelson's (2006) studies imply that memories from the ICU are related to the level of sedation and stressful memories seem to increase psychological distress after the ICU. Storli et al. (2007) claims that patients strive to understand the chaotic memories for many years after the ICU-stay. Her research also implies that DM in fact are filled with meaning and that the patients should be given the opportunity to scrutinize their experiences from their critical illness.

A literature review (Stein Parbury & McKinley 2000) based on 26 qualitative and quantitative studies 1967-97 involving 1235 patients shows that between 30-100% of former ICU patients could recall fragmentary memories of their entire ICU-stay. Many patients recalled negative feelings, but they also recalled some positive experiences. Negative experiences were related to fear, anxiety, sleep disturbance, cognitive impairment, pain and discomfort. Positive experiences were related to feelings of being safe and secure. Often these positive memories were attributed to the care provided by nurses (Granberg et al. 1998; Green 1996; Laitinen 1996). After an ICU-stay patients may need help piecing together events from their time in hospital (Hupcey & Zimmerman 2000). In this aspect, relatives may provide an important link to reality and the patients' life (Maddox et al. 2001). By reading diaries that were written during their ICU-stay, patients also gain insight into what has happened to them during the ICU-stay (Bäckman & Walther 2001; Bergbom et al. 1999). This can also help the survivors of a trauma to create a history of what has happened.

When interviewing fourteen patients Hupcey & Zimmerman (2000) described that patients had confusing perceptions about people trying to hurt them in the ICU. These memories were the most intense for patients who were on mechanical ventilation. DM are easily recalled and with substantial details by former patients in the ICU (Jones et al. 2000a; Löf et al. 2006). It seems that patients often remember experiences that are of a more disturbing nature from the ICU-stay than neutral experiences (Rotondi et al. 2002). According to Samuelson et al. (2007), patients being admitted emergent to the ICU have more disturbing memories than others. A recent study shows that small children also seem to have disturbing memories during their ICU-stay (Colville et al. 2008). The

differences in gender regarding memories from the ICU-stay are small (Johansson et al. 2008).

When studying the DM in detail, it was found that the patient often had a central role in the delusions. These sometimes involved the care procedure which was experienced as terrifying (Löf et al. 2006). Another common theme was to be running in tunnels or being on a journey (Karlsson & Forsberg 2008). Hallucinations are often a source to discomfort for patients in the ICU (van der Luer et al. 2004). An extreme fear and an inner tension while patients were cared for in the ICU have also been described by Granberg et al. (1998). They state that this fear was triggered by only small routine changes in the care. Roberts & Chaboyer (2004) interviewed 31 patients 12-18 months after ICU and 74% of these patients reported vivid and scary dreams in the ICU. However, only 12 of these patients were showing signs of having these memories while they were in the ICU. These findings show that signs of these experiences are difficult to discover and observe. In a study with 289 former ICU patients treated with mechanical ventilation, 65% of the patients had no recall of any event from the ICU directly after discharge but 48-72 h later they reported high incidences of unpleasant delusions during the ICU-stay. Prolonged ICU-stay was in general associated with more hallucinations and nightmares (Rundshagen et al. 2002). The memory of these hallucinations including emotions may exist for a longer period which is described by a patient in a case study.

Twenty years after the ICU-stay a former patient describes his delusions as visual and auditory hallucinations. He describes monsters waited on the ceiling and more paranoid delusions such as conspiracy among the staff trying to poison him. He felt that he was struggling for his life (Hartwick 2003). The ICU can also be described by patients as a quiet place. In a qualitative study with 26 former patients in the ICU, one third of the patients could recall their nurses' names. These patients felt safe despite of recall of pain, dreams and that some were still unsure if their dreams had been real or not (Green 1996).

Health related quality of life after intensive care

Patients who suffer from a physical trauma experience a decrease in their QoL after the ICU-stay which is greater than in other groups of critical care patients (Vazquez Mata et al. 1996). Thiagarajan et al. (1994) reported that one year after the trauma and ICU-stay there was a decrease in overall health and happiness. Two years after the trauma the QoL continued to be lower than on admission, QoL was also influenced by age and severity of injury (Vazquez Mata et al. 1996). In a follow-up 5 years later, 11% of the survivors were severely disabled (Frutiger et al. 1991). In a more recent study by Sluys et al. (2005), patients with physical trauma reported considerable physical (68%) and psychological (41%) disabilities after 5 years.

In a current study with patients 2-7 years post-injury, 74% reported impaired HRQoL and a majority still suffered from pain (Ulvik et al. 2008). Other studies showed that women were at risk of worse QoL outcome as they experienced more psychological morbidity after trauma than men (Holbrook & Hoyt 2004; Holbrook et al 2001; Ulvik et al. 2008). On the other hand Sampalis et al. (2006) claim that no gender differences in QoL exists. Before the trauma, patients often reflected the norm for a healthy adult population. However, after the trauma there was a significant decrease in health and well-being (Holbrook et al. 1998). After discharge from the ICU and hospital, the patients' health improved but the completeness of this recovery and further health remained uncertain (Ulvik et al. 2008).

Memories may affect the patients' psychological health after an ICU-stay (Griffiths & Jones 2007; Samuelson et al. 2007) but few studies have elucidated the memories effect on HRQoL after intensive care (Granja et al. 2005). According to Rundshagen et al. (2002) memories from the ICU-stay may hinder a full recovery. However, even those patients who made a full recovery refer to their experience during the ICU-stay as the most traumatic experience of their lives (Russell 1999). Concerning ICU patients in general, 43% had anxiety and 30% had symptoms of depression after the ICU-stay. The anxiety was related to the patients' ICU experiences, but even if the study is interesting and clinically useful it includes a rather small sample (n=80) and a limited response rate of 56% (Scragg et al. 2001). In another study which also contained a small group of medical ICU patients 11 of 34 patients had neuropsychological impairments 6 month after the ICU-stay. These patients also showed more symptoms of depression (Jackson et al. 2003).

For all of the patients with different diagnoses cared for in Swedish ICUs, there were very small changes in health status after the first 6 months following discharge from the ICU (Zaren & Hedstrand 1987). In a review of 21 international studies from 1986-2004 involving 7320 adult ICU patients, HRQoL improved over time but remained poorer than the general population levels throughout a long-term follow-up (Dowdy et al. 2005). Flaatten & Kvale (2001) showed that two years after an ICU-stay, the HRQoL normalized and became comparable with the normal population. However, survivors of critical illness in general, have poorer perceived health (Pettila et al. 2000) in a short-term perspective

In conclusion, there is substantial evidence that many patients experience stressful and frightening memories during the ICU-stay and that these memories are recalled for many years following the ICU-stay. Some patients also have an impaired psychological health after the critical illness but there is still limited knowledge about the impact of these memories on the patients HRQoL and future well-being. Many patients have a poorer HRQoL after critical illness compared to a normal population in the short-term. There are some difficulties when investigating and comparing patients in the ICU. They differ regarding their diagnosis, treatment and previous health and often these pre-

existing circumstances are not known. Research ought to focus on specific groups of patients and to what extent the experiences from the care in the ICU affect the rehabilitation process in a long term perspective for a specific group of patients.

RATIONALE FOR THE STUDY

How DM from the ICU-stay affect patients' health in the long and short term is still rather unexplored. It is important to gain such knowledge to be able to improve caring actions in the ICU and inform patients and their family about possible health problems related to these memories after the ICU-stay, but also to prevent negative consequences to patients' health and well-being. Few studies have described HRQoL in patients after trauma and ICU care from a long-term perspective. Up until now, most studies have included patients with severe trauma but not those with mild injuries. There is no evidence or knowledge that shows that patients with trauma involving mild or few injuries have fewer problems following the trauma and the intensive care treatment. Furthermore, there is little research of DM and of groups of patients with a specific diagnosis in the ICU. Most patients recalled DM while they were on mechanical ventilation, but there are few studies of patients without this treatment. Knowledge about patients' memories following a trauma and during the ICU-stay as well as the influence from long and short-term perspective may result in a development of nursing care strategies and actions for patients cared for in the ICU. Care that focus on nursing strategies to support the patient and their family after the trauma is vital.

AIMS

The overall aim of the thesis was to acquire a comprehensive understanding of patients' memories from the ICU-stay and their putative effects on outcome after physical trauma from a long and short-term perspective. Specific aims were:

- To describe trauma patients' memories of their stay in the ICU, factors that may influence delusional memories, problems experienced after discharge from the ICU and the patients' return to work (paper I);
- To examine the relationship between delusional memories from the ICU-stay, HRQoL, anxiety and symptoms of depression in patients with physical trauma 6-18 months following their ICU-stay (paper II);
- To acquire a deeper understanding of patients' memories of being injured and the trajectory of care before, during and after the ICU-stay (paper III); and
- To describe changes in HRQoL, anxiety, depression and RTW from 0.5-1.5 to 4.5-5.5 years after trauma in patients with and without DM during their ICU-stay. A secondary aim was to explore factors that were related to HRQoL and to compare patients' HRQoL 4.5-5.5 year after trauma with a reference sample (paper IV).

METHODS

Two different methodological approaches have been used. In paper I, II and IV an empirical analytical positivistic tradition has been used whereby the intention has been to measure and quantify phenomena. In paper III a humanistic and hermeneutic approach and tradition has been used. This latter tradition is based upon a holistic view of knowledge and understanding, while the former strive to attain objectivity and explanations.

Design

The overall phenomenon that was studied was the patients' memories in relation to trauma, intensive care and their future influence on health. Such a complex research area requires various approaches to elucidate the memories from different points of view. An overview of the included studies is shown in Table 1. Different methodologies gives altered perspectives on the same reality and enrich each other. When both qualitative and quantitative methods are used, the purpose is to create a comprehensive understanding of complex human phenomena and give pragmatics knowledge (Creswell 2003). This thesis explores patients' memories by both measuring and interpreting data in order to understand how patients' memories from a critical period in their lives affect their health.

A multi-centre study design was used for all studies and the same study sample was followed in all studies. In the first study (paper I, II), a descriptive design was used to describe the patients' memories and the relationship with demographic and clinical variables in the ICU as well as the relationship to HRQoL, anxiety and depression at 6-18 months after the trauma. The last study (paper IV) was a follow-up study 4 years later of the same patients who were involved in the first study. The qualitative study (paper III) was an explorative study, aimed to interpret and understand patients' memories in relation to the trauma and hospital care.

Table 1. Description of the thesis

Paper	Design	Inclusion criteria	Participants	Data collection	Time after the trauma	Data Analysis	
I	Description of memories and return to work after trauma (Study I)	Descriptive Cross-Sectional	>18 years old Trauma diagnosis in ICU	239 Patients	Patients' records review ICUM tool Return to work	0.5-1.5 years	Descriptive statistics Fisher's exact test Student's t-test Logistic regression analysis
II	Memories and health-related quality of life, anxiety and symptoms of depression (Study I)	Descriptive Cross-Sectional	>18 years old Trauma diagnosis in ICU	239 Patients	Patients' records review ICUM tool SF-36 HAD	0.5-1.5 years	Descriptive statistics Fisher's exact test Student's t-test Pitman's test Multiple linear regression analysis Logistic regression analysis
III	Patients experiences of memories and care after trauma (Study II)	Explorative	Participated in study I >18 years old Trauma diagnosis in ICU Delusional, fragmentary memories, or amnesia from ICU	18 Patients	Face to face Open-end interview	2-3 years	Interpretative Phenomenological hermeneutical analysis
IV	Follow-up memories and health-related quality of life, anxiety and symptoms of depression, and return to work (Study III)	Longitudinal Comparative	Participated in study I >18 years old Trauma diagnosis in ICU	153 Patients	Patients' records review SF-36 HAD Return to work	4.5-5.5 years	Descriptive statistics Chi-square Fisher's exact test McNemar's test Mann-Whitney test Wilcoxon signed-rank test Spearmans's rank correlation test

Settings

Seven hospitals in the western region of Sweden, serving the population of 1 500 000 inhabitants, were invited to participate in the study. All the hospitals have ICUs that treat and care for emergency patients with trauma. The units were requested to identify patients from their databases who were over 18 years old and who had been consecutively admitted to the ICU over a one-year period (from September 2001 to August 2002) with the diagnosis of trauma. Five hospitals agreed to participate in the study; one university hospital, two county hospitals and two districts hospitals. Out of the two hospitals that declined participation, one hospital already had a study going on. After a discussion with that same hospital it was decided that the invitation should be withdrawn as there was concern over patients becoming stressed by more questionnaires. The second hospital could not find the possibilities to participate.

The five ICUs that participated were different regarding size of the unit (beds for patients) and number of staff. The university hospital had the largest ICU fitting fourteen beds and approximately 200 members of staff. The two ICUs at the county hospitals had eight beds each and approximately 100 members of staff per unit. The two smaller district hospitals had four and five beds respectively and 50 members of staff in their ICUs. All the ICUs had postoperative units as well where the staff were also working. There were most often two patients in each room. 50-60% of the staff members were specialist ICU registered nurses, and one nurse was always at the bedside, thus patients were never left unattended. Nor were patients ever physically restrained, and people who were well-known to the patients, such as close family and friends, were free to visit them at any time.

Participants

An overview of participants involved in paper I-IV is shown in Figure 1.

Paper I, II

During the one-year study period, 4424 patients were admitted to the five ICUs, of which 11% were patients with a diagnosis of trauma. 10% of the adult patients with trauma did not survive. Finally 344 patients were involved in study I, and the final study group consisted of 239 patients (70%) of the involved patients (Figure 1).

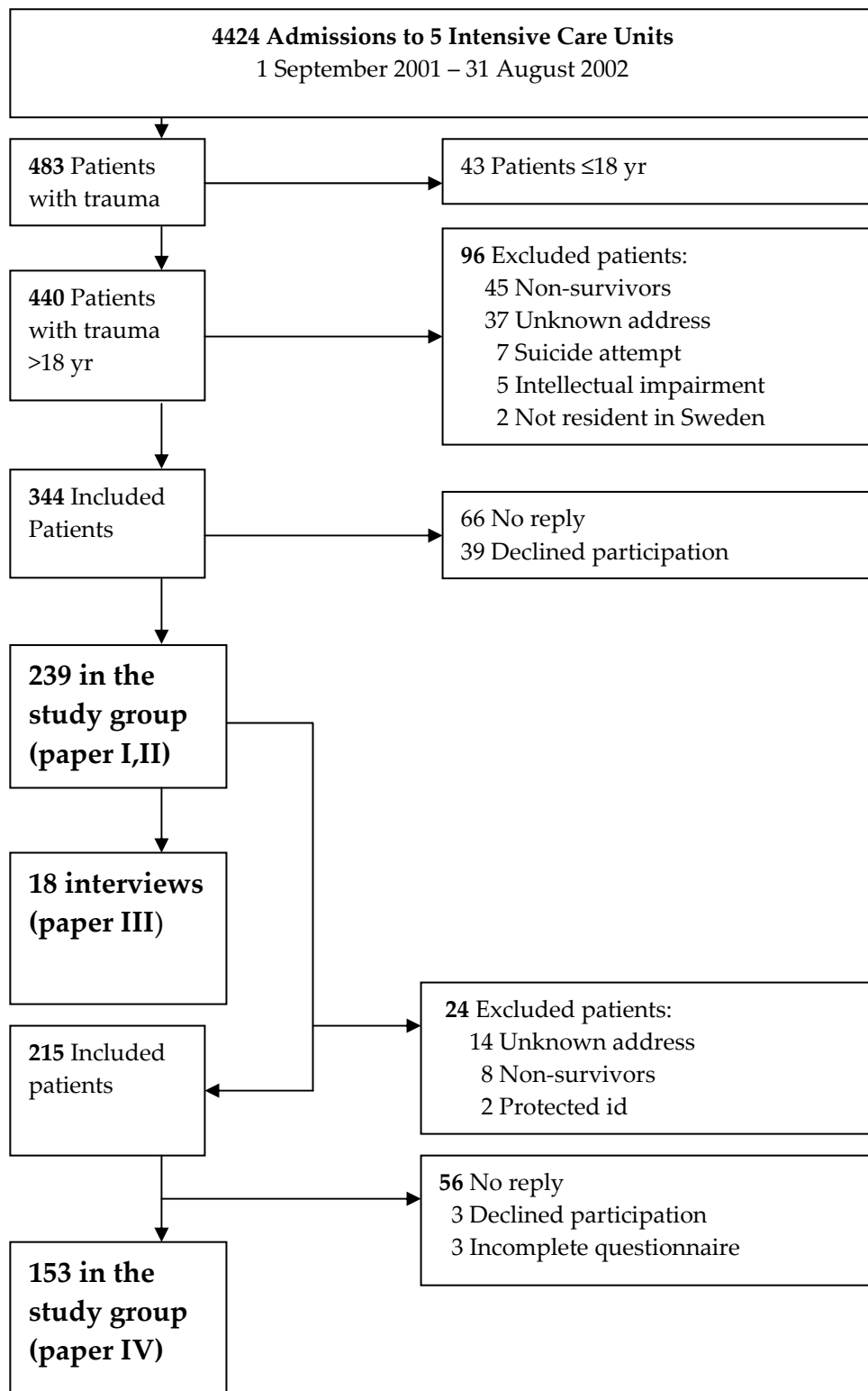


Figure 1 Overview of participants' i.e. patients in the different studies of the thesis

Paper III

A purposeful and convenient sampling approach was used (Coyne 1997), seeking information from informants with various memories (factual, delusional, fragmentary memories or amnesia) following a trauma in order to understand what memories patients had from the event of injury to their arrival at home. Of the 239 patients included in paper I, 61 patients stated that they experienced DM, and 27 patients experienced amnesia or fragmentary memories but no DM. In the interview study ten informants were invited from each group. The intention was to reach a maximal variation of informants due to different age, gender, traumas, memories and time in the ICU. The participants were not intended to represent all patients with trauma, but rather to help us gain a perspective on the range of injured people's perspective on their memories of being injured and cared for. One participant declined participation and one was impossible to reach. The final study group consisted of 18 participants.

Paper IV

Follow-up data were available for 215 patients 4 years after the first measurement (paper I, II). A review of the hospitals' databases identified that the 231 of 239 patients involved in the first study, were still alive at the time of the beginning of this study. The questionnaire was sent to 215 and the response rate for those who could be followed up was 153 (71%) (Figure 1).

Non-responder analysis

In the short-term study (paper I, II) the only significant difference in available data between participants and non-responders showed that the latter had had a shorter ICU stay (Table 2). From study I with 344 included patients the follow-up 4.5-5.5 years after the trauma represent 44% of the original group (paper IV). In this follow-up study, there were no significant differences regarding descriptive or clinical data among those lost prior to follow-up with the study group except for intentional injury with more patients in the lost prior to follow-up group (4 % vs 12% $p=0.022$).

Table 2 Comparison between responder and non-responder (paper I, II)

Variable	Patient included n=239	Non-responder n=105	p-value
Male	75%	84%	ns
Mechanical ventilation	25%	17%	ns
Age	45 ±17,9	40.6 ± 17,5	ns
LoS (ICU days)	4.0 ± 6,1	2.9 ± 3,1	0.037

Continuous data are presented as mean ± SD and categorical data as n (%). LoS: length of stay

Reference sample

An age and gender-matched reference sample (n=159) was randomly drawn from the Swedish Short Form 36 (SF-36) norm database (n=8930) (Health Care Research Unit, Sahlgrenska University Hospital, Gothenburg, Sweden) and compared to the scores from the study trauma group. The reference sample was drawn by means of a computer algorithm from the Swedish SF-36 national normative database. In this algorithm, the minimum ratio referent individual patient is first determined. In this first phase no referents existed for 2 male patients aged 85 and 87. Therefore the age interval for matching was increased to 5 years. Owing to the fact that the database contains relatively few individuals over the age of 85, only 2 male referents were located for the 3 male patients in the 85-90 age interval. Hence, the minimum ratio was 3 patients to 2 referents (0.667). This ratio was then used to determine the number of patients to draw in the other sex-age categories. Within each category referents were drawn randomly. (Personal communication: Associate Professor C. Taft 25-03-08)

Procedure

The nurse coordinators from the five different ICUs were requested to identify patients who were over 18 years old and who had been admitted to the ICU for a consecutive period of one year due to trauma (September 2001 to August 2002). All patients were checked with the Swedish registrar's office. All surviving patients who were discharged from the ICU and were eligible for the study were sent a letter inviting them to participate. The letter was sent 6-18 months after the patient's discharge from the ICU and included information about the study and the need for informed consent. A self-administered questionnaire containing three instruments SF-36 (Sullivan et al 1995; Ware & Sherbourne 1992), Hospital anxiety and depression (HAD) scale (Snaith & Zigmond 1983) and Intensive care unit memory tool (ICUM tool) (Jones et al. 2000b) was used. Non-responders were phoned after one written reminder (paper I, II).

In paper III, patients that had participated in the first study were contacted by the author (MR) by letter. In this, the participants were invited to participate further in an interview face to face about memories in connection to the trauma and ICU care. Telephone contact with the participants was established one week after the letter was sent to obtain verbal informed consent and to arrange a suitable time for an interview. The author (MR) conducted the interviews from April 2004 to September 2004, 20-36 months after the occurrence of the trauma. The participant chose the location of the interview and it took place either in the participant's home (n=11), in a quiet room at the university (n=6) or at the hospital (n=1).

In paper IV the patients were contacted by the author (MR) by letter, 4 years after the first study. A questionnaire containing the two instruments SF-36 (Sullivan et al. 1995; Ware & Sherbourne 1992) and HAD (Snaith & Zigmond 1983) was used. Two written reminders were sent to the non-responders (paper IV).

Data collection

Data collection methods for each study are shown in Table 1. The results are based on data from assessments of memories, clinical variables and health-related experiences by means of instruments (paper I, II, IV) and from interviews (paper III). In addition to the validated instruments three further items were constructed by the author (MR) and added to the ICUM-tool in order to investigate whether or not the patients remembered the trauma (one item) and if they suffered from mood swings and problems related to lack of recollection (two items). These questions were to be answered by yes or no (paper I). The demographic form contained questions about age, home circumstances, gender, employment before and after the trauma (paper I-IV) and education (paper IV).

Instruments

Intensive Care Unit Memory Tool

The ICUM tool (Jones et al. 2000b) is a memory related questionnaire developed for measuring patients memories in the ICU. The fourteen items are divided into three parts, of which the first part concerns the time in hospital before the ICU, that is the emergency unit, and the second part concerns the time period in the ICU. The third and last part includes two items which are formulated to identify post-traumatic stress disorder (PTSD) related symptoms. Five of the items give the participant possibility to comment and describe their memories further. These answers are not included in this thesis. Finally there is a checklist of 21 different words helping the participants to remember different kinds of memories from the ICU-stay. According to this checklist, patients have DM if they; experience any hallucinations, nightmares, dreams, or sensation of people trying to hurt them. Emotional memories experienced by the patients were characterized by; pain, panic, fear, feeling down, confusion or feeling uncomfortable. Factual memories were; ward rounds, suctioning, breathing tube, lights, alarms, darkness, clock, tube in your nose, faces, voices and family (Jones et al. 2000b).

The instrument has primarily been tested and validated on ICU patients in England and Italy (Capuzzo et al. 2004; Jones et al. 2000b) Cronbach's alfa was 0.86 for the full instrument (Jones et al. 2000b) and the DM appeared to be the most persistent variable over time (Capuzzo et al. 2004) with a kappa value =0.7. It has been translated into Swedish and then translated back into English and validated with good agreement between instrument and interview in cross groups in a Swedish pilot study (Blomqvist-Hedén 2003).

Medical Short form 36

HRQoL was measured with SF-36 (Ware & Sherbourne 1992), validated in a Swedish study (Sullivan et al. 1995). This is the generic tool recommended for assessing HRQoL experienced by trauma survivors (Bouillon et al. 2002). The SF-36 with the 36 items form a quality of life instrument which is widely used and it is scored based on eight domains, each with a range of values from 0-100 (100 is optimal). The eight domains

encompass; 'physical functioning' (PF=10 items) limitation in physical activity including self-care activities, 'role physical' (RP=4 items) work and activity limitations due to physical problems, 'bodily pain' (BP=2 items) limitation due to pain, 'general health' (GH=5 items) overall self-rated health, 'vitality' (VT=4 items) energy versus fatigue, 'social functioning' (SF=2 items) limitations in social activities due to emotional problems, 'role emotional' (RE=3 items) work and activity limitations due to emotional problems and mental health (MH=5 items) emotional symptoms (e.g. nervous or depressed). The eight domains form two overall domains, total physical component summary (PCS) and mental component summary (MCS). The PCS summary measures from: PF, RP, BP, and GH in total 21 items. The MCS summary measures from 14 items: VT, SF, RE, and MH. There is also an additional item which assesses changes in the respondent's health over the past year. The reliability for the Swedish version of SF-36 is more than 0.70 in a general population (Sullivan et al. 1995).

Hospital anxiety and depression scale

The HAD scale (Snaith & Zigmond 1983) was employed to measure psychological outcome. This instrument helps showing anxiety and symptoms of depression in patients without psychiatric disorders and it has 14 items dealing with psychological health, seven with anxiety (HAD-A) and seven with symptoms of depression (HAD-D). Each item has four response categories, reflecting a continuum of increasing level of emotional distress. The score ranges between 1 and 21, and scores ≥ 8 indicate probable or definite anxiety or symptoms of depression. The aim of the HAD scale is to reflect the present state of mood and the scale reflects how the patient has felt during the last week. The scale scores are not affected by the presence of physiological illness (Zigmond & Snaith 1983). The validity of the HAD scale was found to be satisfactory for assessing the severity of anxiety and symptoms of depression in somatic care patients (Herrmann, 1997). Cronbach's alpha for the HAD-A was 0.83 and for the HAD-D 0.82 (Bjelland et al. 2002). When evaluated on a Swedish population, the Swedish version of the HAD seemed to be bidimensional for anxiety and depression as it also is in the original instrument (Lisspers et al. 1997).

Review of patients records

An assessment tool was developed in order to obtain data from patients' records. The assessment tool was critically evaluated by all of the co-workers in the study. Patients' records were reviewed at two occasions. The first time by the researcher (MR) who reviewed the patients' records in four of the hospitals. An intensive care nurse, also a co-worker reviewed the records in one of the hospitals. At the time of the reviewing the two reviewers discussed the different way of coding the data to avoid inconsistencies. Complications were measured by the Sequential Organ Failure Assessment (SOFA) score (Antonelli et al. 1999) and severity of injury measured by the Injury Severity Score (ISS) (Baker et al. 1974), but these were not commonly used scores by the clinical

physicians at the ICU. For this reason a second review was conducted by the author (MR) and this time the ISS and SOFA were calculated in retrospect from the patients' records with support from the Swedish trauma registry (KVITTRA) (Örtenwall 2000) and a trauma coordinator.

Length of stay was calculated in days and if patients were transferred to another ICU the ICU-stay was seen as continued. If the patients were readmitted to the ICU within 48 hours, it was still calculated as one care occasion. Evidence of head injury from an abnormal computed tomography (CT) scan was noted and so was also unconsciousness which was rated from the physicians or nurses notes when we examined the medical records. Other data recorded from patients' records were: pre-existing disease prior to the trauma, injury mechanism, Acute physiological and chronic health evaluation (APACHE II) (Knaus et al. 1985), body temperature $\geq 38^{\circ}\text{C}$, S-haemoglobin $\leq 100\text{g/l}$, B-glucose $\geq 15\text{ mmol/l}$, surgery, mechanical ventilation (in days), intravenously sedation with Propofol mg/day, and days of intravenously administered benzodiazepine and opioids.

Injury and Severity Score

The ISS (Baker et al. 1974) is an anatomical description of injury used to quantify the severity of injury and it allows a comparison of severity of different types of anatomical injuries. ISS is a score (0-75) where 75 represents a lethal injury, and a score above 15 indicates severe injury. This method makes it possible to assign a numerical description of the overall severity or impact of trauma in persons who have sustained injuries to more than one area of the body, i.e. multi or polytrauma. It is based on the Abbreviated Injury Scale (AIS). ISS has been shown to correlate directly to survival.

The Acute Physiology and Chronic Health Evaluation

The APACHE II (Knaus et al. 1985) is a severity of illness classification system based on physiologic changes induced by the disease which takes both age and co-morbidity into account (0-71 where higher scores indicate more severe illness). This scoring system is widely used as an index of illness severity for both clinical and research purposes. It is internationally established and validated in different studies (Chiavone & Sens 2003; Giangiuliani et al. 1989). Usually the attending ICU physician calculates the score when the patient arrives at the ICU. One of the participating hospitals with 51 involved patients in this thesis did not calculate the APACHE II score. The APACHE score was assessed retrospectively in this hospital from the patients' record by the researcher (MR).

Sequential Organ Failure Assessment score

Failure of vital organs was measured by the SOFA score (Antonelli et al. 1999). Six different organ systems were evaluated: respiratory measuring the quotient between arterial oxygen tension and fractional inspired oxygen ($\text{PaO}_2/\text{FIO}_2$), cardiovascular (mean arterial pressure, and use of vasoactive drugs), renal (creatinine, urine output), liver (bilirubin), central nervous system (Glasgow Coma Scale), and coagulation

(platelet count). The score was 0 for normal value to 4 for maximum failure for each organ. Maximum score for each organ was assessed in retrospect from the patients' records on one occasion and the total SOFA score was defined as the highest total score recorded during the ICU-stay. The SOFA score can reliably describe organ failure in trauma patients (Antonelli et al. 1999). The SOFA score seems to be a good indicator of prognosis and is useful as a predictor of outcome for critically ill patients (Ferreira et al. 2001).

Interviews

A research interview is a specific form of conversation with a special purpose; to obtain descriptions of the informant's life-world in order to interpret the meaning of a phenomenon. Compared to an everyday conversation, the research interview has a methodological awareness (Kvale & Torhell 1997). The interview is a dialogue between the researcher and the informant and is influenced by the researcher. The researcher should be adaptable and facilitate the informant's story telling (Dahlberg et al. 2008). It is also important for the researcher to be open to new and unexpected aspects of a phenomenon. A goal of the interview is also to encourage the informant to reflect upon the phenomenon. A good interview is signified by both the researcher and the informant understanding the phenomenon better as a result of the interview (Dahlberg et al. 2008; Kvale & Torhell 1997). In the present study, the interview was initiated with an open question. The informants were requested to narrate their memories of being injured in an accident and cared for at the hospital. In order to elucidate or receive explanations from the participants' stories, additional questions were asked, for example: What were your feelings? Please explain. The interviews lasted approximately 60-120 minutes and were audio taped and transcribed verbatim. The text from 18 interviews consists of 171 single spaced pages in total.

Data analysis

Statistical analysis

The Statistical Package for the Social Sciences (SPSS version 12.0-15.0) was used to analyze the data. Categorical variables are presented as numbers and percentage and continuous data are presented as means and standard deviations (paper I, II, IV)

Paper I

Descriptive statistics were used to illustrate the results. Fisher's exact test and Student's t-test were used for comparing demographic and a number of clinical variables in relation to the patient's clear or no recollection of the total ICU-stay. The demographic and clinical variables were then dichotomized and a bivariate analysis with Fisher's exact tests was used for comparing differences in relation to DM. A confirming model with logistic regression using only significant variables (p -value < 0.05) from the bivariate analysis was then used to identify factors that influenced DM (Altman, 1995).

Fisher's exact tests was also used for comparing patients with or without DM related to different types of memories (factual and emotional) during ICU-stay, problems after discharge and rate of RTW (Table 1).

Paper II

Fisher's exact test was used for categorical data and the Student's t-test for continuous data when comparing groups. Pitman's test (Good 2000) was used for the correlation between on one hand the eight domains of the SF-36 and HAD and on the other hand gender, DM, head injury, mechanical ventilation, pre-existing disease, age, ICU-stay in days, ISS, APACHE II and total SOFA score. For the multivariate analysis with all correlations from Pitman's test, forward multiple linear regression analysis was used for SF-36 and forward logistic regression for HAD. Independent variables were DM, head injury, mechanical ventilation, pre-existing disease, age, ICU-stay in days, ISS, APACHE II and total SOFA score, and dependent variables were HRQoL with the eight domains of SF-36 and HAD (Altman 1995; Hair et al. 1998) (Table 1).

Paper IV

The Chi-Square test and, when required Fisher's exact test were used for categorical data, McNemar's test for comparing changes in groups over time, and the Mann-Whitney test was used for continuous data when comparing groups. The Wilcoxon signed-rank test was used for comparing continuous data over time. Subgroups analysis evaluating a variety of factors was also preformed by splitting the cohort on the basis of; loss prior to follow-up, different memories from the ICU-stay (delusional or not), pre-existing disease, mechanical ventilation. With the exception of loss prior to follow-up, the subgroups were assessed for impact on outcome. Spearman's rank correlation test was used for correlation between clinical, descriptive variables and HRQoL. Statistical significance was attributed to $p < 0.05$ (Altman 1995) (Table 1).

Phenomenological hermeneutical analysis

Paper III

The inductive method of phenomenological hermeneutical, mainly inspired by Ricoeur (1976) and described as a method by Lindseth & Norberg (2004), was used in order to reveal perceptions and interpretations from the informants' narratives about their memories from a trauma and the care afterwards. The phenomenological hermeneutical method searches for essential meaning in a phenomenon, in this study the participants' memories, which will be revealed by the interpretation of the text of the participants' stories. According to Ödman (1979), to interpret is to convey meaning. Understanding in a hermeneutic way is to understand that your existence is affected by, and changes because of, this understanding. The pre-understanding is the foundation for our understanding. Pre-understanding had always a direction and it can be an obstacle as well as a resource. It's contributes to a first orientation in the process of interpretation and makes it possible to move further. Concerning the pre-understanding in this study

the author has several years of experience as a critical care nurse, and the supervisors as researchers within the field of intensive care.

The analysis of the text began with a naïve reading where every interview was read several times and condensed into a summary of all the interviews. Here the first expression of the text is viewed, what does the text say? The naïve reading from the interview text (paper III) reveals that; 'the memories of being injured and cared for in the ICU were experienced as both good and bad. Regardless of there being memories of the trauma and the ICU care or not, there was a fear concerning what had happened, but also good memories of care. The family became extremely important as a source of security and love. There was a fight for coming back after the trauma and they needed a lot of support. Returning to work was central and was also a way of gaining health'.

The naïve reading was then validated by several structural analyses in which the interviews were read again and 17-27 shorter or longer 'meaning units' were extracted from each interview, condensed and interpreted into subthemes and four final themes. An example of a theme is shown in Table 3. The subthemes were first put in chronological order. These describe the informants' memories before, during and after the ICU. The second structural analyses describes in what ways the different subthemes were connected to each other and assembled into themes. The comprehensive understanding finally describes the whole interpretation of the phenomena which discloses new possibilities for being in the world.

Table 3 Examples from the analysis process of the theme ‘a surrealistic world’

Meaning units	Condensed	Subtheme	Theme
<p><i>“ I drove off the motorway and the car started skidding. A thousand thoughts came and went. I saw my whole life in that second, just as when you rewind a tape quickly.”</i></p> <p><i>We had a car crash and I wake up hanging upside down in my safety-belt. It was is very quiet, dark and then I got panic..</i></p>	<p>Something unexpected happens</p> <p>Fear and panic</p>	<p>To be in a floating existence</p>	<p>Being connected to a surrealistic world</p>
<p><i>“I was relieved when he finally came. I said: I’m sorry for ruining our holiday.”</i></p> <p><i>“I cried a lot in the emergency. It was the first Christmas that my children weren’t at home. They were abroad with their dad and I couldn’t get hold of them. My mother was away and my boyfriend, who I’d been with, had stayed at the party and didn’t know what had happened. I felt pretty lonely. Yes, I did.</i></p>	<p>Relief and guilty of the change in situation</p> <p>Feeling lonely and sad when the plans had been changed</p>	<p>Changes of plans</p>	
<p><i>“It felt as if I didn’t see them around me. I heard them talking to me, but it didn’t feel like I saw them; I just lay there crying.”</i></p> <p><i>“The hallucinations were unpleasant, but I’m still grateful to that Michael who was sitting above my bed. He was there for me, and helped me with those nasty people. He defended me when the others were sitting there throwing stuff at me. Daniel threw pieces of paper at me. I was a bit angry with Michael as well, though. Why didn’t he tell them off more forcefully so that they would’ve gone a bit earlier? I have told everybody about this; they just laugh.”</i></p>	<p>Not being present in the real world</p> <p>Scary hallucinations about nasty people who were very real at the time</p>	<p>To be in an unreal world</p>	

ETHICS

This thesis was designed and implemented in compliance with the principles in the World Medical Declaration Association's Helsinki Declaration (2000) which includes; the principle of respect for autonomy, the freedom of the will to participate or not in a study, non-maleficence, not harming the participants, beneficence implying that the research contributes to welfare, and finally the principle of justice which implies that the research contributes 'to each person an equal share' (Beauchamp & Childress 2001). Written information was given to all participants, and it was emphasized that participation was voluntary. The studies were approved by the Ethics Committee of the Medical Faculty, University of Gothenburg, Gothenburg, Sweden (No Ö 312-02, T 461-02, T 669-06).

In order not to harm these individuals after the trauma it was decided to wait at least 6 months after the trauma. However, it was important to ask these rather vulnerable individuals about their self-estimated health and memories in connection to the trauma in order to improve their care. Furthermore, ethical consideration was taken into account regarding the interviews. Both written and verbal information was given about the interview study and the participants chose the time and place for the interview. The participants talked about the trauma which often had changed their whole life and they had powerful memories from the time when they were injured (paper III). Many of them felt a need to talk about the trauma and following care. All participants were given the opportunity to continue the conversation after the interview, and they were encouraged to call the interviewer or a named registered nurse at the ICU after the interview if needed. The text from the interviews has been treated with respect for the participants' integrity during both the analytical and publishing phase. The participants were guaranteed confidentiality and anonymity in the presentation of the results.

RESULTS

The findings from the different studies are presented in a comprehensive way where patients' memories are presented both from the quantitative study (paper I, II) and the qualitative study (paper III) and mixed in the presentation of the findings. Patients HRQoL, anxiety and depression are presented both from a short-term (paper II) and a long-term perspective (paper IV) so is also RTW (paper I, IV).

Demographic and clinical variables

Paper I, II

In study I, the average age of all patients in the group (n=239), was 45 years (range 19-87), and 25% were woman (Table 4). Duration of stay in the ICU ranged from 1 to 45 days. More than half of the patients (62%) remained in the ICU for ≤ 2 days and 27 patients (11%) for more than one week. The majority 55%, suffered from trauma caused by traffic injuries and 19% from falls. Although 43% of the patients were temporarily unconscious at the scene of the accident, only 25% were diagnosed as having suffered a head injury.

Table 4 Clinical and demographic variables (paper I, II)

Variable	n=239	
Mechanism of injury		
Traffic injury	133	(55%)
Falls	46	(19%)
Recreational injury	19	(8%)
Intentional injury	16	(7%)
Occupational injury	16	(7%)
Other	9	(4%)
Male	178	(75%)
Delusional memories	61	(26%)
Head injury	60	(25%)
Mechanical ventilation	60	(25%)
Pre-existing disease	78	(33%)
Body temperature $\geq 38^{\circ}\text{C}$	85	(36%)
S-Haemoglobin $\leq 100\text{g/l}$	68	(29%)
B-Glucose $\geq 15\text{ mmol/l}$	5	(2%)
Propofol	75	(32%)
Benzodiazepines	57	(24%)
Opioids	193	(81%)
Age (years)	45	± 17.9
LoS (ICU-days)	4.0	± 6.1
ISS	10.8	± 7.5
APACHE II	5.3	± 6.1
Total SOFA score	2.3	± 3.1

Continuous data are presented as mean \pm SD, Categorical data as n (%) ISS: injury severity score, APACHE II: acute physiological and chronic health evaluation, SOFA: sequential organ failure assessment, LoS: length of stay.

Of the total group (n=239) of patients with trauma 38.5% had ISS<9, 33% had ISS≥9 and 28.5% had ISS≥15. More than one third of the patients (38%) had had at least one surgical procedure. Sixty patients had been on mechanical ventilation. Out of these, 28% were mechanically ventilated for one day, 52% for two to six days and 20% for seven or more days. Sedation routines for patients on mechanical ventilation consisted of continuous intravenous infusion of Propofol, on average 2000 mg/day and 45% of the patients received benzodiazepines. Muscle relaxants or physical restraints were never used. Opioids were used as pain treatment for all patients that needed pain treatment. Out of the 78 patients with pre-existing diseases six were related to psychiatric history, and 72 to somatic history. There were no significant gender differences due to age, APACHE II, SOFA score or ICU-stay apart from severity of injury where men had a significantly higher mean ISS than women (11.5 vs 8.8 p =0.01)

Paper III

The studied sample consisted of 18 participants from four different hospitals; one university hospital (n=11), two county hospitals (n=6) and one district hospital (n=1). Fifteen informants (eight men and seven women) worked before the injury occurred, two were retired and one was on sick leave. Nine (five men and four women) had returned to full or part time work at the time of the interview. Seven of them lived alone. Thirteen informants suffered from multiple injuries, two had an isolated head injury and three had unspecific smaller injuries (Table 5).

Table 5 Demographic and clinical variables (paper III)

Variable	Total n=18	Men n=9	Women n=9
Mechanism of injury			
Traffic injury	14	6	8
Falls	1		1
Recreational injury	1	1	
Occupational injury	2	2	
Mechanical ventilation	12	7	5
Days of mechanical ventilation	2 (1-37)	3 (2-37)	1 (1-21)
LoS (ICU-days)	5.5 (1-38)	5 (1-38)	6 (1-22)
ISS	15 (1-29)	17 (4-29)	5 (1-29)
Age at injury	48 (22-67)	54 (27-67)	40 (22-55)

Continuous data are presented as md (range), Categorical data as n.

ISS: injury severity score, LoS: length of stay

Paper IV

In the follow-up study (n=153), the mean ICU-stay was 4 days and 106 (69%) patients stayed there for two or more days. Most patients (58%) were injured by traffic injury, followed by falls (18%). Age at follow-up was 49±16.5 and 27 were singles. Thirty-two participants (21%) had a university education. Nearly half, 73 patients (49%) had had an additional hospital stay after the trauma, 20 patient (13%) was cared for in the ICU once more, 11 (7%) due to trauma, one patient after a concussion of the brain and the remaining patients after traffic injury. Three patients did not answer the question about additional hospital stay. Thirty-five patients (23%) experienced DM during their first ICU-stay. These patients' median age mean age at follow-up was 38 and median ISS was 10.

Patients' memories (paper I-III)

When the trauma occurred the world was experienced as uncontrollable and the participants became dependent on others. At the scene of the accident the participants had good memories of receiving attention from others who helped them and called for the paramedics (paper III). Nearly half of the 239 patients (46%) remembered being admitted to the hospital. More than half (59%) remembered being admitted to the emergency unit (paper I). In the emergency care there were memories of being in a floating existence not knowing what was happening, participants remembered feeling lonely and that the plans they had for tomorrow had to be changed. They recalled feelings of both security and anxiety in the emergency when being taken care of (paper III).

The whole ICU-stay was clearly recalled by 30%. Those 71 patients with a clear recall had a shorter ICU-stay, received less sedatives and there were also on mechanical ventilation less. Factual memories such as occasional memories of family members and faces were remembered by 83%. Emotional memories such as pain were remembered by 70% (paper I). Memories from the ICU-stay imply that they had been in an unreal world with DM and many patients had fragmentary memories from the first days (paper III).

Of all patients 61 (26%) had DM during their ICU-stay. Among the 61 patients who reported DM, 38 (62%) had nightmares and 29 (48%) had dreams. There were also 12 patients who had paranoid memories of other patients or staff trying to kill or hurt them. Hallucinations were reported by 26 patients (43%). Patients with DM also reported more emotional memories such as pain, panic, fear and confusion. Patients younger than 50 years of age seemed to be more prone to DM. Renal failure was also a significant predictor of DM. The results including all patients (n=239) revealed that patients with DM suffered to a greater extent from complications e.g. fever, anemia and vital organ failure compared to the patients with no DM. Patients with DM were more on mechanical ventilation and received more Propofol per day than patients without such memories (919 mg/day vs 319 mg/day p=0.003) (paper I).

Twenty-seven patients reported amnesia related to the ICU-stay (paper I). Some patients did not want to remember while others were curious about it. In some cases the family and close friends had told them about their ICU-stay. Some of the participants did not think what had happened in the ICU was real (paper III). More of the patients with no clear recollection also reported DM ($p < 0.01$) (paper I).

Family members' visits together with memories of being loved and cared for appeared to be important. This care made them realize that people are responsible for each other, and they felt comforted but also vulnerable. There was also a feeling of gratitude for life (paper III). Fewer patients with DM recalled the presence of family members compared to patients with no DM (57% vs 84% $p < 0.05$) (paper I).

At the nursing ward, patients had memories of enduring, and the struggle to win life back, and accepting that their lives had become different after the trauma, realizing that it was up to themselves to get well. When returning home, there were memories of not fitting in and these feelings limited their life. To exist in this world of trying conditions implied that life would be forever different and the future more uncertain. The delusions were still remembered clearly and some participants experienced that the delusions came back to them when they were tired or stressed (paper III).

When returning home, more patients who had reported DM described problems related to the fact that they had only fragmented memories from the ICU and they experienced unexplained feelings of panic or apprehension after the ICU-stay ($p < 0.001$). Of all patients ($n = 239$) 56% had discussed their ICU-stay with their family, 8% had talked to physicians or nurses, 14% had spoken to both family and hospital staff, while 22% had not talked about their ICU-stay at all (paper II). However, family and friends helped them and gave them courage to live and move on even if the future in many ways was felt to be uncertain (paper III). Subthemes and themes are shown in Table 6.

Table 6 Subthemes and themes in the trajectory of care after injury

Scene of the accident	Emergency unit	Intensive care unit	Nursing ward	Coming home	Being Connected to:
To be in a floating existence	Changes of plans	To be in an unreal world			A surrealistic world
		To be injured	To be enduring	To be in No Man's Land	An injured body
To receive attention	To be taken care of	To be cared for			Care
		To be loved	To win life back	To be in acceptance	Gratitude for life
Subthemes					Themes

In the comprehensive understanding it was found that the different memories were balancing each other during the trajectory of care before, during and after the ICU-stay. Bad memories of a surrealistic world and of being injured seemed to connect the individual to feelings of hopelessness and worthlessness. This could be counteracted by good memories of care and of a gratitude for life. Some informants moved on, experiencing a gratitude for life despite their limiting injured body and an uncertain future, while others had difficulties to move on because they felt connected to an injured body with limitations and consequently their future seemed more uncertain. The meaning of living with memories from an injury and intensive care was an uncertain future and this became their living in the world (Figure 2). This comprehensive understanding will disclosed new possibilities for living with memories of an injury during the trajectory of care (paper III).

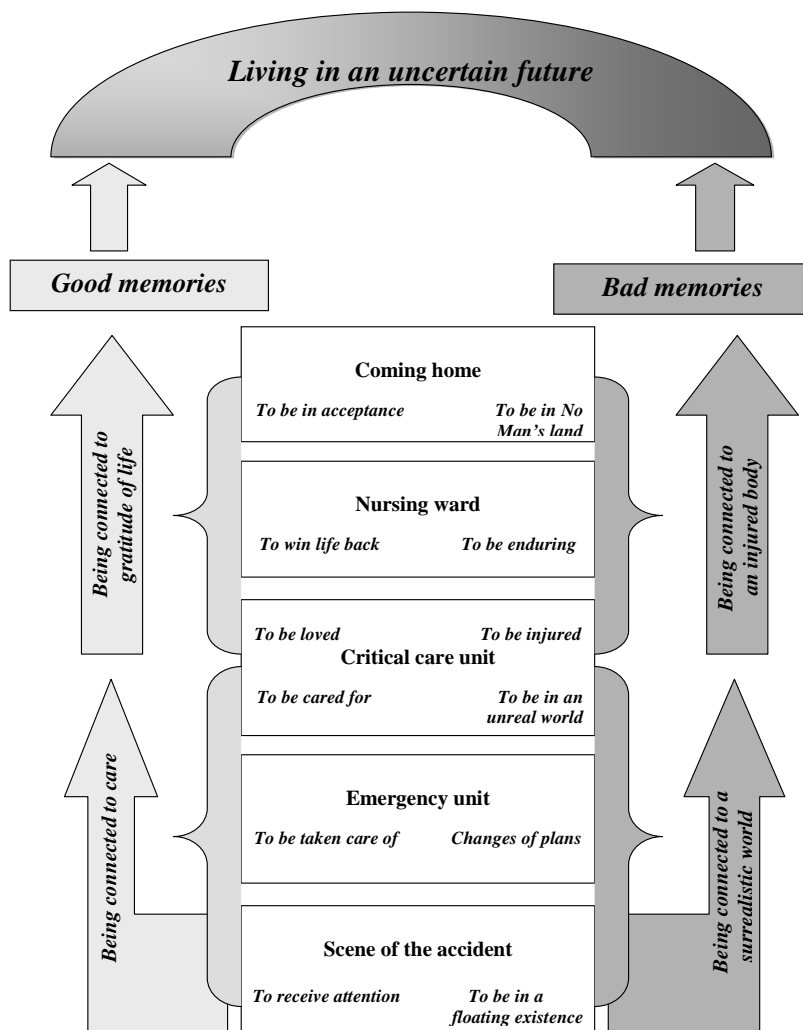


Figure 2 The trajectory of care after injury. Good memories balancing bad ones in an uncertain future. (Ringdal M, Plos K, Bergbom I. Memories of being injured and patients' care trajectory after physical trauma BMC Nursing 2008, 7:8, p 5)

Health Related Quality of Life (paper II, IV)

In the short-term perspective 0.5-1.5 years after the trauma (paper II), patients with DM, as well as patients with pre-existing diseases had correlation with all eight domains of SF-36 which meant lower HRQoL. Older age, prolonged ICU-stay, higher ISS, APACHE II and total SOFA score had correlation with the lower physical functioning and lower role physical domains. Patients on mechanical ventilation had correlation with five domains: physical functioning, role physical, vitality, social functioning and mental health. Moreover, patients with head injury had a correlation with the mental health and social functioning domains (Table 7).

In the multivariate analysis (paper II) comparing all significant variables from the univariate analysis, DM had a significantly importance in all eight domains of HRQoL (Table 7). If patients experienced DM they scored 14-24 units below in all domains compared to those who did not have these experiences. Also, patients with pre-existing diseases had significantly lower scores, 8-18 units below in all domains of SF-36 compared to those without pre-existing diseases. APACHE II affected physical function, and when APACHE II increased by one unit, physical function decreased by 1.3 units. The total SOFA score influenced the role due to physical function; when the total SOFA score increased by one unit, role due to physical function decreased by 2.7 units. Head injury had an effect on social function and mental health with 8-9 units below. This influence from the variables on HRQoL was independent of each other.

Table 7 Associations between SF-36 and different variables (paper II)

SF-36 Domains	DM	Pre-existing diseases	Age	LoS	ISS	Apache II	SOFA	Mechanical ventilation	Head injury
Physical function	X	X	x	x	x	X	x	x	
Role physical	X	X	x	x	x	x	X	x	
Bodily pain	X	X							
General health	X	X							
Vitality	X	X						x	
Social function	X	X						x	X
Role emotional	X	X							
Mental health	X	X						x	X

x = correlation in univariate analysis, **X** = the variable has significant importance in the multivariate analysis.

When comparing the patients with trauma with a reference sample matched for age and gender, the patients with trauma scored significantly lower in all eight SF-36 domains ($p < 0.001$) after 0.5-1.5 years. Patients with DM scored even lower (paper II). After 4.5-5.5 years the patients with trauma still scored significantly lower than the reference sample in all domains (paper IV).

When comparing the scores over time (paper IV) for the total trauma group there was an improvement in four domains of HRQoL; physical function, role due to physical function, role due to emotional function and mental health from the first 0.5-1.5 years to the second measure 4.5-5.5 years post-trauma. When comparing HRQoL scores over time for patients with and without DM, both groups scored significantly higher in four to five domains for SF-36. Patients without DM followed the same pattern as the total trauma group with improvement in 4 out of 8 domains of SF-36 (Figure 3). For patients with DM there was an improvement in 5 out of 8 domains; physical function, general health, social function and mental health (Figure 4).

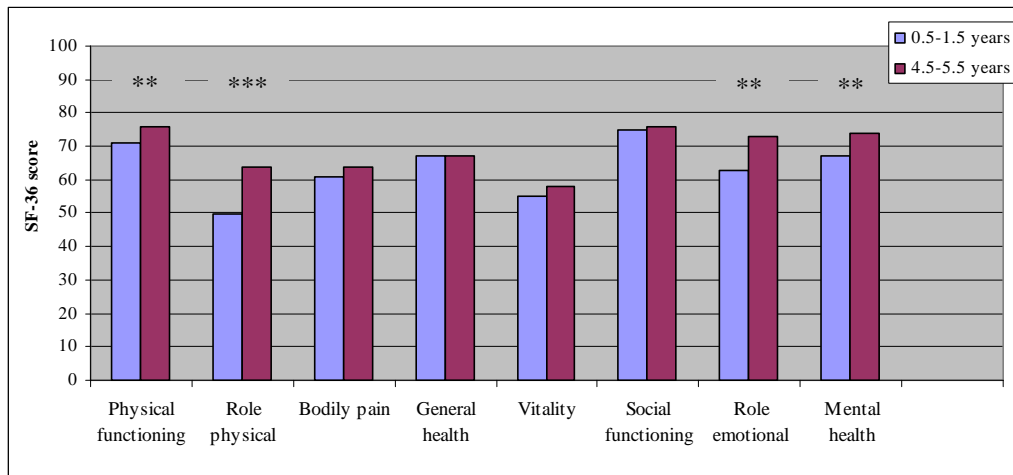


Figure 3 Changes in SF-36 scores over time in patients without DM (n=118) ** $p \leq 0.01$, *** $p \leq 0.001$

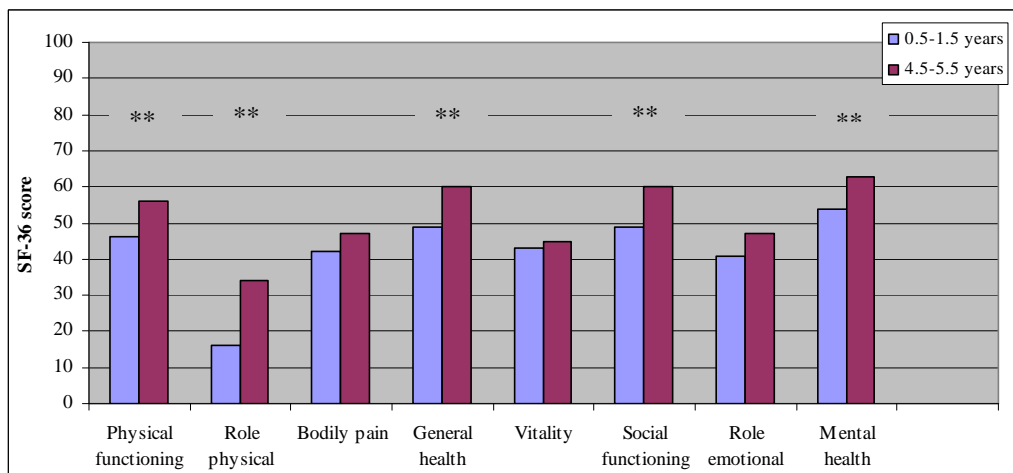


Figure 4 Changes in SF-36 scores over time in patients with DM (n=35) ** $p \leq 0.01$

When analysing the clinical factors influence on the SF-36 domains in the long-term (paper IV), most correlation was found in physical function and role physical. Physical function correlated with age, ICU-stay, APACHE II and SOFA score. Role physical correlated with age APACHE II and SOFA score, and Bodily pain with age. Finally, the ISS correlated positively with mental health. Concerning the two overall domains PCS and MCS, PCS correlated negatively with age, ICU-stay, severity of illness, and failure of vital organs. MCS correlated positively with severity of injury and ICU-stay. When analyzing the two overall domains PCS and MCS over time for patients with and without DM, there was a improvement ($p < 0.05$) in PCS but not in MCS for patients with DM (Figure 5).

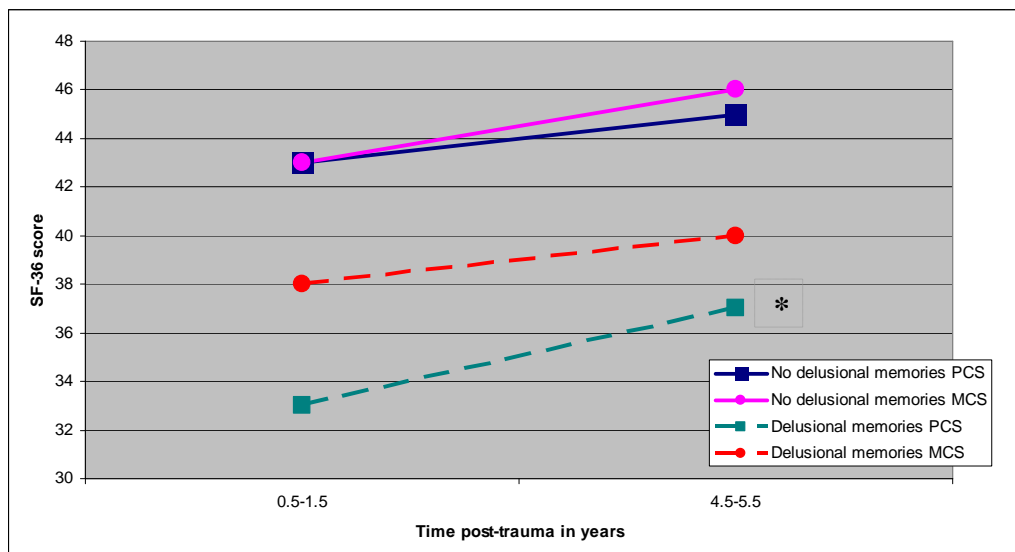


Figure 5 Changes in SF-36 score, physical component summary (PCS) and mental component summary (MCS) over time for patients with and without DM * $p < 0.05$

From a long-term perspective (paper IV), patients with DM were still significantly different to those without DM. The former had lower SF-36 scores in all eight domains except for general health, a domain in which they approached the other group. When subgroups of patients with or without mechanical ventilation or pre-existing disease were compared, patients on mechanical ventilation scored lower in 2/8 domains; physical function and role physical. Patients with pre-existing disease scored lower in 5/8 domains; physical function, role physical, bodily pain, general health and vitality. There was no significant difference found regarding gender or head injury with any of the SF-36 domains (paper IV).

Anxiety and symptoms of depression (paper II, IV)

In the short-term perspective (paper II) 0.5-1.5 years after the injury 39% of all patients (n=239) experienced anxiety (HADA \geq 8) and 31% had symptoms of depression (HADD \geq 8). The univariate analysis showed a correlation between DM and both anxiety (p=0.0028) and symptoms of depression (p=0.0022). Moreover, patients with head injury had a correlation with anxiety (p=0.017). In the multivariate analysis, patients with DM (OR 2.5, CI 1.4, 4.7, p=0.0026) and those with head injury (OR 2.1, CI 1.1, 3.6, p=0.017) still had an association with anxiety. The probability of patients experiencing anxiety when having had DM was 51% and with DM and head injury it was 69%. Without these memories and head injury the probability for anxiety was 29%. Patients with DM also had association with symptoms of depression (OR 2.7, CI 1.5, 5.0, p=0.0013). The probability of symptoms of depression when patients had DM was 48% and without these memories it was 26% (paper II).

The number of DM (one or more) had no impact on the patients' anxiety or symptoms of depression. Fifty-two patients, who had not talked to anybody about their ICU experiences, had significantly more symptoms of depression (HAD \geq 8) than those 179 patients (8 missing) who had discussed this topic with someone (52% vs. 26% p=0.001). There were three patients out of six with pre-existing diseases related to psychiatric history among those with DM (paper II).

In the long-term, 4.5-5.5 years after the trauma (paper VI) there was a significant improvement for all the patients (n=153) concerning mental well-being with lower scores of anxiety. However, anxiety (HADA \geq 8) was more common for patients' with DM compared to those without DM (54% vs. 37%) after 0.5-1.5 years and this pattern was the same after 4 years (43% vs. 24%). Concerning symptoms of depression (HADD \geq 8), the results were similar at the first (47% vs 29%) and the second time (38% vs 19%).

Return to work after trauma (paper I, IV)

Excluding the patients who were in retirement prior to their injury (n=32), the proportion of participants in employment were nearly the same in both groups; 93% (141 patients) in the no delusional memory group and 91% (50 patients) in the DM group. When taking time into consideration and splitting the patients into two groups according to when they answered the question about RTW, more patients without DM had RTW 6-12 months after the trauma compared to patients with DM (67% vs 15% p<0.001). After 13-18 months there were no differences between the two groups (65% vs 50% p=ns) (paper I).

Four years later, 126 adults of the 159 who answered the questionnaire were below 65 years of age and 75% had RTW or studies part or full time. This included 5 adults (3%) searching for work. One participant did not answer the question about RTW. There was a significant improvement of RTW compared with the reported situation 4 years earlier (paper IV).

There were no differences in clinical data, gender or age between those who returned to work or not from a long-term perspective. However, patients who did not RTW, were more often singles (34% vs 17% $p=0.012$) and fewer had not worked before the trauma (84% vs 100% $p=0.000$). When comparing patients who had DM to those who had not had such experiences, there were no differences after 4 years concerning RTW (63% vs 78% $p=0.104$) (paper IV).

Participants with anxiety and symptoms of depression after both 0.5-1.5 years and 4.5-5.5 years were significantly more common among those who were on sick leave. Participants on sick leave also reported significantly more intrusive memories (the PTSD-related symptom) from the time in the hospital after returning home (paper IV).

DISCUSSION

General discussion of the findings

In this thesis, patients who suffered from physical trauma with memories from the time before, during and after the ICU-stay have been studied from different points of view. Some main findings of interest will first be discussed in the light of earlier research and then in what ways these findings are significantly important for improving intensive nursing care for patients after trauma. The findings in relation to the nursing theory 'Responding to threats to integrity of self' (Morse 1997) will be discussed in the light of the results of the qualitative study. Finally the results of a study are directly dependent on the validity of the methods used (Burns & Grove 1997). When using methods based on two different scientific traditions as has been done in this thesis, the methodological considerations are several and these are discussed in the last section of the discussion.

This thesis provides knowledge about patients' memories in connection to a trauma and ICU-stay regarding HRQoL, anxiety, depression and RTW after the trauma. An additional understanding for the trajectory of care after injury and the memories being created during that journey may help the staff to ask the right questions and act in a way which shows an understanding for the patients' situation after trauma, something which may result in avoiding bad memories.

Delusional memories and health

Patients suffering from trauma and with DM during the ICU-stay had considerably poorer HRQoL compared to other patients 6-18 months after trauma. Similar results in general patients in the ICU were found in a study by Granja et al. (2005). Four years later, this discrepancy in HRQoL remained for the participants in the present study. To our knowledge comparative data investigating long-terms effects from memories during the ICU-stay and HRQoL have not been presented earlier.

DM and pre-existing disease were the only variables which influenced on all eight domains in SF-36. The role of pre-existing disease in HRQoL has previously been investigated (Holtslag et al. 2007; Orwelius et al. 2005). Orwelius et al. (2005) claims that most patients (74%) admitted to the ICU have pre-existing diseases and a majority have at least one. In our study, only one third of the patients had one or more pre-existing diseases. This result implies that patients with trauma in the present study were healthier than other patients in the ICU, but also that pre-existing disease is of importance when self-estimating health after trauma.

Most patients (83 %) in the present study had some factual memories such as memories of faces, voices or family members. This is in agreement with a recent study in Sweden where 82% had memories from the ICU. In that study however, all patients were on

mechanical ventilation for more than 24 hours (Samuelson et al. 2006). In the present study, most patients were not on mechanical ventilation. This implies that mechanical ventilation is not the main cause to amnesia. In previous studies recall from ICU differs from 30-100% (Stein Parbury & McKinley 2000), and 62-66% (Capuzzo et al. 2001; Rotondi et al. 2002; Russell 1999) in more recent studies. One explanation for the differences compared to our study can be measurements at different times in the ICU, for example only during the mechanical ventilation, the use of different data collecting methods or the use of different sedation regimes in different countries that may affect memories. In the present study, significantly more patients with no clear memory had been treated with sedative drugs and opioids. These findings are in line with Samuelson et al (Samuelson et al. 2006) who found that amnesia was associated with deeper levels of sedation and it is also in line with Hallenberg et al. (1990) regarding amnesia and intravenous opioids.

One out four patients' in the present study had DM. This can be compared to 34%-60% in other studies using the same instrument (Capuzzo et al. 2004; Jones et al. 2000b; Samuelson et al. 2007). There are possible explanations for the differences compared to these studies, for example that the sample was from a general patients group in the ICU. More patients in these studies were also on mechanical ventilation and there were different types of restraints (physical or chemical). A patient who suffers from trauma in the ICU differs from the general patients in the ICU due to better conditions before the trauma.

Several factors such as younger age, prolonged ICU-stay, mechanical ventilation, fever, anemia, surgery, renal failure and sedation were associated with DM in the present study. Apart from a younger age, this is in accordance with previous research (Capuzzo et al. 2004; Granberg Axell et al. 2002; Rotondi et al. 2002; Rundshagen et al. 2002). Patients younger than fifty years of age seem to report more DM. These findings are supported by Rundshagen et al. (2002) who found that younger people seem more prone to recalling dreams more frequently than older ones. In contrast to these findings, hallucination had also been reported more often with increasing age (van der Luer et al. 2004). More patients in the present study who remembered DM also had memories of pain, fear, panic and confusion. These findings confirm earlier research as well (Bergbom-Engberg & Haljamae 1988; Granberg et al. 1999; Magarey & McCutcheon 2005)

A Comparison with other studies of patients may help to interpret the relationship of DM during the ICU-stay to HRQoL in patients who suffer from trauma. Lippert-Gruner et al. (2007) studied patients' HRQoL during the first year after trauma. These patients' mean age was 32 years and the patients suffered from severe brain trauma with or without polytrauma with severity of injury with mean ISS of 40 vs 27. All patients had been cared for in the ICU. Sluys et al. (2005) determined patients' HRQoL 5 years after trauma, where their median age was 39 years and median ISS was 14. As shown in

Figure 6 patients with trauma and DM in our study, where the median age at follow-up was 38 years and median ISS was 10, had lower scores in all domains except for general and mental health approximately 5 years after trauma. It seems that the samples in Sluys' et al. (2005) and the present study are rather similar regarding ISS and age, but the patients with DM have poorer HRQoL after the same time of 5 years. One explanation for the lower scores can be that in our study the patients suffered from more complications during the ICU-stay or that the DM may have influenced also the physical health as well since the scoring for mental health are quite alike. In Lippert-Gruner et al. (2007) study the patients were younger and more severely injured, but despite that the patients had better HRQoL after a shorter time compared to the present study.

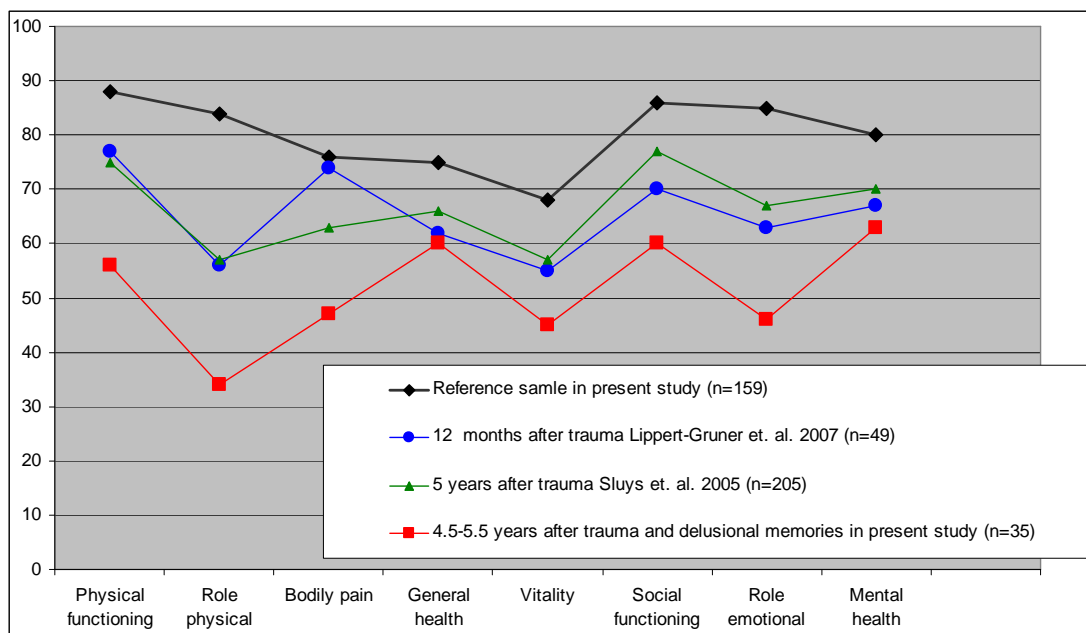


Figure 6 SF-36 scores (mean value) in different studies of patients after trauma and ICU-stay

After trauma and intensive care there was a decrease in HRQoL compared to a reference sample of the Swedish population even up to 4.5 years after the trauma. This is in line with previous studies for patients with trauma (Sluys et al. 2005) as well as for general patients after intensive care in a long and short-term perspective (Flaatten & Kvale 2001; Orwelius et al. 2005; Ridley et al. 1997). Patients who suffered from acute trauma and were admitted to the ICU and reported having had a good HQoL before the trauma, had a significant decrease of their HQoL following discharge from the ICU (Ridley et al. 1997; Thiagarajan et al. 1994). In our study (paper IV), there was an improvement in both physical and mental health for all patients after trauma in the long term but they did not reach the scores of the reference sample. The question is whether five years is too short a time for achieving complete recovery. Some of the patients also had additional hospital stay as there can be several surgical operations a long time after trauma that may affect health.

The present study (paper II) shows that the probability of symptoms of depression and anxiety when patients had DM was rather high. Jones et al. (2001) also found that DM without factual memories during an ICU-stay causes anxiety among patients. It appears to be important to have these factual memories, e.g. memories from family members visiting the ICU. All the patients with trauma in our study who had DM also had factual or emotional memories. However, Samuelson et al. (2007) claim that stressful events during the ICU-stay, rather than DM cause anxiety in the short term. In the long term there is no evidence that stressful events at the time are related to anxiety. The reason for development of anxiety and depression after trauma and intensive care are probably several, for example Richmond et al. (2007) found that psychological problems prior to physical trauma was common. In the present study only six patients had a history of psychiatric illness. Also, the trauma itself may cause psychological distress. Wang et al. (2005) claims that traffic injuries have an impact on individuals' psychological well-being. Welch (1995) found when interviewing patients after the trauma that depression was a hindrance to recovery. Schnyder et al. (2001) discuss that individuals' subjective sense of threat to life is predictive for the development of psychological problems after the trauma.

Delusional memories and return to work

Of the whole trauma group (n=153), 75% had RTW after approximately 5 years (paper IV). This is in accordance with Frutiger et al. (1991) who in their study showed that 79% of severely injured ICU patients were working after 5 years. It is also in line with other studies of RTW after major trauma where 75% had RTW six years after trauma (van der Sluis et al. 1998) and 80% to full or part-time work at follow-up (Holtslag et al. 2007). Despite the lower scores in HRQoL, in the present study the patients with DM had RTW to the same extent as patients without those memories after approximately 5 years. Patients who were not being able to RTW had more anxiety and symptoms of depression. They also had more intrusive memories from the hospital which may be PTSD related symptoms, and this may also impair the HRQoL further. Other research supports these findings (Connelly et al. 2006; Michaels et al. 2000). To be in employment creates participation in society and establishes the foundation for durable social contacts. However, RTW is a complex process especially for injured persons (Beardwood et al. 2005).

Many of the patients who had not been able to RTW after 5 years were living alone. The reason for this is difficult to find out, i.e. what is the cause and effect, but the question is whether social support and sharing experiences is of importance for recovery? To have a supporting family and friends can be of vital importance for the individuals' possibility to manage to return to working society and to recover. However, RTW does not show the whole picture nor is it directly connected to well-being. According to Baldwin et al. (1996) RTW can be a misleading measure of outcome of healthcare. Firstly, because of RTW is influenced by factors not related to health care. Secondly, if RTW only is

measured only once after trauma, it marks that the person RTW but there can be several episodes of work disabilities caused by the original injury. For these reasons the RTW must be evaluated over a period of time, as has been done in the present study where RTW was measured twice after 0.5-1.5 years and again 4 years after that.

The importance of memories

In the present study (paper III), it was found that many years after the trauma patients still had powerful memories of the trauma and the following care in the ICU and the hospital. Participants often felt ashamed about DM and not being themselves with an injured body, losing some of their dignity during the hospital-stay. This was interpreted as bad memories. Good memories, on the other hand, were memories from family and care that restored the dignity. Walker (2003) argues in a literature review that good memories tend to persist and allow people to look forward towards tomorrow. The main theme in the present study was an uncertain future after the trauma but when bad memories were balanced by good ones there seemed to be more possibilities to move on despite of the uncertainty.

The trauma as a life-threatening event often changed the patients' lives and many of the patients valued their lives in a new way. Richmond et al. (2000) discusses that injury forced people to face their own mortality. Participants in the present study who experienced DM in the ICU remembered them clearly and expressed them vividly. The delusions were scary most of the time. Previous qualitative research has also reported that confusions, nightmares, and hallucinations are highly distressing (Johnson et al. 2006; Magarey & McCutcheon 2005; Roberts & Chaboyer 2004). This world of critical illness with horrifying memories is also described by Gjengedal (1994). Memories of the injured body produce feelings of panic and vulnerability and patients remembered the difficulty to communicate their thoughts and needs due to the mechanical ventilation. This has also been stressed in previous research (Bergbom-Engberg & Haljamae 1993; Wojnicki-Johansson 2001). If the communication with the patient in the ICU is impaired, it can cause anger, sadness and sometimes a feeling of giving up (Hafsteindottir 1996). Johnson et al. (2006) also discusses that long-term mechanical ventilated patients experienced their body as unfamiliar. All these memories described above can be interpreted as bad memories.

However, there are also good memories of love and care. Important memories included receiving attention from others who helped them at the scene of the accident. Nurses at the emergency unit who located the relatives as soon as possible and gave physically care with empathy brought comfort to the patients. The injured patient realized that people are responsible for each other and that he/she was not alone in the world. According to Lögstrup (1997), being in need of help can be seen as an ethical demand. This demand is implicit and brought about by the patients putting their lives in the hands of people at the scene of the accident, of paramedics and nurses, trusting the

notion that each human being is considered to be responsible for another human being in distress. Other good memories were to be loved, to win life back and to be in acceptance and these memories connected patients to gratitude for life. Family support was extremely important here. Visits from close relatives should be facilitated by the nurses because they are often the motivation for the critically ill patient to stay alive (Engström & Söderberg 2007). In the present study, most patients had memories of family visits and they also referred to family in the interviews as a source of comfort and love. They also referred to unknown people at the scene of accident and the emergency unit who cared about them. Recent research in Sweden emphasizes how important the presence of loved ones is to the patients in the ICU and in the emergency unit (Engström & Söderberg, 2007). For this reason, a great effort is being made in the Swedish ICUs to facilitate visit from loved ones to the patient during their stay in the ICU, but also to develop a more family friendly environment and care.

The trauma was an important event in the participants' lives, and it will never be forgotten, but it was important to leave it behind them and move on with their life. These findings in the present study are consistent with previous research showing the 'event', 'fallout' and 'moving-on' in a life that is forever different after the trauma (Richmond et al. 2000). It can therefore be discussed what can help the patient to regain their life, to reach a sense of dignity and to 'move on'. Being cared for, feeling appreciated and being of important to loved ones, even if disabled, might be one important thing.

Patient memories and nursing care

When caring for the injured patient, the nurse is a central person for providing trust and safety. Seriously injured patients arriving at the emergency unit and later to the ICU can be partly conscious and having only fragmentary memories of the event. In this often life-threatening situation, the goal is to assess and stabilize the patients as quickly as possible. The role of the nurse is to coordinate care and to assess the patients in term of early signs of deterioration in their medical condition, but also to make patients feel safe and secure (Wiman et al. 2007). According to Morse (1999), if patients obtain consolation and well-being in this situation they feel safe and they will trust the staff and cooperate better. The present study also indicates that memories of these caring actions are important for the patients' recovery. It can therefore be discussed if the effect of an early established caring relationship can contribute to a feeling of being safe and well taken cared of and thereby also become a good memory in the recovery process. In a case study, Davidhizar (1997) revealed how essential it is for the nurse to maintain a hopeful outlook on the patient's life. A person who feels that her feelings are recognized and understood will be more likely to share additional feelings about odd experiences. It appears to be important to establish a trustful patient-nurse relationship to support patients' own inherent joy of life and will to fight for survival (Wahlin et al. 2006). Wilkin & Slevin (2004) claims, that caring for patients in the ICU described by nurses

involves feelings, professional knowledge, competence, skill and nursing actions. To provide the patients with good memories of care and to help patient them through painful activities, caring actions such as comforting talk (Morse & Proctor 1998) and trying to find relatives as quickly as possible are important (paper III). Beeby (2000a, 2000b) claims that caring for the patient in the ICU is to be involved. This means showing concerns for the patient and sustaining the patient which in turn means that the nurse is providing support to the patient. Receiving care from a nurse who communicates warmth, care and personal closeness makes the patient feel less stressful and a gives them a feeling of well-being (Holland et al. 1997).

Bad memories are connected to fear and sadness and of being humiliated. This creates additional suffering to being injured. Patients may also suffer from DM about which they have difficulties expressing their feelings. According to Morse (2002), suffering is the fundamental response to injury and nurses are the caretakers of the suffering. In intensive care, the nurse is working at the bedside most of the time and is therefore in a position to ease and relieve the suffering both to the patient and the family who is visiting a loved one.

In order to understand the patients' situation after a trauma, Morse's theory (1997) 'Responding to Threats to Integrity of Self' has been reflected upon in relation to the findings in the qualitative study (paper III). Through a meta-analysis, this theory has proceeded from The Illness Constellation Model and Preserving Self (Morse & O'Brien, 1995). The theory focuses on the process of recovery from serious injury or illness in which it integrates family and focus on the meaning and changes for the person after injury. The theory has five phases; Vigilance, Disruption, Enduring, Suffering and Learning to live with the altered self (Morse, 1997). The theory focuses on a person's 'self' and on the meaning and changes to the self. There were several attributes in our findings from the interview study (paper III) that were in accordance with the different phases in Morse's theory (1997). However, Morse (1997) is also discussing how some individuals were using self-comforting strategies better than others and hence there is a also need for nurses' comforting strategies to support the patient.

The present research reveals that patients had both good and bad memories in the trajectory of care after injury. It seemed to be important for the individuals to counterbalance bad memories with good ones, as the good memories seemed to be caring and alleviating suffering while bad memories increased suffering and was uncaring. If this balance was not present, the individuals found themselves stuck in the consequences of the trauma with rather bad memories from the trauma and care and the movement towards health and well-being was aggravated. They tried to move on but they did not have the possibility to do so because they seemed to be captured in suffering. These individuals seemed not to reach the fifth phase; 'learning to live with the altered self' (Morse, 1997). One possible explanation for the individuals who did not move on, is that they were not capable of visualizing a future or bringing meaning too

what had happened. When suffering, it can be difficult for both patients and their families to support each other and also to receive and accept the support of other's. Suffering can be a natural part of life and health. If suffering becomes unbearable it can paralyze the individual and the ability to experience health can be limited (Eriksson 1995). Participants had difficulties to find strategies to recover and found themselves in 'no man's land' even 2-3 years after the trauma.

Caring actions, when the patients felt cared for and safe, made them realize that they fitted in just as they were. In other words, the courage to be is the courage to accept oneself despite of the fact that one might feel unaccepted. To accept oneself is the foundation of the courage to trust (Tillich 2000). According to Morse & O'Brien (1995), a part of the rehabilitation process is to know and trust the altered body, revising life goals and accept the consequences of the experience. The process of 'preserving self' throughout this process requires focused energy, tremendous effort and a strong will. But it also seems that tender loving care from others is necessary.

Methodological considerations

To establish knowledge is the general purpose of scientific research. In order to elucidate injured patients' memories before, during and after an ICU-stay, to explore these memories and possible influence on health, interviews and validated instruments have been used. Using both an empirical analytic and humanistic understanding, scientific traditions including different methods for analysis such as statistical analysis and interpreting analysis, it is a challenge because different methods are rooted in different outlooks on the human being. The research question determines which method is the most appropriate (Sackett & Wennberg 1997), and in order to get a comprehensive understanding of the patients' memories, both quantitative and qualitative methods were used. The way of using data differs, but the interpreter gains the possibility to reflect and discuss the results in a holistic way. Foss & Ellefsen (2002) claims, that different types of knowledge are necessary to obtain a more comprehensive picture of the issue that is studied.

Certain aspects concerning the sample selection and data collection should be discussed. The study sample was gathered on one occasion. It included all injuries required ICU care which had occurred during one year. This was important as some injuries may be more common at certain times of the year. The study sample was collected retrospectively in the spring of 2003 from the five hospitals' databases. The review of the patients' records was also done in retrospect. Another part of the design was patients' self-estimated health, memories and RTW after the trauma. The first study (paper I, II) was cross-sectional, meaning that all patients answered the questionnaire at the same time. The time between the occurrence of the trauma and the patient answering the questionnaire ranges from 0.5-1.5 years and this can add some uncertainty regarding the results of measuring the HRQoL. It had been desirable that the patient had given their

answers at the same time after the trauma. The follow-up study (paper IV) provided useful information about changes in health four years after the first measurement. Using samples from five hospitals in the same region with consistent inclusion and exclusion criteria and validated instruments has strengthened the generalizability for the present studies (Burns & Grove 1997; Polit & Hungler 1999).

The data collection from the patients' records was firstly carried out by two persons (author and co-author) and in secondly by one person (author) to strengthen the validity. Feeding the data into the data analysis programme was also done by the same two persons who worked together and the data were then checked and double-checked. The review of the medical records was done after the questionnaires were returned. For ethical reasons, medical data were not collected from non-participants.

Regarding the instruments that have been used, both SF-36 and HAD are well-known widely used instruments with good psychometric properties. SF-36 (Ware & Sherbourne 1992) is the instrument that is recommended for assessing HRQoL in studies of patients after trauma (Bouillon et al. 2002; Neugebauer et al. 2002) and for follow-up studies after intensive care (SIR 2007). It is used in several studies for patients both after the ICU-stay (Dowdy et al. 2005) and after trauma (Lippert-Gruner et al. 2007; Sluys et al. 2005). It has been validated in Swedish studies (Sullivan et al. 1995; Persson 1998). HAD has been extensively used in studies with injured and critically ill patients (Eddleston et al. 2001; Scragg et al. 2001). The instrument shows good validity and reliability in both nationally and internationally (Bjelland et al. 2002; Lisspers et al. 1997).

A Swedish version of the ICUM tool is used in this thesis. The validity was tested in thoracic intensive care patients where the questions in the instrument were tested against interviews with the patients with good agreement (Blomqvist-Hedén 2003). The alpha coefficient was calculated to 0.88 in a recent study with 250 patients after ICU-stay (Samuelson 2006) The instrument has recently been used in a study regarding children's memories during their ICU-stay (Colville et al. 2008). Although introduced in 2000, there is still no comprehensive documentation of the usefulness of the ICUM tool. There may also be a certain disagreement regarding the presentation of the findings of patients' memories. At the time of the study, there where no other instrument available for measuring patient memories from the ICU-stay and therefore the ICUM-tool was used.

Three questions were added after the questions in the original instrument. They should be seen as separate questions, not included in the instrument. These questions were constructed by the author and concerned memories from the trauma (one item) and problems due to amnesia (two items). The possible answer was yes, or no. The reason for these questions was to focus on the trauma and also on amnesia. The answers from these questions added more information about pre-hospital memories and amnesia, but the questions could have been more specific.

Statistical analysis

When determining the sample size for the first study, a discussion with a statistical consultant was held and sample sizes from similar studies were also studied. No power analysis was done as this study mainly has the character of a descriptive study.

In paper I and II, both a parametric (Student-t test) and non-parametric test (Pitman's test) were used for statistical analysis. In paper IV, non-parametric tests (Mann-Whitney test, Wilcoxon sign rank test, Spearman's rank correlation test) were used due to a smaller sample. For the same reason no further multivariate analysis was done on the data in paper IV. Several comparative statistical analyses were done in paper I, II knowing that the statistical probability of finding a significant relationship increases as the number of such comparisons increases. Most of the comparison showed a statistical significance at $p < 0.01$ even if the level was set at $p < 0.05$. However, all statistical comparison should be regarded with caution and no causal connection can be drawn from a cross sectional study (Altman 1995).

In the follow-up study (paper IV), the sample size was rather small. However, this sample size is comparable to most studies addressing the same topic and this illustrates the problem of conducting long-term follow-up studies of trauma patients.

Phenomenological hermeneutical analysis

The participant was invited to an interview 2 to 3 years after the injury. To interview participants at least 6 months after the injury is recommended by Morse (1999) in order to obtain rich and descriptive information. Participants often recall more of what has happened some time after the trauma when they have had the time to piece things together and make sense of the event. They may also have had the opportunity to reflect upon the changes in the body and the effects of the injury on their future. For the same reason, the patients were not invited to participate in the questionnaire study until after at least six months.

It is important in all research to have a good structure in order for the reader to be able to follow the reasoning and understand what the main themes and the subordinate themes are. In this thesis, the intention was to guide the reader through the analysis process by using two tables (Table 3 and 6) and a figure (Figure 2). Table 3 shows the meaning units who were condensed. Table 6 described the subthemes relationship to main themes. Finally the comprehensive understanding was illustrated with a figure which shows the parts and the whole understanding of the interpretation of patients' memories of being injured. According to Larsson (1993), the interpretation is like an act were different parts of a text will form a whole. To achieve quality in qualitative research there must be internal logic with a harmony between research question, collection of data and analysis.

In a hermeneutical way of thinking, the quality criterion is the level of harmony between the parts and the whole. If the interpretations have rich meaning with several shades, this implies that the interpretation is of high quality (Larsson, 1993). In the interpretation of the present study the trajectory of care was found through different chronological places after the injury. Good and bad memories were also found, as well as the balance between them.

Larsson (1993) discusses that the aspect of validity in qualitative research may be described in different criteria or conformability. A 'discourse criterion' is when the analysis can produce results that nobody has conclusive reason to doubt about. The findings of this study are in line with Morse (1997) and Richmond et al. (2000), but according to Popper (1997) there will always be a reason to doubt the present discourse.

Another important criterion is the 'heuristic value', which involves to what extent the reader can be convinced to look at some part of reality in a new way. The new way can be that memories are of more importance for the recovery than we first thought. The 'consistency criterion' is met when there are few contradictions between the parts and the whole and an inner logic is formed. It is like a puzzle where every little piece has to fit in order for the picture to appear. There are some contradictions in how the patients' memories are described in the present research because of the differences between those who had amnesia from the time in the ICU and those who did not. These patients narrate their memories of having amnesia and what it meant to them. Finally, the 'pragmatic criterion' of hermeneutical interest involves creating platforms for understanding between people and producing new questions and question old ones (Larsson 1993). In this research, new questions have arisen concerning the impact of memories on health and whether the creation of caring actions can be useful in the recovery process and become a strength in the patients' future life.

CLINICAL IMPLICATIONS

To provide good memories for patients during ICU care is a challenge to everyone working in the ICU. The injuries, but also the care, sometimes cause pain and fear. The suggested implications are based on the findings in this thesis and have to be further evaluated.

To recognize and decrease DM is not a simple task but the knowledge that some patients are at greater risk for developing DM may guide the nurse to be more observant in the care of patients with trauma. During the ICU-stay, in order to alleviate fear and stress for injured patients, the nurse should ask the patients if they experience any nightmares or delusions. To provide good memories can be to support the caring relationship between the nurse, the patient and the family. To create this caring relationship the nurse has to be involved in the patients and, if possible, follow the same patients while they are cared for in the ICU. This arrangement can create security for both patient and family. To understand and recognize the patients' needs during critical illness may improve their well-being and comfort for the patient. The caring work in the ICU involves feelings together with professional knowledge, skill and nursing actions (Wilkin & Slevin 2004).

In order to help patients to remember not only DM, diaries may be used to contribute to recollection. Diaries written in everyday language both by nurses and relatives in the ICU may provide a useful tool in the debriefing process following intensive care (Bäckman & Walther 2001; Egeröd et al. 2007). Diaries may also contribute to sharing the story, presence, feelings and support with the patients after the ICU experience (Roulin et al. 2007). The diary helps the patient to resume the fragmentary memories and also to return and adjust to everyday life (Bergbom et al. 1999). This diary can also be an important tool for carrying on a conversation about the critical illness. In the present study, 22% of the patients with trauma had not mentioned their memories from ICU-stay to anybody.

After the ICU-stay, the recovery period in the nursing ward can also be very stressful when patients learn how severe their illness is and how close to death they were (Compton 1991). Here the patients can benefit from early follow-up (Engström et al. 2008). The findings in the present study support early follow-up visits in the nursery ward as well, but also after hospital discharge. These visits should allow the patient to express their memories from the ICU-stay and be informed about what happened to them while they were critically ill and the most injured. Special attention should be given to those patients who express DM.

FURTHER RESEARCH

Further research is needed:

- To investigate in randomized clinical trials whether supporting and caring strategies may reduce DM in patients during the ICU-stay;
- To further validate the ICUM-tool;
- To gain a deeper understanding of the problems the patient experiences when returning home after trauma;
- To investigate the benefits of follow-up for patients after trauma and ICU-stay in a special nurse led clinic; and
- To investigate family burden after trauma regarding patients' memories from the ICU-stay.

CONCLUSIONS

This thesis shows that individuals' memories from a trauma and ICU-stay affect their lives and direct them in different directions. Patients who remember DM from the ICU-stay score lower HRQoL and experience more anxiety and symptoms of depression than other patients. Even in the long-term perspective, up to 4.5 years, this discrepancy remains. After a trauma most patients RTW and it seems to be vital to be a part of society. In the short-term perspective both physical and mental dimensions of HRQoL are affected. From a long-term perspective it seems that the physical dimension is affected in most patients, except for patients with DM who are affected in both dimensions of HRQoL in both the long and short term. Efforts and actions therefore must be taken in order to alleviate these patients' suffering. Memories have an impact on peoples' lives and seem to influence the outlook on their present and future lives. It seems that good and caring memories from this period in the patients' lives can counteract bad or frightening memories and increase the possibilities of experiencing feelings of health and well-being. This appears to be of vital importance for being able to encounter an uncertain future after trauma. It is also important to facilitate the possibilities for patients to share the memories with their families in order to create a gratitude for life after the trauma.

Main findings are summarized below;

- Patients with DM had a significantly lower HRQoL after 0.5-1.5 years compared to those without DM. This difference remains after 4.5-5.5 years regarding all eight domains in SF-36 except for general health, in which patients with delusions had approached the other group.
- Anxiety and symptoms of depression were more common in patients with DM compared to those without DM both 0.5-1.5 years after trauma and 4 years later.
- Approximately five years after the trauma 75% of the patients were working. RTW significantly improved over time. Patients with DM did not RTW to the same extent as other patients in the short term, but this difference was equalized later on.
- Four out of five patients had some memories of factual events from their ICU-stay, mostly visits by family members.
- One patient out of four had DM. These patients were younger, more severely injured, and had more complications. Also more patients in this group received sedatives and opioids during the ICU-stay compared to patients without DM.

- Compared to the reference sample patients with trauma had a significant decrease in their HRQoL 0.5-1.5 years after the trauma. This difference was still present 4.5-5.5 years after the trauma even if there was an increase in four out of eight domains in SF-36.
- There were both good and bad memories during the trajectory of care after the injury. The good memories were from care and a gratitude for life. Bad memories came from delusions in the ICU and memories about the injured body.
- When bad memories are balanced by good ones, there are more possibilities for patients to move on from the trauma and the ICU care, despite of an uncertain future.
- When caring for the injured patient it is vital to support the presence of caring relatives who help the patient concentrate on acceptance and a feeling of gratitude for life.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Minnen och hälsorelaterad livskvalitet

– hos patienter som efter trauma är vårdade på Intensivvårdsavdelning

Bakgrund

I samband med kritiska händelser i en persons liv är minnena ofta starka och betydelsefulla då det handlar om överlevnad och insikt om livets skörhet. Då en person drabbas av skada som följd av ett olycksfall kan denna skada vara så kritisk att det krävs vård på en intensivvårdsavdelning (IVA). Skadan i sig men också vistelsen på IVA kan sedan innebära att personen får minnesförlust från vissa tidpunkter efter skadan. Det kan också förekomma så kallade illusoriska minnen av överklighetsupplevelser under intensivvårdsvistelsen. Dessa illusoriska minnen av hallucinationer, mardrömmar, drömmar och paranoida upplevelser skapar ofta rädsla och osäkerhet hos patienterna eftersom de inte alltid vet vad som verkligen har hänt då de var som mest kritiskt sjuka. Idag vet vi att ett flertal patienter under lång tid bär med sig dessa minnen från vårdtiden på IVA. Vissa studier tyder också på att illusoriska minnen kan ge psykiska problem i efterförloppet framförallt i ett kort perspektiv. Om patientens hela livskvalitet och hälsa påverkas av illusoriska minnen är däremot inte tillräckligt utforskat, framförallt inte i ett längre perspektiv. Tidigare forskning har till största delen inriktats på de svårast sjuka patienterna som vårdats på IVA oavsett diagnos. Att istället undersöka vissa patientgrupper ger en fördjupad kunskap om dessa patienters speciella behov och problematik. En sådan grupp är patienter med trauma som ofta är yngre och har en god hälsa före olyckan. Traumat är alltid oförutsett och patienten är fullständigt oförberedd på det som hänt och på den efterföljande vården på IVA. För att kunna identifiera de mest sårbara individerna i samband med fysiskt trauma behövs mera kunskap om deras minnen efter traumat och hur de upplever sin livskvalitet efter olyckan. För att kunna vidta adekvata åtgärder för att förbättra vården av dessa patienter är det därför viktigt att studera patienternas upplevelser av sina minnen och den eventuella påverkan dessa minnen kan ha på deras livskvalitet efter olyckan.

Syfte

Det övergripande syftet med avhandlingen var att få förståelse av patienters minnen från IVA vistelsen och hur dessa minnen eventuellt kan ha påverkat patientens livskvalitet och mentala hälsa efter traumat både i ett kort och långt perspektiv .

Metod

Avhandlingens uppläggning är beskrivande och omfattar fem sjukhus i Västra Götaland där alla patienter som under ett år har vårdats på intensivvårdsavdelning med traumadiagnos har ingått. 239 patienter besvarade en postenkät 6-18 månader efter

olyckan med frågor om minnen från vårdtiden på IVA, hälsorelaterad livskvalitet (HRQoL), psykisk hälsa och återgång till arbete. Fyra år senare gjordes en uppföljande studie med 153 individer ur samma patientgrupp. Som referensgrupp för HRQoL användes 159 slumpvis utvalda personer ur en databas av normalbefolkningen. Uppgifter om skadegrad, tidigare sjukdomar, komplikationer och behandling på IVA hämtades från patientjournalen. Dessa medicinska uppgifter samt ålder och kön relaterades sedan till patientens grad av minnesförlust samt olika minnen. Svaren från enkäterna och journalgranskningen bearbetades sedan med statistiska metoder. Djupintervjuer genomfördes därefter med 18 patienter som valdes ut från gruppen om 239 patienter. Patienterna berättade om sina minnen från olyckan och vården efteråt. Intervjuerna analyserades slutligen med en tolkande fenomenologisk hermeneutisk metod.

Resultat

Av de 4424 patienter som vårdats på IVA under året var 11% patienter med traumadiagnos. Av de 239 patienter som ingick i studien kom endast en tredjedel tydligt ihåg hela vistelsen på IVA. De minnen som var mest framträdande var minnen av anhöriga. En fjärdedel av patienterna beskrev också illusoriska minnen så som hallucinationer, paranoida minnen, drömmar och mardrömmar. Jämfört med de patienter som inte hade illusoriska minnen, var de patienter med dessa minnen oftare yngre, de hade fått lugnande medicinering och var i större utsträckning respiratorbehandlade. Fler hade också genomgått kirurgi samt hade mer komplikationer under vistelsen på IVA. Patienter som hade illusoriska minnen hade också mera minnen av rädsla och panik. Patienter med illusoriska minnen skattade sin livskvalitet lägre och upplevde sämre mental hälsa än övriga patienter efter traumat både i ett kort perspektiv 6-18 månader efter olyckan och i ett längre perspektiv 4.5-5.5 år senare. De patienter som hade andra sjukdomar förutom traumat skattade också sin livskvalitet lägre. Alla patienter upplevde en förbättrad livskvalitet över tid men upptill 4.5 år efter olyckan hade alla patienter fortfarande en sämre livskvalitet jämfört med normalgruppen. Efter ca fem år hade 75% återgått till arbete vilket är en förbättring jämfört med 6-18 månader efter olyckan. Patienter som hade illusoriska minnen hade till en början en lägre återgång till arbete men detta utjämnades över tid. Minnena i samband med olyckan var känslösa, patienterna upplevde sig sårbara och det fanns både kränkande minnen och skrämmande illusoriska minnen. Samtidigt mindes patienterna att de hade blivit väl omhändertagna både på olycksplatsen och på sjukhuset. Att få ha anhöriga nära upplevdes som betydelsefullt både på akutmottagningen och på IVA. Att senare under vårdtiden på vårdavdelningen kämpa för att bli frisk efter olyckan var målet, likaså att få komma hem. Vid analysen av patienternas minnen, tolkades vissa minnen som dåliga, medan andra tolkades som goda minnen. När dåliga minnen av en överklig värld med hallucinationer, minnesluckor och en skadad kropp balanserades upp av goda minnen, god vård, stöd från anhöriga och en tacksamhet över livet, fanns det möjlighet att gå vidare trots att framtiden kändes osäkrare efter olyckan.

Diskussion

Yngre patienter i denna studie hade mera illusoriska minnen och detta står i kontrast till tidigare forskning som framför allt visar att äldre patienter är mer drabbade. Patienter med trauma är generellt sett ofta yngre än andra patienter på IVA men studie gruppen har ändå ett åldersspann mellan 19-87 år. Patientgruppen bestod av patienter med både större och mindre skador där alla var vårdade en viss tid på IVA. Skadans omfattning verkade inte påverka HRQoL i ett längre perspektiv. De patienter som respiratorbehandlades beskrev mest illusoriska minnen vilket bekräftar tidigare forskning där patienter haft andra diagnoser än trauma. Den uppföljande studien visade att de patienter med illusoriska minnen som skattade en sämre livskvalitet 1.5 år efter olyckan även gjorde det 4 år senare. Detta kan bero på ett flertal faktorer. Dels att de efter traumat drabbades av mera komplikationer på IVA och dels att de genomgick mer kirurgi som kanske innebar en längre konvalescenstid efter traumat. Dessa patienter förbättrade ändå sin totala fysiska livskvalitet över tid men den mentala hälsan förbättrades däremot inte. Ett flertal patienter hade fortfarande 4-5 år efter olyckan ångest och symtom på depression. Relativt många av alla de patienter som ingick i studien, återgick till arbetet efter traumat och intervjustudien bekräftar också att det var viktigt att återvända till arbetet. Minnen av anhöriga var framträdande och stödet från dessa var viktigt för patienten under hela sjukhusvistelsen, vilket bekräftar tidigare forskning.

Konklusion

En fjärdedel av patienterna hade illusoriska minnen och de var också räddare under IVA-vistelsen. De som hade illusoriska minnen skattade även sin hälsorelaterade livskvalitet lägre och hade mer ångest och symtom på depression även ca fem år efter olyckan jämfört med patienter utan dessa minnen. Trots detta återgick de flesta till arbete. Avhandlingen är av en beskrivande karaktär och resultaten bör därför tolkas med viss försiktighet. Det finns troligtvis ett flertal faktorer som inte tagits upp i avhandlingen men som även dessa skulle kunna ha betydelse för patienternas minnen och livskvalitet. Avhandlingens kunskapsbidrag till vårdvetenskapen är att patienternas minnen från IVA-vistelsen ofta är betydelsefulla för den framtida hälsan och livskvaliteten. Vidare blev det uppenbart att god vård med empati och känsla för patientens emotionella behov samt närhet och stöd från anhöriga och vänner, hade stor betydelse för lindrandet av de negativa effekter illusoriska minnen kunde ha. Om de dåliga minnena från en överklig värld och en skadad kropp balanserades upp av goda minnen från vården, anhöriga och tacksamhet för livet, var förutsättningarna bättre för att kunna gå vidare i livet mot en framtid som upplevdes mera osäker efter olyckan. Trots den höga tekniska nivån på vården på IVA och en patient som har svårt att kommunicera, bör vården följaktligen starkt präglas av empati och lyhördhet för patientens behov, uppmuntra engagemang av familj och vänner samt verka för en långsiktig uppföljning av patienten för att få bästa förutsättningar att lindra patienterna lidande efter en olycka.

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DISSERTATIONS

from Institute of Health and Care Science,
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Doctoral dissertation

Skärsäter, I. (2002). The importance of social support for men and woman, suffering from major depression – a comparative and explorative study.

Ahlberg, K. (2004). Cancer-Related Fatigue – experience and outcomes.

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Wickström Ene, K. (2008). Postoperative pain management – predictors, barriers and outcome.

Wigert, H. (2008). Föräldrars delaktighet i sitt barns vård vid neonatal intensivvård.

Licentiate dissertations

Moene, M. (2006). Samtal inför ett kirurgiskt ingrepp.

Lindström, I. (2007). Patienters delaktighet – en studie om vård i livets slutskede.