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# **Nurses' Experience In Caring For Patients With Traumatic Spinal Cord Injury**

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**Thesis Submission:**

**Master of Nursing Science**

**November 2015**

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## SIGNED STATEMENT

I certify that the work in this thesis contains no material that has been accepted or offered for the award of any other degree or diploma from any university or other tertiary institution, and to the best of my knowledge has no material previously published or written by another person, except where due reference had been made in the text.

I also certify that any assistance received in preparing in the thesis, including all the sources used, had been acknowledged within the thesis.

I give consent to this copy of my thesis, when deposited in the School of Nursing library, being available for loan and photocopying.

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SHAREENA BIBI MOHD ARIF

## ACKNOWLEDGEMENTS

All praise for God who is the most Gracious, most Compassionate.

*'He who does not thank people, does not thank Allah'*

(Prophet Muhammad, peace be upon him)

This thesis may never have seen the light of day without the help of many generous people.

My sincerest appreciation goes to my supervisors, Dr Philippa Rasmussen and Mr Paul McLiesh, who made the effort to supervise me knowing that I had no experience of phenomenological research. Many thanks for the guidance, advice, patience and the constant motivational words; for which I am grateful. Above all, to have both of you as my supervisors was a priceless gift from the Almighty.

I would like to thank Dr Frank Donnelly for helping me understand and develop the concept of this research.

My gratitude also goes to the School of Nursing, University of Adelaide and the Spinal Unit staff, Royal Adelaide Hospital, who have supported this thesis throughout.

Thanks to my mother Skina Bibi and my siblings Daud, Nina, Ajin, Penn, Tote and Sarina for their constant support and prayers for me.

Special thanks to my beloved husband Asrof and my son Hanzalah for their patience, love and understanding throughout the years. My struggle is for our future In sha Allah for this life and the hereafter.



## ABSTRACT

The aim of this study was to explore nurses' experiences when caring for patients with traumatic spinal cord injury that had neurological deficit at a spinal unit in Australia. The study used a hermeneutic phenomenological approach. Three registered nurses and three enrolled nurses with a broad range of experience were recruited and interviewed. The data were transcribed and analysed using Burnard's (1991) 14-step approach to analysis. Four essential themes emerged: *'Nurses' interpretation of the patients and family'*, *'The passage of care'*, *'Patient needs'* and *'Hope and grief'*. The study revealed the experiences of six nurses, highlighting the passage of nursing care that the nurses underwent while caring for spinal cord injury patients. Although these patients had physical disabilities and were dependent physically, the nurses in this study showed that their concern and attentiveness was directed more towards fulfilling their patients' psychological needs. During the acute phase, the nurses identified patients that were going through the process of grief. They believe in providing patients with hope in order to motivate them to move on in their lives; however, they knew that giving false hope may have a negative impact. Finally, the experience of caring for these patients and going through the passage of care gave the nurses the opportunity to understand their patients and their families. This suggests that the time spent with patients and their families gave the nurses a broader understanding of them, which in the long term helped the nurses to plan the care for future patients, and at the same time help their families to go through the traumatic life changes resulting from their family member's injury.

## CHAPTER 1: INTRODUCTION

Trauma is generally linked to terrible events that occur in a person's life that produce physical and psychological wounds. Patients that have a traumatic spinal cord injury have experienced a life-shattering event (Hickey 2002). Undergoing a traumatic event can be a life-changing experience that has a significant impact on the individuals and families concerned (Thompson & Walsh 2010). Nurses' involvement in caring for these patients starts from the time the patient is admitted to the hospital until they end their rehabilitation (Pellatt 2003; Sheerin 2005). However, there are no studies that specifically examine nurses' experiences when caring for these patients. This phenomenon has yet to be explored from the nursing perspective. Therefore, this opens an opportunity for the researcher to explore nurses' experiences in caring for patients with traumatic spinal cord injury that had neurological deficits.

In this previously unexplored area, hermeneutic phenomenological research offers an opportunity for nurses working in a spinal unit to reflect on their experiences and give an in-depth understanding of these phenomena.

The knowledge gained from this study will provide an understanding of what is involved in nursing spinal injury patients for the benefit of all nurses, and especially novice nurses, who would like to work in a spinal unit. Furthermore, on a larger scale, this study will provide a broad range of experiences for future nurses and this indirectly will give ultimate benefit for the patients and their families in dealing with the traumatic life event as well. The findings of this study will also provide a reference point for the development of nursing education and practice.

This chapter provides a brief explanation of the research, and concludes with a summary of each of the chapters that follow.

## **Context of the Study**

The spinal cord is a complex system that connects the body and brain, and has both sensory and motor functions (Sheerin 2004). Therefore, injury to the spinal cord can greatly impact an individual's life. Spinal cord injury is usually a sudden, traumatic, unexpected and irreversible event (Hickey 2002). According to Morse and O'Brien (1995), patients experience major changes due to traumatic injuries, and these range from facing their 'shattered reality' to overwhelming physiological shock. These obviously represent lifelong challenges, and as a result of the loss of certain body functions may even cause complications, such as post-traumatic depression, an ongoing sense of loss especially in terms of personal control, loss of spontaneity and independence in life (Chen 2010; Chun & Lee 2008; Chun & Lee 2013; Dickson, Allan & O'Carroll 2008). During these vulnerable stages, patients need all the support they can get, especially from the nurses who spend the most time with them.

The involvement of nurses is essential, and the initial nursing support and care of spinal injury patients is very important, no matter if their nurses are novices or experienced (Grundy & Swain 2002). Nurses need to structure their care from an acute care nursing approach to a rehabilitation approach (Pellatt 2003). Therefore, understanding and learning from the experiences of other nurses in caring for patients with spinal cord injury is very important for all nurses, and

especially for novice nurses, preparing themselves for future challenges and decision-making.

The best way to understand nurses' lived experiences is through qualitative research, because it provides deeper and richer insights (Polit & Beck 2012). The researcher believes the exploration and understanding of the phenomena investigated in this study will contribute to the body of knowledge for all nurses.

### **Statement of the Research Problem**

The worldwide incidence of spinal cord injuries comprises 40–80 cases per million of the population (World Health Organization: Spinal Cord Injury 2013). Nurses' involvement in providing support and care, from the acute phase to rehabilitation, is undeniable (Pellatt 2003). Therefore, it is essential for other nurses that intend to work in a spinal unit to understand how it feels to care for patients with traumatic spinal cord injuries, deal with challenging situations and meet their unique needs. Furthermore, a literature search demonstrated that there were no previous studies exploring this phenomenon. Therefore, this study provides an added body of knowledge for all nurses dealing with these patients, or other patients undergoing traumatic events.

### **Purpose of the Study**

The purpose of the study was to explore, interpret and understand nurses' experiences in caring for patients with traumatic spinal cord injuries who also have neurological deficits. The articulation of the research findings contributes as an added body of knowledge for all nurses, and especially novice nurses, interested to work in a spinal unit and care for these patients. It also contributes

to a greater understanding of the challenges and issues nurses face while caring for these patients, and further, provides a basis for improvement in nursing care.

### **Aim of the Study**

To explore nurses' experiences of caring for patients with traumatic spinal cord injury who also have neurological deficits.

### **Specific Objectives**

1. To explore the lived experience of nurses caring for patients with traumatic spinal cord injury who also have neurological deficits.
2. To develop an understanding of these nurses' experiences in dealing with patients with traumatic spinal cord injury who also have neurological deficits.
3. To expand the knowledge of this area, to assist novice nurses (and potentially experienced nurses) of the future when caring for patients with traumatic spinal cord injuries who also have neurological deficits.

### **Statement of the Research Question**

The research question initially emerged from the researcher's curiosity during her clinical posting at a spinal unit. As a nurse from Malaysia, the researcher had experience caring for patients with traumatic spinal cord injuries who also had neurological deficits; however, the researcher was curious to know more about the experiences of the nurses at this particular spinal unit. Furthermore, since there were no previous studies on this topic, the researcher felt it would provide added knowledge for nurses in the future.

## **Significance of the Study**

The involvement of nurses begins at the time the patient arrives at the hospital and continues when they are discharged from acute care and move into rehabilitation (Pellatt 2003). Therefore, understanding and learning from the experiences of other nurses when caring for patients with spinal cord injuries will help nurses, and particularly novice nurses, to prepare themselves for future challenges and decision-making when caring for these patients.

In addition, many well-documented concerns have been raised in the nursing literature about the decision-making abilities of novice nurses, which tends to be linear due to their limited knowledge and experience (Chase 1995; Itano 1989; Radwin 1998). Exploring the experiences of nurses caring for these patients will assist future nurses in building their knowledge and skills. On a larger scale, it will increase patients' satisfaction, experience and reduce complaints (Belcher & Jones 2009; Hallin & Danielson 2008; Radwin 1998; Tzeng, Ketefian & Redman 2002).

## **Researcher Assumptions**

During this study, it was essential for the researcher to acknowledge prior assumptions and beliefs. Identifying these assumptions and beliefs gave the researcher a basis to justify the methodology of the study and gave the judgements dignity (Gadamer 1975). In addition, the acknowledgement of assumptions was a form of exposing the researcher's opinions beforehand in order to facilitate an ongoing understanding of the new insight gained from exploring the nurses' experiences.

The assumptions were documented within the summary of the transcript in order to enhance the validity of the research outcomes (Streubert & Carpenter 2011a) (Appendix 8). As a registered nurse working at several public hospitals in Malaysia and currently in charge of an orthopaedic ward, the researcher had many years of experience in caring for these patients, and this gave the researcher pre-existing ideas with regard to the phenomenon. Listed below are the researcher's acknowledged preconceived ideas (assumptions) about the phenomenon:

1. Nurses that work in the spinal unit belong to a unique group of nurses.
2. The nurses remember their experiences precisely when caring for traumatic spinal cord injury patients that have neurological deficit.
3. Caring for patients with traumatic spinal cord injury who also have neurological deficits is like taking care of patients in intensive care, where they need individual emotional and physical care.
4. It is hard to give hope to these patients when there is a strong possibility that they will be completely paralysed.
5. It is difficult to communicate with these patients and their families.
6. When the patients are silent, it may mean that they are afraid or that they have given up.
7. These patients are very dependent on their nurses.

### **Definition of the Key Terms Used in the Study**

**Fusion of horizon:** A process of coming to an understanding that occurs when the interpreter understands the concepts of the written text (interview transcript) in such a way that they also include the interpreter's own comprehension of

them.

**Hermeneutic:** The theory and methodology of text interpretation and reflection.

**Hermeneutic cycle:** Refers to the cycle of interpretation involved in applying the text to be understood in the context of the interpreter's present situation and preconceived ideas. The hermeneutic cycle is not static, but rather, is dynamic and fluid. The cyclic process directs the search for the basic patterns in the texts, which leads to an understanding of new knowledge.

**Hermeneutic phenomenology:** A phenomenology becomes hermeneutic when the method is taken to be interpretive. Through the use of language, the nature of questioning and preconceived ideas, it projects human understanding.

**Lived experience:** Each experience and all feelings contribute to human experience as it is lived, and this cannot be conceptualised.

**Phenomenology:** A qualitative research methodology that study an individual's life world (lived experience).

**Spinal cord injury:** Spinal cord injury refers to damage to the spinal cord due to trauma, disease or degeneration (Grundy & Swain 2002).

**Trauma and traumatic:** The word 'traumatic' is derived from the word trauma, a kind of wound. An event is considered to be traumatic when there is an injury associated with it. The injury can be physical and/or psychological.



## **Summary of the Thesis**

This study reveals a hermeneutic phenomenological interpretation of nurses' experiences when caring for patients with traumatic spinal cord injuries. The summaries of all chapters are detailed below.

### **Chapter 1: Introduction**

The introduction provides an outline of the background, purposes and significance of this study. The researcher's interests and preconceptions are highlighted. Summaries of the research chapters are given in this chapter as well.

### **Chapter 2: Literature Review**

The literature review provides a summary of the evidence-based literature related to the experience of caring for patients with spinal cord injury. It also reviews the phenomenological historical evidence that underpins this study.

This chapter discusses the prevalence of spinal cord injury, the impact of trauma and defines spinal cord injuries. It also discusses the impact that trauma has on patients, their families and nurses' lives. The gaps in the literature are noted and provide strong support for the need for the researcher to proceed with the study.

### **Chapter 3: Methodology**

This chapter discusses the theoretical framework of this research study. It gives an introduction to hermeneutic phenomenology and the philosophy of Gadamer

that underpins this study (Gadamer 1975). It also offers a clear justification of the chosen methodology.

This chapter also describes Van Manen's methodological structure, which was used to break the philosophical idea down into a process (Van Manen 1997).

#### **Chapter 4: Method**

The research method was designed to answer the research question and is outlined in this chapter. The sample population and the recruitment strategies are discussed in detail. The ethical considerations, data collection and analytic methods are also discussed. Van Manen's steps in operationalising the data and the interrelated connection with Gadamer's hermeneutic philosophy in the data collection and analysis are outlined. The methodological trustworthiness of the study is described in this chapter.

#### **Chapter 5: Analysis**

The data analysis method used is outlined stage by stage in this chapter. Burnard's (1991) 14-step approach was used to analyse the interview transcripts. The emergence of essential themes and sub-themes is discussed in this chapter, and this provides the basis for the interpretation of the nurses' experiences given the next chapter.

#### **Chapter 6: Findings and Interpretation**

This chapter reveals and reflects on the findings and the interpretations of the nurses' experiences when caring for patients with traumatic spinal cord injuries who also have neurological deficits. Four final essential themes emerged:

*'Nurses' interpretation of patients and families', 'The passage of care', 'Patients' needs' and 'Hope and grief'.*

## **Chapter 7: Discussion**

This final chapter concludes this hermeneutic phenomenological research study. This chapter emphasises the essential themes and their significance in answering the research question. The significance of the findings is also discussed in the context of the literature reviewed. In addition, the limitations and recommendations of the study are described in this chapter.

## **Appendices**

The attached appendices contain an approval letter from the human ethics research centre, a recruitment flyer, the participant information sheet, consent form, memos, summary of the interviews and examples of the data analysis statements that highlight the emergence of the sub-themes and essential themes.

## **Chapter Summary**

This introductory chapter has provided an overview of this study. It also explained the researcher's commitment and interest in exploring the phenomena of nurses' experiences when caring for patients with traumatic spinal cord injuries.

## CHAPTER 2: LITERATURE REVIEW

### Introduction

This chapter will review the literature related to nurses' experiences when caring for patients with traumatic spinal cord injuries. The synthesised knowledge gathered from the literature has enabled the researcher to view the gap that needed to be addressed and distinguish the contribution of this research from what has gone before. Knowledge of spinal cord injury and its implications, the concepts of nursing, caring and previous related studies were used to generate an understanding of the areas relevant to this study.

A computer-based literature search was conducted using the Cumulative Index to Nursing and Allied Health (CINAHL), PubMed and SCOPUS databases. Different keywords from major headings and Medical Subject Headings (MeSH) were used to find relevant articles in each database. The keywords employed in the searches were nurse, experience, feeling, emotion, caring, empathy, patient, traumatic and spinal cord injury. There was no time restriction placed on the searches because not much previously published information related to this study was found. The use of an asterisk as a wildcard (\*) allowed the expansion of the search in terms of American and English spelling as well as any plurals. The literature search was further refined to include full text, peer-reviewed and English language only articles. The appropriate literature was then selected from the searches.

There were no empirical studies on the experiences of nurses caring for patients with traumatic spinal cord injury who also had neurological deficits. The

majority of the literature focused on patients' experiences with these injuries, primary caregivers' experiences and the care of patients during the rehabilitation phase. The phenomenon is yet to be explored from a nursing perspective. In this study, the aim was to identify the experiences of nurses caring for patients with traumatic spinal cord injuries that had resulted in neurological deficits.

### **Spinal Cord Injury: Statistics and Facts**

Spinal cord injury indicates damage to the spinal cord following trauma, disease or degeneration (Grundy & Swain 2002). The worldwide incidence is 40–80 cases per million of the population, with up to 90 per cent of cases being trauma-related (World Health Organization: Spinal Cord Injury 2013). The gender most at risk is males, with the highest risk seen in those aged between 20 and 29 years, and also those in older age (70+ years). In females, those at risk are adolescents aged 15–19 years and those in older age (60+ years) (World Health Organization: Spinal Cord Injury 2013). The range of ages at risk is due to risk taking behaviour in the younger population and degenerative changes in the older populations. The ratio between adult males to females is 2:1 (World Health Organization: Spinal Cord Injury 2013).

The Spinal Cord Injury Association of Australia (2015) indicates that statistics on spinal cord injury vary because there is no collective national registry. However, based on the information gathered from the Spinal Cord Injury Network (2015), more than 10,000 people are living with spinal cord injuries in Australia.

The vast numbers of spinal cord injuries worldwide are largely preventable,

because the majority are due to road traffic accidents, falls or violence (World Health Organization: Spinal Cord Injury 2013).

## Understanding Spinal Cord Injury

Spinal cord injury is a life-threatening condition and has been recognised since ancient times. According to Grundy and Swain (2002, p. 1), in the Edwin Smith Papyrus from about 2500 BC an unknown Egyptian physician described the clinical features of traumatic spinal cord injury event as 'an ailment not to be treated'. It shows the awareness of the poor prognosis when dealing with this traumatic condition.

To better appreciate the potential for injury to the spinal axis and its surrounding structures and functions it is necessary to understand the anatomical structure involved. The vertebral column consists of 33 vertebrae stacked on one another. These vertebral bodies are separated by the intervertebral discs, which act as shock absorbers. The ligaments, muscles and other supporting structures of the spinal column hold the vertebrae in position (Shoen 2000; Solomon, Warwick & Nayagam 2001). The vulnerable spinal cord passes through the vertebral column via the spinal cord canal, which provides protection (Solomon, Warwick & Nayagam 2001).

Spinal cord injuries result when excessive forces are exerted on the vertebral column. Excessive forces and unusual movements can produce compression and fractures to the vertebral bones (Iencean 2003). These also cause disruption to the supporting structures that hold the vertebral column, resulting in injury to the soft and vulnerable spinal cord (Iencean 2003; Thompson 2009).

Injury to the spinal cord can be devastating to the patients because it affects the motor and sensory functions of the extremities (Hickey 2002). The loss of these functions results in the loss of independence. This loss of function may be permanent or temporary, depending on the type of injury (Smith 2005). Several terms are used in relation to spinal cord injury: quadriplegia or tetraplegia, refers to a significant injury involving one of the cervical segments of the spinal cord, resulting in dysfunction or loss of function of the arms, legs, bowel and bladder (Hickey 2002). Paraplegia refers to a lesion involving the thoracic, lumbar or sacral region of the spinal cord that results in dysfunction or loss of function of the lower extremities, bowel or bladder (Hickey 2002). A complete lesion is a term used to suggest total loss of sensation and voluntary muscle control below the injury (e.g., complete quadriplegia or complete paraplegia) (Hickey 2002). Incomplete lesions involve preservation of the sensory or motor fibres or both below the level of injury (Hickey 2002). The incomplete lesions are classified according to the area of damage, which may be central, lateral, anterior or peripheral (Hickey 2002). The terms related to spinal cord injury show the magnitude of the trauma, which is overwhelming, especially for the individual who endures the impact of the injury (Dewar 2000).

### **Trauma: The Effect on People**

Trauma is a kind of injury and when it is associated with an event, the event can be called traumatic (Garland 2002). According to Garland (2002), trauma is a Greek word and it is defined as a piercing of the skin, a breaking of the bodily envelope. However, according Thomson (1996), Freud used the word trauma metaphorically to emphasise how the mind, too, can be injured or wounded by events. The mind can be thought of as a protective shield against horrific

external stimuli. Therefore, it is crucial for the mind to maintain balance by being selectively sensitive to external stimuli.

Patients that have suffered a trauma may feel that their lives have been turned upside down. In a matter of seconds they suffer injuries that change them from being completely healthy and independent to not being able to move, or even to be allowed to move, and this has both physical and psychological effects on them (Tutton, Seers & Langstaff 2008). Following injury the absence of normal sensation, combined with the absence or weakness of motor ability, creates a high risk for many other complications, such as pressure ulcers, joint contractures, deep vein thrombosis, bowel/bladder dysfunction and compromised respiratory function (Fries 2005; Hickey 2002). Psychologically, these patients are likely to have deep-rooted feelings of despair, grief, stress, denial and even withdrawal, depending on their personality, perception and self-esteem (Partridge 1994; Westgren & Levi 1999). However, they may hold on to hope as a motivation to move further in their lives (Lohne & Severinsson 2004a). The transition from living independently to being dependent on others often forces a redefining and re-evaluation of all their goals in life for these patients (Gill 1999). Hence, this eventually leads to them finding meaning in the injury itself (Lohne & Severinsson 2006).

One of the most important elements of the healing process following trauma is the quality of human compassion one has for another person's suffering, regardless the nature of the trauma (Watts & Horne 1994). Traumatic spinal cord injury is an unexpected and shocking event (Watts & Horne 1994). The disability limits the ability of the patient, and indirectly affects emotional,



psychological, economic and environmental aspects of the family members' lives (Gill 1999).

In the nursing field, trauma encompasses a large variety of specialties, including spinal nursing. For patients suffering from trauma, an urgent multidisciplinary approach is required from nursing and other healthcare providers to provide effective care (O'Mahoney 2005). The nursing care of trauma patients legitimises the foundation of a particular relationship between these patients and nurses (Fealy 1995). Therefore, it has the potential to negate the awakening of emotions, which can be negative at times. According to Alzghoul (2014) in his study on nurses' experiences of working with trauma patients in critical care and emergency settings, the negative emotions that affected nurses were feelings of stress, upset, vulnerability, exhaustion and also trauma. The care and visualisation of trauma patients was found to be difficult and traumatic for nurses as well.

### **The Concept of Caring In Nursing**

Caring is an important component in nursing practice (Fealy 1995; Lea, Watson & Deary 1998). The concept of caring involves the ability to care for patients as a whole person (Fealy 1995). In addition, the concept of caring also involves the psychological care and support of the patients' family (O'Mahoney 2005). Nurses caring for patients and their family members undergoing traumatic events embrace both of these elements of caring, which distinguishes nursing from other professions (Patistea 1999).

No doubt nurses' caring behaviour has an enormous influence on healthcare organisations. This is manifested through the components of caring in nursing,

which are compassion, competence, confidence, conscientiousness and commitment in performing their job (McCance, McKenna & Boore 1999). Contributions such as these can increase patients' satisfaction, enhance patients' wellbeing and improve organisations' financial performance (Al-Mailam 2005; Tzeng, Ketefian & Redman 2002).

Caring for patients in general requires nurses to be both knowledgeable and also equipped with emotional and spiritual intelligence, as these are some of the important qualities that may affect the caring behaviour of nurses (Kaur, Sambasivan & Kumar 2013).

Spinal cord injury is particularly devastating because the resulting loss of body function also involves the loss of independence. It changes the physical, psychological and psychosocial aspects of a person (Hickey 2002). Therefore, the medical management and nursing care received by these patients is crucial to their future.

The management of patients who have sustained a traumatic spinal cord injury focuses on controlling and preventing progress towards secondary damage, to optimise the stability of the spinal cord and to pursue rehabilitation as early as possible in order to prevent associated complications (Grundy & Swain 2002). Care of the patient with a spinal cord injury initially focuses on the acute and preventive aspects, then moves on to emphasise supportive care and then restoration of function, as far as is possible. Therefore, thorough observation is needed to detect complications, and patient care on the whole needs to be managed accordingly (Hickey 2002).

In nursing, one of the greatest challenges and one of the greatest satisfactions is to understand patients (Mok & Chiu 2004). Nurses caring for patients who have experienced traumatic events face many challenges while delivering the best possible care for their patients (Alzghoul 2014). The care of these patients requires insight and skill in the management of their physiological systems as well as the psychosocial aspects of their care, which focus on the acceptance of their current condition and also their future development towards ongoing rehabilitation (McLeod 2004). It is known that nurses with experience, and those with a specialised education, have a higher level of practical competence (Gillespie et al. 2011). Therefore it was considered essential to explore the lived experience of these nurses in order to develop future competent nurses.

### **Research Related to Spinal Cord Injury and Traumatic Events**

The majority of the studies on spinal cord injury are focused on the patients' and the primary caregivers' experiences (Chen 2010; Chen & Boore 2009; DeSanto-Madeya 2006; Lohne & Severinsson 2004a). What is known about the lived experience of patients with acute and unexpected spinal cord injury is largely based upon empirical studies that investigate how certain emotional experiences emerge in the first few months after being diagnosed until rehabilitation. Lohne and Severinsson (2004b) explored patients' experiences of hope following a spinal cord injury and it is interesting to note that the idea of hope—being able to walk again and recover—was a universal experience for patients. Overall, they understood and had positive expectations even though the experience of hope involved a continuous journey of 'ups and downs' for them. Lohne and Severinsson (2004b) added that it was important for nurses to learn the skills needed to foster hope in their patients in order to direct and

energise their efforts towards rehabilitation.

Lohne and Severinsson (2004a) also considered the concept of the awakening of hope following acute spinal cord injury. Interestingly, in this study it revealed that the concept of awakening hope, which was referred to as 'silent hopes', happened shortly after the occurrence of their spinal cord injury (Lohne & Severinsson 2004a). The findings also emphasised that even in the essence of 'hope', the patients still go through uncertainty and despair (Lohne & Severinsson 2004a). Other studies by these researchers revealed that the patients' experiences of suffering generated hope and longing, and these slowly led to comfort (Lohne & Severinsson 2005).

A number of other studies have investigated patients' experiences of spinal cord injury in depth (Chen 2010; Chun & Lee 2008; Chun & Lee 2013; Dickson, Allan & O'Carroll 2008; Hwang et al. 2012). However, these studies focused on different components of their experiences. Chen (2010) explored the lived experience of moving forward in life with a spinal cord injury and Chun and Lee (2008) explore the characteristics of post-traumatic growth in patients with spinal cord injuries. Chun and Lee (2013) explored the experience of gratitude in everyday life following a traumatic spinal cord injury, while Dickson, Allan and O'Carroll (2008) studied the biographical disruption and experience of loss following a spinal cord injury and Hwang et al. (2012) focused on understanding the experience of women with spinal cord injury. Overall, the findings demonstrated that patients benefited from their efforts to face their challenging life experiences. In addition, the studies also provided a deep understanding that these patients feel an ongoing sense of loss, especially towards their

personal control. These studies were focused on the implications for developing effective nursing interventions to improve the quality of life of these patients.

There are few studies that explored the experiences of the caregivers of patients with spinal cord injuries. Chen and Boore (2009) and DeSanto-Madeya (2006) explored the meaning of living with a patient who had a spinal cord injury, and these studies showed that the challenges did not disappear, even in the long term. It was a continuous learning experience for the patient and the family, and they felt as if they were entering a new and unknown world. The relevance of these studies is that they provide a platform for the future structuring of effective nursing care and education for families who are facing a dramatically changed way of living.

Research on nurses' experiences when caring for patients undergoing traumatic events (not spinal related) has suggested that caring for trauma patients is complicated (Alzghoul 2014). It requires a high level of concentration, because nurses do not have any control over what is going to happen from one minute to the next and they are not sure about the patients' prognosis (Kornhaber & Wilson 2011). Nurses tend to be affected emotionally and this leads to a feeling of powerlessness (Kornhaber & Wilson 2011). Caring for these patients is considered to be unique as well, because the occurrence of the traumatic event itself is unpredictable and the patients were not prepared to face it (Alzghoul 2014; Bostrom, Magnusson & Engstrom 2012). At times, nurses tend to develop an attachment to their patients and this awakens emotions of sorrow, vulnerability and sadness when dealing with them (Alzghoul 2014). However, they suppress these feelings in order to maintain their

professionalism (Bostrom, Magnusson & Engstrom 2012).

Nurses also described that many patients affected by trauma conveyed anxiety about their future (Bostrom, Magnusson & Engstrom 2012). The nurses then tried to help the patient to focus on what was happening at that moment and to get them through the traumatic situation (Bostrom, Magnusson & Engstrom 2012). The nurses also understood the importance of good communication with regard to patient care and of building supportive relationships among nurses (Bostrom, Magnusson & Engstrom 2012; Daines et al. 2013). This is essential as the job itself comes with a heavy workload (Alzghoul 2014).

Nurses also felt that providing support to their patients' families was difficult and that this was mainly due to lack of time to delve deeper into more complex problems (Daines et al. 2013).

The literature reviewed demonstrated that there was no research directly identifying an understanding of nurses' experiences in caring for patients with traumatic spinal cord injury who also had neurological deficits. Therefore, it was important to explore the lived experience of these nurses in order to develop future competent and experienced spinal nurses.

## **Chapter Summary**

This chapter has presented the literature relating to spinal cord injuries and traumatic events. However, there was no research available that explored nurses' experiences when caring for patients with traumatic spinal cord injuries who also had neurological deficits. The lack of information surrounding these

experiences provided the justification for a qualitative research methodology to be conducted in this study and this will be explained in the next chapter.

## CHAPTER 3: RESEARCH METHODOLOGY

### Introduction

This chapter discusses the methodology used in this qualitative research study. There are two major schools of phenomenology: the descriptive phenomenology of Edmund Husserl and the interpretive phenomenology of Martin Heidegger (Polit & Beck 2012). This study used hermeneutic phenomenology, which is derived from interpretive phenomenology, as a basis for the research design (Annells 1996). Max Van Manen's methodological structure was used to guide the philosophical approach, as described later (Van Manen 1997).

### Phenomenology

Phenomenology is a research paradigm that studies the phenomenon or experience of an issue (Van Manen 2014). It was developed by Edmund Husserl and Martin Heidegger, and this approach has been used to understand human life experiences (Cohen 1987). The differences between the two philosophers are based on how the findings are produced and used to expand professional knowledge, which is discussed further in this study (Lopez & Willis 2004).

A phenomenological question may be developed at any stage where there is a certain experience or phenomenon that causes us to stop and reflect (Van Manen 2014). Phenomenologists believe there is an essence to every phenomenon, that this essence can be understood, and that without an essence a phenomenon it would not be what it is (Polit & Beck 2012).



Phenomenological study is useful when exploring a poorly defined or conceptualised phenomenon (Polit & Beck 2012). Through phenomenology, participants reflect and talk about their experiences and this provides a pathway to the illumination and understanding of their lived experiences.

In this study, the researcher raised the question: What is the experience for a nurse to care for patients with traumatic spinal cord injuries who also have neurological deficits? This question can be answered through phenomenological study.

### **Husserlian Phenomenology**

Edmund Husserl is respected for his work in philosophy and is considered to be the founder of phenomenological philosophy (Koch 1995; Streubert & Carpenter 2011b). Husserl introduced the concept of the 'life world' or 'lived experience' and claimed that the life world is not readily available because it constitutes what is taken for granted (Spiegelberg 1960; Van Manen 2014). He examines the pure essence of lived experiences, without interpreting, explaining or theorising. Husserl used the concept of bracketing in his philosophy. This is about bracketing the belief or assumptions out of the phenomenon (Dowling 2007). He defined phenomenology as descriptive philosophy of the essence of pure experience (Polit & Beck 2012).

Phenomenology was considered the right methodology to explore the lived experience of nurses when caring for spinal injury patients. However, the concept of bracketing was not suitable in this research, because as a researcher and a nurse with experience caring for patients with spinal cord injuries, the researcher could not eliminate pre-understood experiences from

this study. This brought the researcher to the other branch of phenomenology; Heideggerian phenomenology.

## **Heideggerian Phenomenology**

The second branch of phenomenology is interpretive phenomenology, which is derived from the ideas of Heidegger (Van Manen 2014). Heidegger's insight into phenomenology was to interpret phenomena in order to uncover hidden meanings that serve as knowledge (Van Manen 2014).

The Heideggerian phenomenological approach was considered a suitable branch for this research because it looks into the interpretation of the experience rather than just the description. However, the researcher chose an evolved version of this interpretive phenomenology developed by Heidegger's student, Hans-Georg Gadamer, and known as hermeneutic phenomenology (Austgard 2012).

## **From Heidegger to Hans-Georg Gadamer: Further Development Towards Hermeneutic Phenomenology**

Heidegger's interpretive phenomenology, considered as his prestige work, was further developed by his student, Hans-Georg Gadamer, who is considered to be among the foremost representatives of hermeneutic phenomenology (Van Manen 2014). Gadamer developed hermeneutics as a field that is purely philosophical, as he does not offer researchers a method or a set of rules to follow in their investigations. Gadamer (1975) believed that a written text must be approached with openness and that interpretation does not circle around the text alone, but also involves the person who does the interpreting and this

person's interactions with the world. Gadamer considered that all human knowledge of the world is mediated linguistically, and he believed that only in dialogue can language portray its true being, which leads to further understanding (Gadamer 1975).

### **The main concepts in Gadamer's philosophy**

The research within this thesis was structured according to Gadamer's philosophy. Several of the main concepts in this philosophy are highlighted below, and each of these are important and mutually intertwined. These key concepts are:

#### ***Belonging to tradition***

According to Gadamer, the person who wants to understand a phenomenon has already built a relationship with the phenomenon they want to study from the way it is handed down through tradition and culture (Gadamer 1975). He believes that as human beings we have preconceptions, also known as assumptions or prejudices, in common, and this makes understanding possible (Austgard 2012).

#### ***Situation***

*The interpreter of texts is always located in a situation.*

*Austgard (2012, p. 830)*

According to Gadamer (1975), every present (now) has its limitations that confine the possibility of clear vision. The interpreter must be aware of the preconceptions (prejudices) overriding their understanding, so that the written

text can stand out and be valued on its own. Gadamer believes that prejudices need to be provoked in order to suspend them and he further explains that the encounter with a text can provide this provocation (Gadamer 1975).

### ***Text***

All written text is considered as a kind of alienated speech because the meaning has gone through a process of self-alienation when it is being written down and any transformation back to speech requires a hermeneutic task. Texts need to be understood with regard to what they say and nothing should be added. The most important aspect of this process is that the interpreter needs to be provoked by the text because only the text has the answer to the research question (Gadamer 1975).

### ***The true question***

According to Gadamer (1975), a person may acquire knowledge by learning to see what deserves to be investigated. This means that our question does not arise unexpectedly (Austgard 2012).

### ***The dialogue***

Gadamer (1975) explains that knowledge is a dialectic movement and this movement is created in the conversation between the interpreter's previous understanding and the written text (Gadamer 1975). The back-and-forth dialectic movements during interpretation are known as the hermeneutic cycle. The hermeneutic cycle not only refers to the concept of the entirety and the part of the text, but it also involves the communication between the interpreter's

previous understanding and the text, and it applies to dialogue between people (Gadamer 1975).

The movement of interpretation from an entire text to its parts and back to the entire text results in an 'abundance circle' of ideas about what the dialogue might mean (Annells 1996). Every time researchers explore a dialogue, it opens more possibilities of meaning (Koch 1995).

### ***The fusion of horizons***

According to Gadamer (1975), the concept of 'fusion of horizons' is an illustration for understanding. Gadamer explained that fusion is the merging of different standpoints (horizons). The process leading to the fusion of horizons is a way of conducting oneself to be willingly open to the standpoint of another so that one can allow their standpoint to speak and be influenced. The final touch of understanding shows that fusion has occurred.

### **Hermeneutic Phenomenology: Taking Residence in this Research**

Hermeneutic phenomenology is a phenomenology of human understanding (Austgard 2012). It explores the role of language, the nature of questioning, human conversation, the significance of human prejudices and human existence (Van Manen 2014).

Hermeneutic phenomenology gives nurses the individual's human experience rather than the conceptualisation of the individual's life experience (Van der Zalm & Bergum 2000). It provides living knowledge for nursing practice by probing deeper into the understanding of the nature of meaning in everyday life experiences (Van der Zalm & Bergum 2000).

Gadamer's hermeneutic phenomenology was identified to be congruent with the research question of this study and the researcher's view of the phenomenon. Therefore it was considered to be an appropriate methodology for use in this study.

## **Operationalising the Research: Van Manen's Methodological Structure**

The hermeneutic phenomenological field by Gadamer is the philosophical idea that framed this research, but Van Manen's methodological structure was used to break the philosophical idea down to a process that enabled the research process to unfold the whole experience. The six steps of the methodological structure, which are discussed below, offer a practical approach that is helpful in undertaking hermeneutic phenomenology based human science research.

### **Turning to the nature of lived experience**

There are times when we encounter a certain experience that makes us pause and reflect, and these are bound to awaken a phenomenological question (Van Manen 2014). As a researcher with experience caring for patients with traumatic spinal cord injury and associated neurological deficits, the researcher considered what the experience of other nurses caring for these patients was. According to Van Manen (1997) the first step in making sense of a certain human phenomenon is through the commitment to explore that aspect of human existence.

## **Investigating experience as it is lived**

Lived experience is the experience that we have lived through before we take a reflective view of it (Van Manen 2014). The researcher aimed to renew contact with the original experience of the participants, and this was done through semi-structured interviews.

## **Reflecting on essential themes**

The lived experiences gained from phenomenological research were considered as essential data for phenomenological reflection (Van Manen 2014). The 14-step approach to analysis proposed by Burnard (1991) was used to analyse the phenomenon. This is a method of thematic content analysis that aims to produce a systematic recording of themes. It links the themes and interviews together under a reasonably exhaustive category system (Burnard 1991).

## **The art of writing and rewriting**

Phenomenological writing is a rational process that systematically explores the meaning structure of a phenomenon (Van Manen 2014). In hermeneutic phenomenological writing, it is essential to remain mindful of the whole process to the research question. The texts that are written need to be able to 'speak' to the reader in a way that bring the experience vividly into presence, and evoke the feeling of nearness and understanding (Van Manen 2014). The 'speaking' language of the written texts was constructed in a way to give readers the feeling of being 'in touch' so that they can finally say, 'Yes, I understand'.

## **Maintaining a strong and oriented relation**

Researchers that study lived experiences need to maintain their focus on the kind of experience that they wish to investigate (Van Manen 1997). As the researcher interviews and writes about the participants' experiences, it is imperative to keep full awareness of staying close and oriented to the experiences as lived by the participants. The researcher admits maintaining a few prejudices towards this phenomenon. However, the researcher did not allow these to divert her from the inquiry process. In fact, these prejudices were kept aside and used to provide added value to the research during the fusion of horizons (Gadamer 1975). In this study, the researcher had adopted a 'decision trail' as a way to remain oriented to the phenomenon and establish trustworthiness (Koch 1994).

## **Balancing the research context by considering the parts and the whole**

Research activity in human science studies is closely linked with writing activities. The researcher needs to show a significant capability for producing original insights in narrative form. Thus, the researcher needs to examine the significant text of the study and constantly be certain that it fits the total textual structure and that the whole structure is grounded to the research question (Van Manen 1997). The flexibility of Van Manen's (1997) methodological structure corresponds to the hermeneutic cycle of interpretation by Gadamer (1975). This enables an understanding of the meaning that was given to the experiences examined through the final fusion of horizons (Koch 2006).



## Chapter Summary

This chapter provides an understanding of the methodology used in this study. It discusses the branches of phenomenology and relates these to the justification for using hermeneutic phenomenology. Van Manen's six methodological structures were used to break the philosophical idea down into a process that enabled the researcher to unfold the whole experience. The next chapter explains the research methods used in this research.

# CHAPTER 4: METHOD

## Introduction

This chapter describes and discusses the methods used in this research. The study design employed aimed to answer the research question.

Van Manen's six methodological structures were utilised to operationalise the whole research project (Van Manen 1997). This involves a dynamic interplay among six research activities, and the central notion of Gadamer's work was used as the philosophical guide (Austgard 2012). This concept may be difficult to understand without the appropriate context (Figure 4.1). However, this will be explained later in this chapter and in Chapter 5.

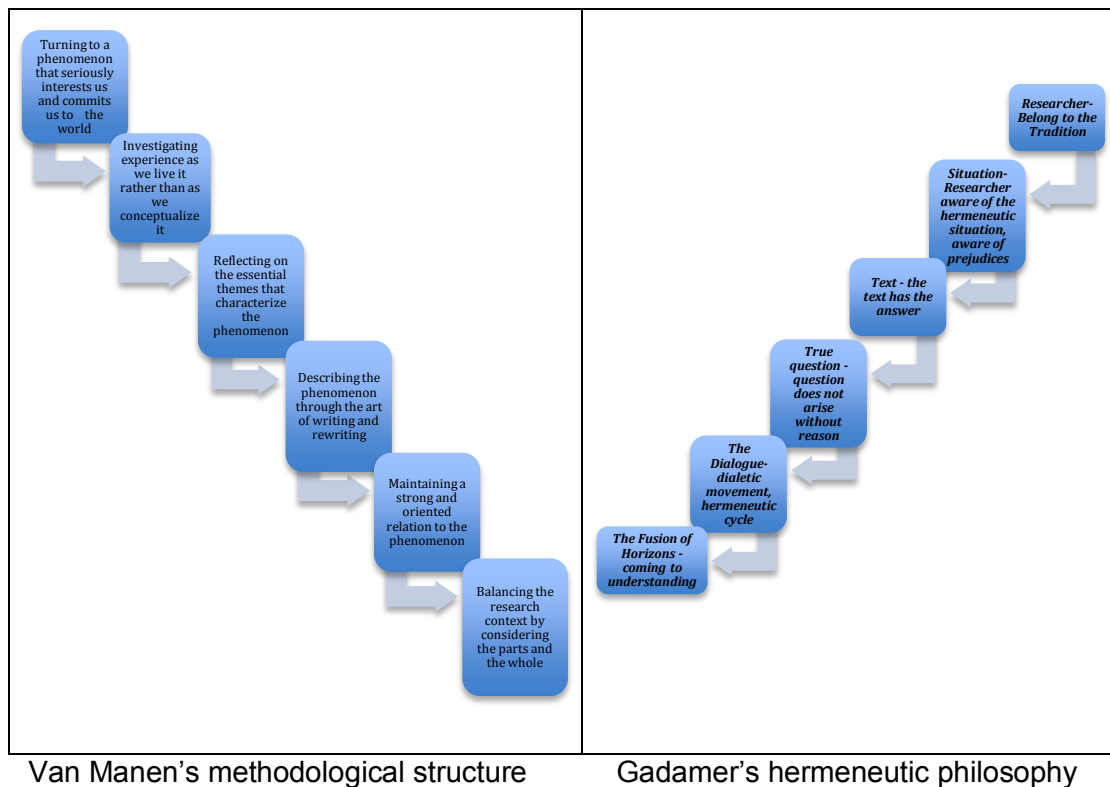


Figure 4.1: Dynamic interplay between Van Manen's methodological structure and Gadamer's hermeneutic philosophy.

This approach aimed to uncover the lived experience of nurses that care for patients with traumatic spinal cord injuries who also have neurological deficits.

### **Study Setting**

This study was conducted in a large metropolitan teaching hospital that provides spinal care and rehabilitation to patients from South Australia, the Northern Territory and some parts of Victoria and New South Wales.

The spinal unit has ten beds and is a dedicated site for the management of patients with an unstable spinal column injury, with or without an acute spinal cord injury sustained through either a traumatic event or medical causes. The spinal injuries unit also provides a service for patients undergoing elective spinal surgery in South Australia. In addition, it provides medical and nursing consultation services focused on advising and managing patients.

### **Sample Population**

Purposive sampling was used to recruit participants; the reason for choosing this sampling process was because the aim of this study was to uncover a particular type of rich, in-depth experiences of the phenomenon. Hence, nurses with a wide range of experience and backgrounds in the field were recruited in order to provide the in-depth information needed to meet the objectives and answer the research question. There were 27 registered nurses and 12 enrolled nurses working at the spinal unit.

### **Recruitment**

Participants were recruited after obtaining ethical approval from the hospital Human Research Ethics Committee (Appendix 1) as well as site specific

approval. Permission was also verbally granted by the Medical Director, Nursing Director and Clinical Service Coordinator. An email was sent to the Clinical Service Coordinator of the Spinal Unit and the Orthopaedic Nurse Educator; they assisted with the recruitment of the participants. An informal 10-minute briefing on the study was conducted early in the research process.

Each potential participant was supplied with a flyer and participant information sheet (Appendices 2 and 3). These documents gave details on the purpose of the study and a guarantee of confidentiality and anonymity to the participants. The benefit of this research was also explained to the participants. There were no significant foreseeable risks associated with this research; however, participants were given the right to stop the interview session at any time if they felt uncomfortable or to withdraw from the study. Contact details for the researcher and the university supervisors were included so that the participants who wished to do so could ask any questions they wanted answered. The hospital Research Ethics Committee reference number and complaints pathway were clearly outlined for the participants' information. The information sheet explained that participation in this research was voluntary and participants had the right to withdraw without any penalty.

Initially there were no responses from the nurses. Feedback from the Clinical Shift Coordinator noted that this was due to nurses being reluctant to take extra time after their working hours for an interview. Therefore, it was suggested that the researcher should be at the spinal unit during the one-hour continuous nurses' education session in order to recruit participants and conduct the interviews. This resulted in six nurses volunteering to participate in the study.

## **Selection Criteria**

The selection criteria used for this research included nurses that were currently employed at the spinal unit and had provided care for patients with traumatic spinal cord injury who had also sustained neurological deficits. Registered and enrolled nurses with broad range of experience in the spinal unit were sought for inclusion in the study. In addition, participants were required to be able to articulate their experience in English and be willing to be interviewed by the researcher.

Phenomenological studies tend to rely on small samples. The quality of the study is seen from the richness of the insight into the lived phenomena being explored (Polit & Beck 2012). Three registered nurses and three enrolled nurses with a broad range of experience (novice and advanced experience nurses) were recruited for this study. This was to enable the researcher to explore a broad diversity of individual experiences (Porter 1999).

## **Ethical Considerations**

Ethical approval for this research was obtained from the hospital's Human Research Ethics Committee, which was granted on 25 March 2015 with approval number HREC/15/RAH/114 (Appendix 1). The University of Adelaide Human Research Ethics Committee (HREC) was notified of this approval. This research complied with the Australian Code for the Responsible Conduct of Research (2007) and the National Statement of Ethical Conduct in Human Research (2007).

## **Consent**

Participants were required to provide written informed consent (Appendix 4) before the start of the study. Participants were made aware that the researcher and a professional transcription service would transcribe all audio recordings. The transcription service was bound by a confidentiality agreement (Appendix 5). Participants were also informed that the research information would only be used for the current research purpose only. Pseudonyms were used to represent each participant and this was clearly outlined in the consent and participant information sheet.

## **Anonymity and Confidentiality**

Participants were assured that only the researcher and the supervisors of this study had access to the research information, which was stored in an electronic password-protected device. The supervisors had access to the data only after it was de-identified. Anonymity was maintained by assigning pseudonyms to each transcript and these are used throughout this thesis.

## **Data Storage**

The information gained in this research was saved on an electronic password-protected device and kept for five years in a secure filing cabinet within the Eleanor Harrald Building, the School of Nursing of the University of Adelaide.

## **Data Collection**

Gadamer's philosophical hermeneutic approach, informed by Van Manen's methodological framework, supported the current research study (refer to Figure 4.1). This framework is not linear and thus it allowed the researcher

flexibility in answering the research question (Van Manen 1997). The following provides an explanation of how this framework underpinned the current research study.

### **Turning to a phenomenon that interests us and commits us to the world of the phenomenon**

The first step in the framework is for the researcher to turn to an experience that truly interests them. As a researcher that had experience caring for patients with traumatic spinal cord injuries that also have neurological deficits, I had a deep interest in exploring this phenomenon. I wondered what the experience of other nurses that care for these patients was, and whether it was the same as I assumed they might feel? What can we understand from it? This provided a strong basis to understand the meaning of the phenomenon.

This step was closely linked with Gadamer's philosophy, where it is essential for the researcher to belong to the same tradition, which means the person that wants to study a phenomenon must already have a relationship with the phenomenon (Austgard 2012). This awakens and brings awareness of the preconceived ideas that the researcher has with regard to the phenomenon, which Gadamer referred to as being aware of the hermeneutic situation (Austgard 2012). As this study progressed, the researcher's ideas were reshaped to add a new understanding of nurses' experience in caring for patients with traumatic spinal cord injuries that had neurological deficits.

## **Investigating experience as we live it rather than as we conceptualise it**

The second step in the framework is to investigate the lived experience as the person lives it, and not how it is intellectualised. In this research, the lived experiences were gathered in the form of dialogue and textual statements. The researcher actively immersed herself in the professional lives of the six nurses in order to gain an in-depth understanding of their experiences.

Data were collected through semi-structured interviews; however, during the interview the researcher listened to each answer and determined the next question based on what was said to gain a deeper understanding of the meaning inherent in the answer. The interviews were conducted in a quiet room at the spinal unit. The researcher felt it was a good idea to conduct the interview session in the spinal unit because this environment is where participants spend much of their time and this helps with the process of reflection on the phenomenon (Mapp 2008).

### **The interview process**

Phenomenological interviews serve as a way to gather and explore experiential narrative material, stories or anecdotes that can be used as a basis for reflection and thus develop a richer and deeper understanding of human experience (Van Manen 2014). The interview process was conducted at the spinal unit at a time that was convenient for the nurses. The interview sessions were conducted once only, because re-entering the field in order to acquire more data does not necessarily mean the researcher would obtain richer



data, but may only lead to dilution of the true essence of the experience (McConnell-Henry, Chapman & Francis 2011).

The interviews took between 20 and 60 minutes, and began with a general question asking the nurses to discuss their experience in caring for patients with traumatic spinal cord injuries who also had neurological deficits (Appendix 6). The length of the interview was determined by the participants' willingness to continue discussing their experiences and until no new information was identified. The researcher was also mindful of any emotional disturbance in the participants while attempting to answer the questions. The majority of the participants showed some uneasiness during the initial phase of the interview; however, they became more at ease and comfortable with sharing their experiences as the interviews progressed.

The interviews were audio recorded with two recorders, which allowed the researcher to fully participate in the interview process and observe non-verbal cues. Additional questions and clarification questions were asked in order to further develop an understanding of the participants' experiences. Throughout the interviews, the researcher maintained a focus on the main research question. The researcher admits there were prejudices (preconceived ideas) throughout this process, but she did not allow these to divert her from the enquiry process. In fact, it allowed her to clearly distinguish between the essences of the participants' experiences and her own.

A memo was kept throughout the research study (Appendix 7). This allowed the researcher to document participants' non-verbal cues and distinct words that related to the participants experiences. After listening to the audio recording

again on the day of the interview, the researcher wrote down a summary of each interview (Appendix 8). This helped the researcher to have an overview of the interview sessions, reflect on the participants' experiences and write down any preconceived ideas. This indirectly added further understanding to the patients' experiences.

### **Reflecting on essential themes that characterise the phenomenon**

After the interview sessions, the audio recordings were transcribed verbatim and assessed for accuracy. This process gave the researcher an opportunity to understand and reflect on the interviews. The process of conducting the interviews, transcribing the texts, writing the memos, writing summaries of the interview sessions and listening to the recordings again and again helped the researcher to become immersed in the data.

In the initial phase, the written transcribed texts of the nurses' experience were seen as individual alienated dialogues. Through the dialectical interpretational movement of back-and-forth that forms the hermeneutic cycle these written texts were transformed to the essence of the experience (Austgard 2012; Gadamer 1977). The hermeneutical cycle also led the researcher in identifying statements and phrases sharing commonalities and provided the basis for the establishment of open coding, sub-themes and essential themes (Appendix 9).

In this study the researcher's prejudices contributed to the personal horizon, while the horizon of the present was continuously being formed through the participants' texts. This, through the process of hermeneutical reflection and

various refinements, opened up an entire new enriched understanding of the world that these nurses experienced.

### **Describing the phenomenon through the art of writing and rewriting**

Describing a phenomenon requires a researcher to go through a cyclic process. The data collection, analysis and interpretation was not a linear process, and involved much reading and writing, which helped the researcher to define and redefine the open coding, categories, sub-themes and essential themes until clarity could be found through the participants' texts.

### **Maintaining an orientation to the phenomenon of interest**

It is essential for a researcher to continuously remain true to the research question. It was imperative for the researcher to show a clear trail of thought from the beginning to the end of the study. It was a real challenge for the researcher to keep the participant interviews within the bounds of the research question, because the participants had never experienced an interview session before. At times they digressed from the main question; however, the researcher managed to divert them back to it by asking related questions. The memos and summaries of the interviews identified the trail of thoughts. In addition, the researcher constantly questioned the accuracy of the themes as a clear representation of the nurses' experiences in caring for patients with traumatic spinal cord injuries. Two research supervisors also checked the accuracy of the themes.

## **Balancing the research context by considering the parts and the whole**

The hermeneutic phenomenological process requires a researcher to go through the cyclic process of the stages of data collection, analysis and interpretation. Throughout this cyclic process the researcher continuously considered the connection between the parts and the whole of the study. The transcribed texts, memos, summaries of the interviews and audio recording ensured the participants' experiences were captured within the context. The thematic analysis allowed the texts to be broken into parts of statements, which provided an understanding of each part towards the whole context of the nurses' experiences.

### **Methodological Rigour**

This part of the study discusses the aspect of rigour and the criteria followed in achieving trustworthiness. Rigour is known as the 'goodness' of qualitative research (Emden & Sandelowski 1998). The 'goodness' of this study is an important issue because it legitimises the body of knowledge that it adds to nursing practice. In this study, researcher used Sandelowski's (1986) qualitative criteria of rigour to ensure systematic, accountable and high quality research to be produced.

The first criterion of rigour is 'credibility', and the credibility of this study was enhanced through the process of recruitment of the participants, the data collection methods and the analysis.

Nurses from the spinal unit that had experience in caring for trauma patients with neurological deficits were selected as participants. They provided an in-depth tour into the world of caring for these patients. The participants were nurses with a broad range of experience and different age groups. This provided the researcher with a range of broad, rich and diverse experiences. A research study is considered credible when it presents a faithful interpretation of the experience, when readers can recognise it and relate it to their own experience, while those that had not yet encountered the experience may recognise it after reading about it through the research findings (Sandelowski 1986). This also fits the second criterion of rigour, which is 'fittingness'. Guba and Lincoln (1989) also use the term 'transferability' and suggest that transferability or fittingness is determined by the degree of similarity between two contexts. The similarities are in the context of the participants and the setting that represents the group of the study. In this study, the researcher had given the final reading material to her supervisor, who is also an orthopaedic nurse, and he was able to see and recognise these experiences.

The audio recording of the interviews allowed the researcher to participate with full concentration in the interview session. This enhanced the accuracy and trustworthiness of the data collection process (Streubert & Carpenter 2011a).

The nurses were interviewed only once. This was because to re-enter the world of their experience again does not necessarily mean the researcher would obtain richer data, but would only lead to the dilution of the true essence of their experiences. It would also affect the credibility and trustworthiness of this research (McConnell-Henry, Chapman & Francis 2011).

The researcher offered all participants the opportunity to review their transcripts and the offer was accepted. The reviews of the transcripts validated the accurate representation of each participant's lived experience and this increases the trustworthiness of this study.

The credibility of this research was further enhanced from the interview process until the theme building, where it was clearly in line with Gadamer's hermeneutic circle. The process of reflecting and clarifying during the interviews and comparing parts of the texts to the entirety of the concept, which Gadamer also described as 'play', illustrate the credibility of this research (Sandelowski 1986). Using direct quotes to explain the essential themes again enhanced the credibility of the research, which was in line with the participants' lived experiences.

In this study, the researcher clearly stated her background and assumptions. It was the researcher's intention to enter the hermeneutic cycle with full acknowledgement of the preconceived ideas that were associated with it. When the researcher is transparent in their research activities, it increases the credibility of the findings produced (Lincoln & Guba 1985).

The third criterion is auditability, which refers to a systematic process of decision-making. According to Sandelowski (1986), a study and its findings are considered auditable when another researcher can clearly follow the 'decision trail' used by the investigator in the study. In this research, the clear statement of the research question, methodology and methods as outlined earlier, identified the beginning of the audit trail. The audit trail was enhanced following each interview, where the researcher created folders for each participant,

containing the transcriptions of the texts, memos, a summary of the interview session and the audio recording.

The decision trail was further enhanced by the distinguishable flow of illumination of experiences. This flow can be accessed from the transcriptions of the audio recording, the open coding, and the formation of categories and sub-themes. The transcriptions were compared with each other for commonalities, which finally led to the identification of essential themes. If another researcher follows this trail they would arrive at the same, or comparable, but not contradictory conclusions based on the same given data, perspective and situation. In this study the auditability of this trail was validated by the supervisors and one participant at the spinal unit.

The final criterion is conformability, which is the degree to which the study results are derived from the participants' characteristics and the study context (Polit & Beck 2012). According to Sandelowski (1986, p. 221) conformability is achieved when credibility, fittingness and auditability have been fulfilled. This has been clearly described by the researcher throughout the study.

## **Chapter Summary**

This chapter explained the systematic process and the criteria used to achieve trustworthiness. The rigorous attempts by the researcher clearly show the legitimacy of this study. The following chapter will discuss the analytical framework used to analyse the data.

## CHAPTER 5: ANALYSIS

### Introduction

Data analysis is not always a direct process, especially for hermeneutic phenomenological research. Analysis of data usually follows its collection; however, in qualitative research this process actually begins when data collection starts (Streubert & Carpenter 2011b). This allows the researcher to constantly review the transcripts and discover any additional questions needed to offer a further description of their findings. In this study, the whole process of analysis began with the interview sessions. This reawakened each layer of the participants' experiences and increased the researcher's understanding of the phenomenon.

### Analytical Framework

The researcher used Burnard's (1991) 14-step approach to analyse the interview transcripts. These 14 steps allow the researcher to immerse him or herself in the data, reflect on it, and generate a rich description of the participants' experiences (Van Manen 1997). This thematic analysis method provided the researcher with concise and systematic steps to codify and categorise the interview transcripts. The texts had all the answers, and through the process of analysis the researcher was able to transform it and make its original meaning stand out (Gadamer 2006).

Throughout the process of thematic analysis, the researcher remained aware of the prejudices that overrode her understanding. Prejudices needed to be provoked in order to be suspended so that the essence of the text was isolated



and valued on its own (Gadamer 1975). The researcher found that her prejudices were evident throughout the whole research process, particularly at the beginning, during the analysis and at the end of this study. Nevertheless, the whole process allowed the researcher to participate in the life world of the participants and understand their experiences of caring for patients with traumatic spinal cord injuries.



**Figure 5.1:** Flowchart of Burnard's process of analysis (Burnard's 1991)

The hermeneutical nature of the interview and analytical process assisted with the open coding and identification of themes. Memos and summary of each interview gave an overall understanding of the interviews (Appendices 7 and 8). Through back-and-forth reading and reflection, many headings were identified.

As the analysis process continued, the researcher grouped the commonalities between the statements. This led to further identification of concepts across all six interviews.

**Table 5.1:** Example of identification of headings and clarification within the transcribed text

<b>N</b>	Well, it's not so much to answer for me. <u>It's difficult to get some people to understand.</u> Some <u>people don't want to believe that this is actually happening,</u> some <u>people are perhaps not very well educated and so they don't understand what's going on,</u> perhaps. (Nate: P4, L25–28)
<b>S</b>	Can you give me an example of some of the cases?
<b>N</b>	We had a patient a while ago, <u>the patient and their family had generally a very low level of education</u> and understanding of any sort of medical things. So, even after being here for couple of weeks and having a family meeting, <u>with everything explained to them,</u> they <u>still didn't actually understand,</u> what was actually happening. (Nate: P4, L30–33)

Note:

N (Nate), Participant's pseudonym;

S, Researcher;

P4, Participant number;

L, line number.

In this research, a pseudonym has been allocated to each participant. Direct quotes by participants that described aspects of the headings and clarification of the content were italicised. This stage is known as open coding.

The layers of the lived experiences of the nurses caring for patients with

traumatic spinal cord injuries and the associated neurological deficits were uncovered within the six interviews, transcribed verbatim to text, a reflective journal (book), memos, a summary of the transcribed texts, as well as audio recordings. The researcher found it was essential to utilise all of these forms of data collection method to reveal each layer of the nurses' experiences.

The audio recordings provided the researcher with a deeper appreciation of the emotional aspect of the participants' lived experience. The memos and the summary of the interviews were completed for each participant right after their interview session in order to help the researcher grasp their raw reflections, understanding, assumptions and non-verbal cues, which were not reflected in the transcribed text or audio recordings.

The researcher continually read and re-read the transcripts in order to be immersed in the data and uncover its essential meaning. At the same time, the researcher was also aware of her prejudices that were activated. However, this awareness of her prejudices helped the researcher to see the participants' experiences more clearly by letting those experiences take over and bring pure meaning to them. The reflective journal (book) enabled the researcher to remain focused and oriented to the research question. Maintaining an orientation to the phenomenon of interest is one of the steps in Van Manen's methodological structure.

### **Burnard's Method of Thematic Analysis**

Burnard's method of thematic analysis is a method of thematic content analysis. It produces detailed and systematic steps linking the interviews to the themes under an exhaustive category system (Burnard 1991). The themes are seen as

threads of experience and they uncover the deeper levels of understanding that the experience offers (Van Manen 1990).

The six interviews provided in-depth of information into the nurses' lived experience when caring for patients with traumatic spinal cord injuries.

Thematic analysis was undertaken by reading and re-reading the transcripts and writing down as many headings (concepts) as necessary to describe all aspects of the content while excluding 'dross'. Dross is unrelated issues or words that are irrelevant to the research topic. In Burnard's method of analysis, this stage is known as open coding, where concepts are identified and their properties and dimensions are discovered in the data (Strauss & Corbin 1998).

The researcher had taken steps to open up the texts by reading through line by line and exposing the thoughts, ideas and meanings that they contained. The purpose of doing this was to enable the researcher to group similar events, happenings, actions or interactions under common headings and categories.

**Table 5:2:** Description of open coding in illuminating nurses' experiences in caring for patients with traumatic spinal cord injuries

Selected Statements	Open coding	Category
Well, it's not so much to answer for me. <i><u>It's difficult to get some people to understand.</u></i> Some people don't want to believe that this is actually happening, some people are perhaps not very well educated and so they don't understand what's	It is not about answering patients questions, the challenge is to make them understand	Making oneself understood

going on, perhaps. (Nate: P4, L25–28)		
Well, it's not so much to answer for me. It's difficult to get some people to understand. Some <u>people don't want to believe that this is actually happening</u> , some people are perhaps not very well educated and so they don't understand what's going on, perhaps. (Nate: P4, L25–28)	Challenges, patient does not want to believe and cannot accept reality	Making oneself understood

The list of repetitious and similar categories was surveyed and grouped together under higher order sub-themes and essential themes. This was done to reduce the numbers of categories by collapsing some of the similar groups into broader ones.

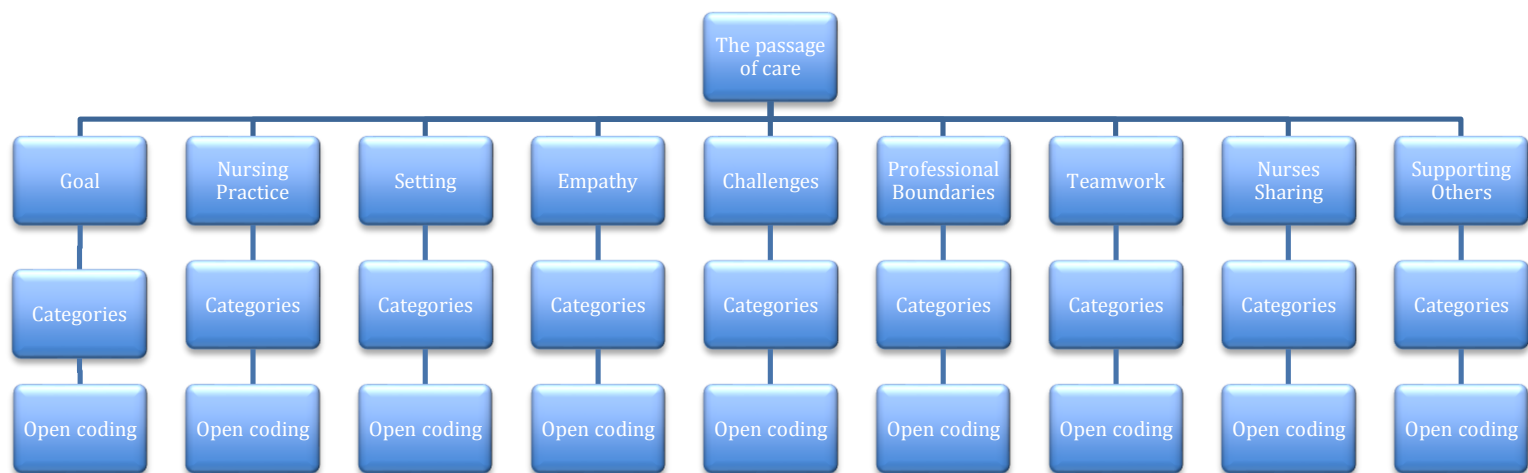
**Table 5.3:** Development of sub-themes and essential themes

Selected Statements	Open Coding	Category	Sub-theme	Essential Theme
<p>Well, it's not so much to answer for me. <u>It's difficult to get some people to understand.</u></p> <p>Some people don't want to believe that this is actually happening, some people are perhaps not very well educated and so they don't understand what's going on, perhaps. (Nate: P4, L25-28)</p>	<p>It is not about answering patients questions, the challenge is to make them understand</p>	<p>Making oneself understood</p>	<p>Challenges</p>	<p>The passage of care</p>

The four essential themes of “The Passage of Care”; “Patients’ Needs”; “Hope and Grief” and “Nursing Interventions of Patients and Families” and their sub-themes were identified through the analytical process

The following Figures 5.2 and 5.3 illustrate development lists of categories discussed in this research.

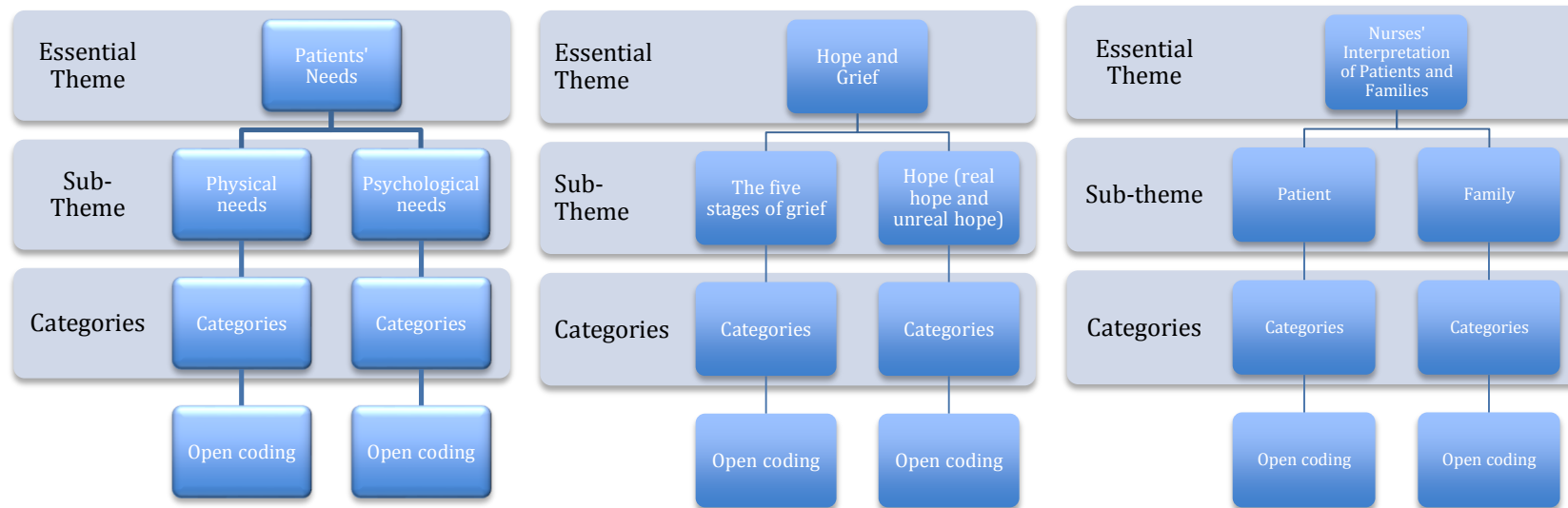
## The Development lists of categories



**Figure 5.2:** Development of the essential theme '*The Passage of Care*'

Note: Refer to Appendix 9 for an example of the analysis that encompasses transcribed statements, open coding, categories, sub-themes and essential themes of this research.





**Figure 5.3:** Development of the essential themes '*Patients' Needs*', '*Hope and Grief*' and '*Nurses' Interpretation of the Patients and Families*'

Note: Refer to Appendix 9 for an example of the analysis that encompasses transcribed statements, open coding, categories, sub-themes and essential themes of this research.

In order to enhance the validity and to prevent bias, two colleagues (research supervisors) were invited to independently to evaluate the knowledge trail and adjust the list of coding and the categorising until the emergence of essential themes, as necessary.

The data were entered into Microsoft Excel and sorted in order so that each coded section of the interview was aligned with the coding and themes. The coded sections were collected together and multiple copies were saved to ensure the contexts of the coded sections were maintained. The transcripts were re-read alongside the agreed lists of categories, sub-themes and essential themes to ensure they covered all aspects of the interviews.

One of the respondents (Nurse Pink) was selected to check the appropriateness of the category system. She was asked: 'Does this quotation from your interview fit this category, sub-theme and essential theme?' She validated the linkage and appropriateness of the category system.

The researcher managed to establish the commonalities and linkages between the themes while building the hierarchy that led to the essence of the lived experience of nurses caring for patients with traumatic spinal cord injuries.

## **Chapter Summary**

This chapter described Burnard's 14-step analysis method. The analysis revealed four essential themes: 'The Passage of Care', 'Patients' Needs', 'Hope and Grief' and 'Nurses' Interpretation of the Patients and Families'. The findings and interpretations from these themes are discussed in the following chapter.

# CHAPTER 6: FINDINGS AND INTERPRETATIONS

## Introduction

This chapter provides detailed findings on the essential themes and sub-themes that were derived from this research and their meaning for the experience of nurses caring for patients with traumatic spinal cord injuries who also have neurological deficits. The findings and interpretations of this research are discussed thematically, and the interconnections between the themes are outlined in order to provide an overall understanding of the whole phenomenon.

## Participant Profiles

Six participants volunteered to be interviewed for this study. Each participant was given a pseudonym to maintain their confidentiality. Short and succinct descriptions of the participants are given below.

### **Pink**

Pink is a young woman in her mid-20s. She has been working at the spinal unit for almost 2 years. She had no previous working experience with spinal patients; therefore her first three months at the spinal unit was very confronting for her. However, over time she became desensitised to seeing and dealing patients' with traumatic spinal cord injuries. During the initial stage of the interview, the researcher found that Pink had mixed feelings when answering certain questions and it was difficult for her to explain her experience. This is probably because she had never considered her feelings about caring for these patients in any great depth.

## **Colette**

Colette is a woman in her mid-50s. She is very knowledgeable and has been working at the spinal unit for nearly two decades. She had a few years of experience working in an orthopaedic ward and was very apprehensive when she was first shifted to the spinal unit. Nowadays, she is considered to be the resource person: most of the other nurses ask her questions with regard to spinal nursing.

## **Rick**

Rick is a man in his late 50s. He has been working in the spinal unit for nearly two decades. He enjoys working in the unit because he likes long-stay patients. He believes it helps in building rapport with his patients. His previous work experience had helped him to care for patients with traumatic spinal cord injury differently. His approach was more towards being empathetic and motivational when dealing with these patients.

## **Nate**

Nate is a man in his late 30s. He has been working at the spinal unit for nearly a decade. He had been exposed to seeing people living with disabilities before joining the spinal unit, and he felt that caring for patients with a traumatic spinal cord injury is the same as caring for any patient because each patient is individual and they all have their own different personal needs.

## **Kate**

Kate is a compassionate woman. She has had experience working in aged care and community nursing. She had just recently joined the spinal unit and one of her

biggest challenges was to learn about the work routine. She believes her job is to provide service to her patients and doing that does not bother her, especially because she feels that nursing is part of her nature.

## **Chris**

Chris is a man in his early 40s. He is a very enthusiastic and knowledgeable registered nurse. He has completed postgraduate studies and would like to pursue studies to a higher level. He has been at the spinal unit for nearly a decade now and had previous experience working in aged care, which had helped him in his transition to the spinal unit. Chris believes in giving hope to patients because it motivates them move on in their lives.

## **Emergence of Themes**

The hermeneutic nature of the interview analysis steps in this study enabled the emergence of the open coding, categories, sub-themes and finally, the essential themes. The final essential themes that reflected the nurses' experience were:

- The passage of care
- Patient's needs
- Hope and grief
- Nurses' interpretation of the patients and families

Significant statements were selected from the transcribed texts to reflect the interconnections between the open coding, categories, sub-themes and essential themes.

## **Essential theme: The passage of care**

The essential theme *passage of care* was characterised by the sub-themes *goals, settings, nursing practice, challenges, empathy, personal boundaries, teamwork, nurses sharing and supporting others*.

The *passage of care* signified the voyage or route these participants went through while caring for patients with traumatic spinal cord injuries and neurological deficits. These participants were clear about their goals and role in delivering care and were committed to achieving their goals. They provide care to their patients and have gone through many challenges while doing so. The feeling of empathy was a natural feeling in response to their patients; however, the participants maintained it within professional boundaries in order to empower their patients to become independent.

Through this passage of care, there was a solidarity that united the participants and this had been built through teamwork and sharing their experiences. At the end of it, while delivering care to these patients, the participants had acknowledged the trauma that the patients had experienced, which also affected their families, and indirectly, the participants as well.

### ***Goals***

The sub-theme *goal* explained that the participants had a clear vision of their goal in caring for patients with traumatic spinal cord injuries. They understood their role and were clear with their mission in achieving their goals. The goal was to settle the patients into the ward, the daily routine and the clinical expectations of the ward.

*...whenever they're being transferred to the ward. It's just a matter of trying to explain to them the routine nursing care, the expectations of*

*the ward, also the journey from here to wherever they're going.* (Chris P6, L215–218)

In order for participants to achieve their goals, their role and mission was to provide care at each stage of the patient's recovery until they went back to their communities. It is about prolonging their life.

*...you know ... you're helping to prolong life not, uh, cure them...* (Rick: P3, L957)

The process of achieving these goals could be difficult at times, especially when the patients' and nurses' goals were not the same. There were times when the patients had their own beliefs and requirements. Here, participants felt that as a nurse they needed to respect their patient's beliefs and negotiate and prioritise them until a mutually beneficial outcome could be attained. By supporting and understanding their patients the nurses could empower them towards the management of their care later on (Knight & Shea 2014).

*You just have to try and work with them now. So, you know, in the future it might help you but right now we need to do this.* (Nate: P4, L80–81)

### **Settings**

*Settings* referred to the surroundings of the spinal unit, which encompasses everything that goes on in the unit while nurses are performing their duties. The spinal unit is a dynamic environment and the working day at the spinal unit could be good or bad, depending on certain factors.

*A good day is when things don't go wrong and it's not too busy and everything gets done without rushing too much. And there are no problems. (Nate: P4, L151–152)*

A bad day at the spinal unit was when there were new admissions and the nurses had to deal with the inefficient support system, which hinders the smooth provision of care. A bad day was also when nurses had to care for spinal patients with other comorbidities or deal with abusive patients.

*...there are patients in hospitals that have medical problems as well, but other problems like, we sometimes get new patients, or you can't get the medication you need because pharmacies haven't dispensed it or things like that. (Nate: P4, L154–157)*

*...and if you had a bad day and then you came to work and got abused. (Colette: P2, L341–343)*

Repeated exposure to traumatic injuries has an effect on nurses (Hinderer et al. 2014), and desensitisation was a common feeling reflected by the majority of the participants.

*I've been working in this environment for quite a while now, I have become a bit desensitised... Well, I've only been here two years, but I would say after the first three months I was used to seeing that. And that's terrible to say, but that's just the way it is. (Pink: P1, L18–19, L63–64)*

There were positive and negative implications related to desensitisation. The positive aspect of desensitisation was described by Pink as follows:



*...it allows me to deal with that person's grief, so I don't go home and lose sleep worrying about them, or I'm able to switch off when I leave work, because it's a very routine ward. (Pink: P1, L23–26)*

The negative aspect of desensitisation was that participants experienced mixed feelings about it; stating that they hated it (guilt) and yet at the same time it could be good for them.

*It's hard to explain, because I've been working in this environment for quite a while now, I have become a bit desensitised, and although I hate that... I think in a way that's good...because it allows me to deal with that person's grief... (Pink: P1, L18–26)*

Being exposed to the same environment tends to change the way the nurses refer to their patients. They tend to refer to them by the patients' condition rather than by their names, and this was done spontaneously.

*...Well, we've had two ventilator-dependent tetraplegics that have decided to withdraw treatment. (Colette: P2, L483–484)*

### ***Nursing practice***

How nurses undertake their *nursing practice* was illuminated in this sub-theme. The senior nurses felt that caring for this group of patients was the same as caring for any patients with a similar disability, as it is highly individualised.

The following statements provided by the participants were used as an exemplar describing nurses caring for spinal cord injury and non-spinal cord injury patients:

*...It is the same as caring for any patients. Really. Everyone has their own different needs... (Nate: P4, L14–16)*

*...you have to be aware of everything going on with both [groups of] patients, but I think be more switched on with patients with neurological deficits, because things can change so quickly with spinal cord injuries... (Pink: L279–280, L270–275)*

In the end, it is all about nurses delivering patient-centred care. In providing care for patients with traumatic spinal cord injuries, the time spent talking to them and providing basic nursing care was considered the best thing a nurse could give:

*...if you sit and have a chat for ten minutes about something, you know, that might be the only contact that they've had for now because they're lying flat, can't see anybody. And just do the basics, everybody need to be fed, washed, cleaned; if you can do that well you're helping those days. (Colette: P2, L556–564)*

For a newcomer that joins the spinal unit, it takes time for them to learn the routine of the nursing practices even if they had previous experience caring for patients with similar conditions:

*So I had been in some places that people were paraplegic and all that... I had a little bit of exposure, but it would have been very limited,... It's a very particular routine that you don't have in other areas...it takes months, yes definitely. (Kate: P5, L597–601, L614–619)*

However, the majority of the participants felt that having experience mattered and that previous exposure opened up new knowledge. It became added value when providing nursing care to these patients:

*It makes it sometimes easier to find problems perhaps earlier than if you don't have the experience. (Nate: P4, L164–168)*

Colette explained that nurses with experiences of life perform better when dealing with the psychological aspect of the care of these patients:

*...there are some people that come in with sort of a few experiences of life that will do better with the mental side of things... (Colette: P2, L548–554)*

On the other hand, in spite of feeling that experience matters, the nurses also felt that most of the learning opportunities in spinal nursing were found on the job.

*...most of the spinal nursing is more, like you learn it on the job than in the literature. (Chris: P6, L180–182)*

### ***Empathy***

Ever present in the participants' minds when caring for patients with traumatic spinal cord injury was the *empathy* they felt for these patients and their family. The feeling of empathy was clearly reflected; it became a mirror for these nurses.

*You put yourself in their shoes, and that's very hard to come to terms with...they come round to our ward, and it's finally starting to sink in what actually happened and the extent of their injuries... (Pink: P1, L36–39)*

However, to some nurses the feeling of empathy was more pronounced for their younger patients than their older ones.

*... some staff members...seem to feel that it's worse being a 20-year-old having an accident... than it is if you're 80 years old because you haven't got long to go...it's not how much longer they've got to go, it's just not a nice situation to be in. (Rick: P3, L859–861, L865–866)*

Empathy is regarded as an important component of any form of caring relationship; however, sometimes nurses need to be tough. Empathy needs to be balanced with the concept of empowering to enable the patients to become independent.

*...sometimes you have to use tough love with patients...if they're paraplegics and they can use their hands you don't feed them...you have to get them to do as much for themselves as they can...because otherwise you're...disempowering them... (Rick: P3, L1033–1034, L1038, L1042)*

## **Challenges**

At times, it can become complex for nurses to provide basic or fundamental care for their patients (Kitson, Muntlin Athlin & Conroy 2014). Nurses had to go through many *challenges* and in this study the participants described these challenges.

In their early stages of working in the spinal unit, Pink and Chris described it to be psychologically challenging and confronting to be exposed to this type of patient and their families every day:

*It can be confronting at times...the hardest part, is seeing them actually realise what their future might be like... (Pink: P1, L18, L20–22, L39–40)*

*And then seeing her sister coping and dealing with what had happened, as well as her parents, you know that was quite hard to see... (Pink: P1, L172–173)*

*...challenges, there are so many, um, psychologically, I mean, they're traumatised, um, and trying to look after these patients can be tricky. (Chris: P6, L104–105)*

Nate described the challenges as having to do heavy work:

*...it's heavier work than in a lot of other parts of the hospital because people are dependent on you... (Nate, P4, L390–391)*

The character of the patients could be a major challenge for the participants. This was due to the requirement to deal with a range of different people:

*Yes, the character makes a big difference looking after a person. (Nate: P4, L103)*

Colette described the pressure she felt when patients could not accept their injury:

*The hardest thing is that people just can't accept a spinal injury at all... (Colette: P2, L95–100)*

*I had one tetraplegic who was angry when he first had his injury, then 35 years later he's still...So then you find that his anger comes out with the way he deals with the nurses... (Colette: P2, L100–108)*

The devastating impact of trauma on patients also has an impact on the nurses. Colette described the pressure she felt to look after the mental and physical state of these patients:

*...for the younger patients...their whole life has changed...it's also difficult because you quite often have the parents and the family to deal with as well...you're looking after the patient's mental state and physical state... (Colette: P2, L41–49)*

*...for older people...they've gone from trying to be fully independent...and all of a sudden they can't do anything for themselves. So I find they're quite emotionally hard to deal with... (Colette: P2, L80–90)*

Dealing with patients' questions on their prognosis was very challenging for almost all participants.

*...a lot of the questions they ask are 'am I ever going to be normal again, or am I ever going to walk again?' Those are very, very hard questions to answer... (Pink: P1, L49–58)*

*It's difficult to get some people to understand. Some people don't want to believe that this is actually happened, some people are perhaps not very well educated and so they don't understand what's going on... (Nate: P4, L25–28)*

The nurses at the spinal unit were from many backgrounds. It was a challenge to understand the language spoken by their colleagues at the unit:

*Well you see you're getting people from different backgrounds too...we have quite a few Indians, we have quite a few Asians, Chinese. (Kate: P5, L426–428)*

The patients were from different backgrounds as well and they had different personalities.

*...we had a patient that was a young tetraplegic...had a rough life before he had his accident,...basically not a nice person...he was verbally aggressive, spat, bit...He had just about all the staff in tears... (Colette: P2, L262–272)*

It required adjustment to deal with these challenges.

*...if they get very uptight, you always withdraw, you come back again. (Kate: P5, L730–731)*

Nurses at the spinal unit were required to understand the nature of the job and challenges that come with caring for patients with traumatic spinal cord injury. However, there were new nurses that did not understand these facts.

*...the nurses who are just new to the ward...there are some things that you have to do for our patients that they don't want to or, um, don't see that it's their job... (Rick: P3, L1015–1021)*

## **Professional boundaries**

The nurse–patient relationship is fundamental to successful nursing practice (Griffith & Tengnah 2013). However, maintaining *professional boundaries* is important in order to achieve this. The sole focus must be on the care and treatment needs of the patients (Griffith & Tengnah 2013).

*I think if you let it become more than a job that is where a lot of people get, uh, they get caught with becoming overly involved in people's lives. (Rick: P3, L352–354)*

However, Rick added that at times, he did get attached to certain patients but was able to maintain that boundary:

*...one of the nicer patients, [patients name], that I mention. He passed away two or three months ago. I wish I would have gone to his funeral. (Rick: P3, L1374–1375).*

One of the ways to maintain professional boundaries is to switch off and disconnect after leaving work.

*I give all of myself to my patients while I'm in here...but no, I don't take it home with me. (Kate: P5, L480–481)*

Even though most participants felt it was important to switch off and maintain boundaries, some of them did think or talk about patients at home.

*Sometimes I'll talk about my day with my partner when I get home, but yes, usually I don't delve into any details. (Pink: P1, L93–94)*



However, according to Colette, she would choose to switch off and maintain that boundary when she encountered difficult patients and had a bad day at work.

*...if you've got really problem patients, I try to switch off at home because...you're not coming home with me... (Colette: P2, L608–610)*

There are times when patients vent their frustration on nurses. This is where in the context of good nursing practice nurses need to maintain the boundaries and remain professional. As Chris described:

*And psychologically everyone is different, sometimes they will try and vent their anger on you, but don't take it personally, just deal as it is. (Chris: P6, L299–301)*

Colette further added:

*...if someone is being particularly vindictive, or you get someone who would make their comments very personal...you've got your boundaries of what you'll accept and what you won't...but you just have to know that nine times out of ten they're not angry at you, they're just angry with their situation. (Colette: P2, L138–146)*

### **Teamwork**

When healthcare providers function as part of a unit and when they act as part of a team, it benefits the patients.

*...so you're working with personalities, and everyone has a different way of doing things, but you're working together for the benefit of your patients. (Kate: P5, L353–355)*

However, there were variations in their experiences with regard to this, and according to Colette, at times nurses were left alone to deal with patients with challenging behaviour.

*...the junior staff were in tears, the doctors would not help us, they just walked in, did their bit and they left. (Colette: P2, L287–288)*

Dealing with the families could also be hard unless the family was able to accept the diagnosis, when they could be an asset in helping to support the patient.

*Families can be, um, it's hard; they can be supportive...sometimes they, accept the diagnosis...more than the patient themselves. So as long as he gets the support from the family, and then with your own clinical expertise and support then at times...and it makes it easier.*

*(Chris: P6, L222–225)*

### ***Nurses sharing***

At the spinal unit, nurses help each other when providing care to patients. They do this by sharing their knowledge and experiences with each other.

*...we help each other...to keep them safe and to you know, um, and to provide the care... (Kate: P5, L510–512)*

Sharing knowledge when caring for patients had become part of the culture of nursing practice in the spinal unit; Colette described her role as a resource person:

*I spend a lot more time doing patient education or chatting to people about questions that other people can't answer...I educate the staff a lot as well, as far as spinal stuff goes. (Colette: P3, L253–255)*

## ***Supporting others***

In the passage of caring for patients with traumatic spinal cord injury, nurses had seen the challenges families go through. With that, providing supports to families becomes part of nursing role.

*Usually I...deal with the patient first...then have a chat with mum and dad aside...we have to be very subtle...keep them involved and educated, but I still make the focus on the patient and gradually get some support for mum and dad... (Colette: P2, L61–68).*

## **Essential theme: Patients' needs**

Traumatic spinal cord injury with neurological deficit has a higher potential for permanent motor and sensory impairment to the individual (Grundy & Swain 2002). In this research the essential theme *patients' needs* was characterised by the sub-themes *physical needs* and *psychological needs*, which focus on the nurses' concerns when fulfilling the needs of their patients. It shows that the nurses give more consideration to the psychological aspects compared to the physical aspects of their patients' needs.

### ***Physical needs***

Respecting the personal needs of patients is the most important dimension in patient-centred care (McCauley & Irwin 2006). It was considered essential to help the patients to become independent, to build their abilities and allow them to return back to society.

*...yeah that's the big thing in here, you get them medically stable so that we can get them to rehab. (Kate: P5, L765–768)*

Rick felt it was important to deal with each patient by removing the emotional side that is attached to the person and look at the physical injuries first:

*...in a lot of ways I can remove the emotional person and just look at the physical injuries...and then react to the emotional things as, as they arrive. (P3, L906–908)*

Colette described that it was good to have a mix of patients in the spinal unit, because it was always hard to care for only patients with neurological loss:

*...they're obviously a lot easier and don't need as much nursing care... Whereas, with the people with loss, you know that you've got a lot more nursing hours involved in basic care, prevention of things, a lot more education... (Colette: P2, L521–528)*

### **Psychological needs**

In this research, the participants' focus was more on helping their patients cope with the psychological trauma of spinal cord injury. Enhancing the feeling of normality helps psychosocial recovery and assisting these patients to have personal and emotional control will help them enhance their self-care skills (Partridge 1994).

*Everyone has their own different needs. Some people are better able to cope with their situation than others. Therefore, they are easier to care for sometimes. (Nate: P4, L14–16)*

Much of the time nurses are busy with nursing care, so quality time given to talk and understand patients' feelings means a lot to the patients:

*...they appreciate the time that you can give to just stop and chat with them, and actually find out how they feel... I think that can be more valuable to someone than any care that you give them. (Pink: P1, L195–199)*

Patients' feedback justified that humour was the best way to bring happiness in the hospital environment.

*I think I've always sort of done it with a sense of humour...and because you get feedback from patients saying, oh, it's so nice to have a few people that are a bit bright or bubbly or have a bit of a joke, otherwise it's all too serious. (Colette: P2, 199–202)*

The bond between patients and nurses may lead to them disclosing personal details; however, this only happened when there was some similarity in their backgrounds.

*...there are some people, um, we had a, a gentleman by the name of [patients name] , um, who we were very similar in age...uh, we'd grown up in a very similar area...um, he had two boys, I had two boys; he'd been a quad for thirty-odd years...and we used to get on very well...I'd sit, sit there talking to him for 20 minutes, half an hour if I had time to spare rather just sitting in the office... (Rick: P3, L682–723)*

At appropriate times nurses would talk about life pre-injury and the things that their patients liked and disliked. This was because to constantly remind patients about their trauma could be too overwhelming.

*...but when it is an appropriate time, I talk about their life outside previous to this, and like what they like and dislike...because it is very...it can be quite morbid all the time when you're in hospital, because you are constantly talking about injury, constantly testing their strengths and their sensations and stuff is a reminder of what you can and can't do now. (Pink: P1, L183–184, L186–190)*

Pink stated that the emotional challenges faced by patients and families also affected the nurses. This is because they are the 'first point of call' and they see everything that the patients and families go through.

*I think mostly for me it's the emotional challenges that they experience, and the emotional challenges of their family coming to terms with that as well...you're the first point of call for all... So that's another challenge. ( Pink: P1, L206–212)*

It is a situation that needs a lot of adjustment from the patients; therefore nurses need to be compassionate:

*Compassion is in my nature; it's what you do. It's the care...it's how you address people, it's your manner... (Kate: P5, L51–52, L 53–56)*

Chris described the importance of providing explanations and giving information to patients, with the hope that they will attain the acceptance phase and move on.

*...so it's just a bit of giving as much information as possible; sometimes they accept the diagnosis and move forward. (Chris: P6, L107–108)*

Rick added by saying that he would use the one-liner philosophy to motivate the patients to look forward:

*...a great one-liner, the, you know, it's not the end of your life, it's just the start of, you know, it's just a new beginning and a new direction.*

(Rick: P3, L70–71)

If the nurses realised patients were not coping well emotionally they would refer them to a psychologist and a social worker.

*...if you find they're not coping well with that we've got clinical psychologists and a social worker, or other people to talk to...* (Colette:

P2, L 138–146)

### **Essential theme: Hope and grief**

The essential theme *hope and grief* was characterised by the sub-themes *the five stages of grief* and *hope (real hope and unreal hope)*.

#### ***The five stages of grief***

Spinal cord injury is considered to be one of the most shattering of all injuries, and so these patients go through many phases of grief and hold on to hope as a means to move on (Dunne 2004; Lohne & Severinsson 2004a; Ross 1973).

*They'll be going through the whole grief syndrome initially...the diagnosis doesn't hit, it takes a while for it to sink in.* (Kate: P5, L193–195)

Kate stated that some patients showed their grief behaviourally and some verbally:

*...sometimes you'll get a verbal one, sometimes...you'll ask questions, um, and you might just get an answer, sometimes you won't. They want the room dark, um, they will not want to talk... Can you just do that and leave me alone... (Kate: P5, L210–214)*

At this point, Kate would normally give them space:

*....you just give them space, come back when you need to, but give them that time, give them time with family, with friends that will help them. Um, because it's, it can be, you know, very dark and lonely. (Kate: P5, L215–217)*

It is challenging for nurses when their patients are going through the stages of grief:

*Sometime there are people that don't want to believe what actually happened so it can be hard to explain to them the reason why they can't do this anymore. (Nate: P4, L19–21)*

At the same time, it was also important to identify the signs and symptoms of grief and to provide necessary interventions:

*...if they start to be quiet...sometimes it may be the diagnosis hitting them. You would be wanting to refer them on, first of all you get a social worker to come in and speak with them, and then they might get a psych review or get a psychologist in to have a talk with them to see what you can offer them. (Kate: P5, L249–252)*

Sometimes when dealing with patients' grief, it opens the opportunity for more questions depending on the patient's acceptance of his or her condition:



*...if they accept the diagnosis then sometimes they will ask more questions. Some of them, they don't accept that they can't move or they've got loss; and for them...sometimes they will just keep to themselves. (Chris: P6, L80–83)*

Chris further commented that those patients who did not accept their condition would ask the nurses the same questions, and he would keep providing support for the patient.

*It's "when am I going to be moving...why am I not moving my arms?" Those are some of the questions they will ask... You explain to them, and then tomorrow they still ask you the same questions...So it's a bit of supporting... Yes, keep on explaining. (Chris: P6, L91–96, L100)*

### ***Hope (real and unreal)***

The phenomenon of hope is defined as the possibility of future improvement. However, in the hope itself, there is still a sense of uncertainty as hope is more focused towards the unknown future (Lohne & Severinsson 2004).

It is a skill to foster hope and enable recently injured patients to look beyond their immediate situation and direct their energies appropriately. To provide hope is considered beneficial; however, to provide false hope is not, and nurses should be able to draw the line between hope and unrealistic hope that may hinder the opportunity to move on (Miller 2007).

*...but always tell them there's hope even if you think there's no hope, because with nature you never know. Also there's a lot of medical*

*research, some people might try different options, so there's always that small chance that they might get that chance. (Chris: P6, L60–68)*

The participants talked about alternatives and how these changed the way patients looked at their future.

*...a lot of people who have their injury, initially...think to themselves that they're going to be quadriplegics, not able to do anything...and when you start talking about technology, um, and that, um, a lot of them...take it on board because so many people these days are very technology oriented... (Rick: P3, L230–260)*

Colette further described:

*...for God's sake, if you don't know something don't say something. Because if someone says something and the patient hones in, that nurse said I might be able to walk again, or whatever, and that's the worst thing, you know, false hope. Hope is good, but false hope is not, but if you're not sure don't, because the patients will cling on to every word you say. (Colette: P2, L568–573)*

There were patients that felt that medicine had no answer for their condition, and they turned towards alternative medicine and believed in a miracle. Nate described this:

*They come from different cultures. Usually they are quite well educated. But not in medical fields, but usually quite educated somewhere else. Hmm...the same happens in other areas too, cancer patients have the same thing. There are some people who like to*

*believe, you know, a crystal will heal them or eating certain foods will do miraculous wonders.* (Nate: P4, L74–78)

Colette considered that it was always better for nurses not to verbalise things that they were not sure of.

## **Essential theme: Nurses' interpretations of the patients and families**

The essential theme *nurses' interpretation of the patients and families* was characterised by the sub-themes *patients* and *families*. Here, the nurses also brought their interpretations of the patients and their families in dealing with this traumatic event.

### ***Patients***

Nowadays, the turnover of patients in the spinal unit was a lot more rapid. However, this depended on the reason why they were admitted. Colette described:

*...and the patients are in and out a lot quicker... But depending on what they're here for...* (Colette: P2, L217, L219–223).

Rick further explained:

*...you remember the really good patients...you remember the really bad patients...and all the ones in the middle sort of all become very blurred...* (Rick: P3, L618–619, L623, L627)

The devastating impact of the trauma changes patients' personalities. Kate described:

*...they may have been a young person who's been outgoing...it can change their personality as the impact of what has happened and what will happen, that they may change totally from an outgoing personality to a very quiet, very depressed, very morose, but you're still treating them as that person. You just have to adjust the way you approach them... (Kate: P5, L721–727)*

Patients in the spinal unit were categorised by the participants into three groups: those that do not want to deal with the reality, those that are optimists and those who are in between. Colette described:

*I had one tetraplegic who was angry when he first had his injury, then 35 years later he's still as angry as he was 30 odd years ago, he's just never dealt with the injury at all... Whereas, some people are the opposite, it's right, I've got this, I get on with my life, I'll deal with this; and then you've got the people in between. (Colette: P2, L100–103, L110–111)*

### **Families**

The caregivers for patients with traumatic spinal cord injury that had neurological deficits seldom receive the necessary preparation for their new role (Dickson et al. 2010). Colette described:

*...sometimes, if the younger people have been living independently, all of a sudden they had an accident, mum and dad just come in, take over, won't let them make a decision because it's my baby, I need to look after you. This person is a functioning adult, but the parents sort*

*of step in and actually, sometimes, get in the way... (Colette: P2, L50–56).*

Colette also added that every culture handled disability differently:

*...we had one, was it Taiwanese...his father basically said, you're dead to me, you're not my son because you're paralysed and that's a problem...eventually he came around, but it took a long time... (Colette: P2, L391–401).\*

Some patients had to be admitted for longer periods in the spinal unit. Therefore, the nurses were able to learn more about their families.

*...there are some of them are here longer than other patients. So, you get to know them and their family a bit more than you would with patients who...hmm...are just here for a few days. (Nate: P4, L187–189)*

## Chapter Summary

The process of hermeneutic reflection opened up an understanding of the world that these nurses had manifested. The prejudices that the researcher held contributed to the personal horizon, while the horizon of the present was continuously being formed through the participants' texts. This unity lead to an understanding of the phenomena through the four essential themes described above. The following chapter provides a discussion of the interpretations described in this chapter.

# CHAPTER 7: DISCUSSION OF MAJOR FINDINGS, RECOMMENDATIONS AND CONCLUSION

## Introduction

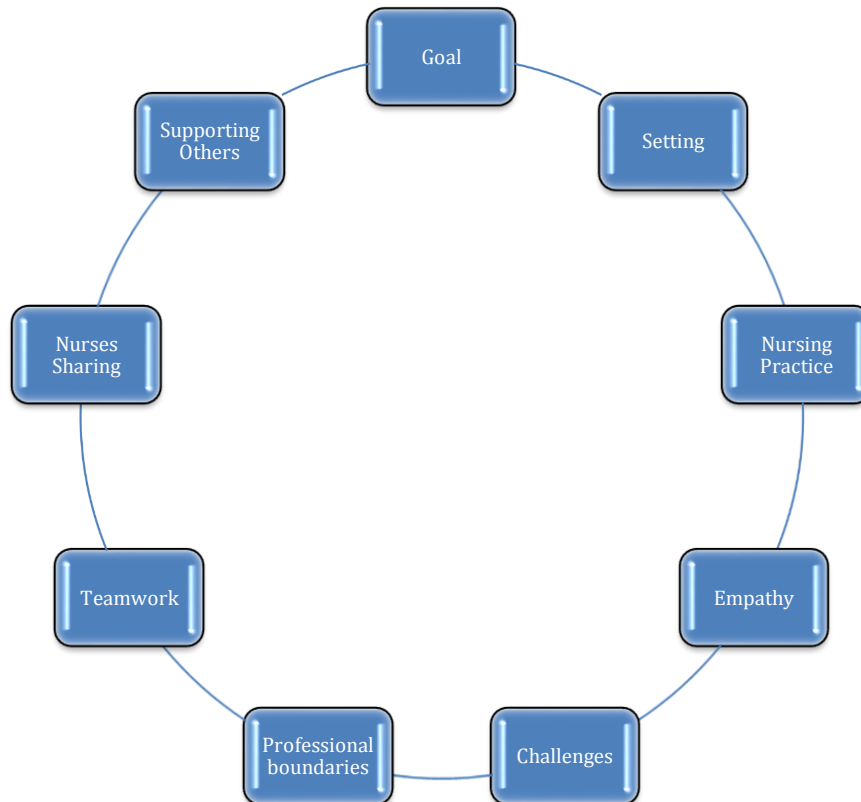
Spinal nursing care is a complex arena; however, the merging of the researcher and the participants' experiences brought together a beginning understanding of the phenomenon. This is known as the fusion of horizons. This study brought to life the four main themes that are discussed in this thesis. Their significance in answering the research question and the limitations and recommendations arising from this study are discussed in this chapter.

## Major Findings and Their Significance

The aim of this study was to provide an understanding of nurses' experiences when caring for patients with traumatic spinal cord injuries that had neurological deficits. The answers from the participants illuminated four major themes: *'The passage of care'*, *'Patients' needs'*, *'Hope and grief'* and *'Nurses' interpretations of the patients and families'*.

### **The passage of care**

*The passage of care* signified the voyage or route that the nurses took while caring for patients with traumatic spinal cord injuries that had neurological deficits. The themes in *the passage of care* do not follow a sequence; however, the majority of the participants went through these experiences (Figure 7.1).



**Figure 7.1:** The passage of caring for patients with traumatic spinal cord injury that have neurological deficits

While moving through this passage of care all participants were clear about their goal, which was to get the patients settle into the ward, the routine and the clinical expectation of the ward. It is about providing their nursing care until the patients medically stable before transferring them to another area for rehabilitation.

The positive effect of goal setting is that it motivates staff to achieve their goals, as has been highlighted in many studies (Elliott & Dweck 1988; Erez & Kanfer 1983; Locke & Latham 2002). However, the process of achieving their goals could be difficult at times, especially when the patients' and the nurses' goals were not the same. Therefore, it was essential for nurses to develop goals that were mutually agreed with their patients. This facilitated a feeling of self-worth and autonomy for

the patients and at the same time enabled the nurses to achieve their mission, which was to stabilise the patient for the rehabilitation process (Playford et al. 2009).

The passage of delivering care in the spinal unit was very dynamic and the participants described it as 'good days' and 'bad days'. A good day was mostly associated with the smoothness of the routine when delivering care, which happened when the nurses had medically stable patients to care for, with the necessary resources for delivering care being easily accessible and a rapid turnover of patients on the ward. Generally, healthcare professionals have an expectation that patients that enter an acute hospital setting will cooperate with their treatment, recover and return to their normal role in society (Larsen 2013). However, in dynamic clinical settings these expectations are not always realised smoothly. At times due to the inefficient support system such as delayed or not getting the medications needed for patients not only affected the nurses' role in delivering care but also resulted in delayed or missed care for their patients. Hence, it had a negative impact on both the recovery and the long-term outcomes of the patients (Winters & Neville 2012).

In some respects caring for patients with spinal cord injuries that have associated neurological deficit was perceived as being the same as caring for any other patients. This was because the nurses believed in delivering their care based on each patient's individuality. It was an evident that the nurses perceived their patients in a very mature way. Instead of seeing patients with traumatic spinal cord injury as unique and special cases, as reported in other similar trauma studies, the nurses in this study managed to see their patients as individual human beings and provided care based on their individual requirements (Alzghoul 2014; Bostrom, Magnusson &



Engstrom 2012). By tailoring individual care, nurses are moving towards the foundation of a therapeutic relationship (Doherty & Thompson 2014).

New nurses joining the spinal unit took time to learn, understand the patients' needs and adapt to the nursing practices and the routine of the unit. This process took time even if the nurses had previous experience in caring for patients with spinal injuries. However, their previous experience benefited the nurses in their ability to identify problems more quickly and understand the patients and the environment they would be working in.

Being exposed to the same environment for months or years had an impact on the nurses. They began to refer the patients based on their condition; for example, as tetraplegics rather than by their names, and this indirectly dehumanised the patients. A study by Haque and Waytz (2012) explains that this can be a spontaneous method to cope with stress while caring for patients. In this study, the nurses exposed to the same environment for months or years also naturally developed a feeling of desensitisation. This made caring for patients with spinal cord injuries that have neurological deficits seem normal. When spoken aloud, the nurses felt guilty for these feelings because a spinal cord injury is considered a tragic and traumatic event (Dandy & Edwards 2009; Grundy & Swain 2002; Hickey 2002). Similar findings were identified among nurses working with trauma patients in critical care and emergency settings; these nurses developed a protective mechanism to shield themselves from emotional attachment to their patients and this happened naturally. They became 'hardened', and the nurses also described feelings of guilt when they voiced this experience (Alzghoul 2014). Although they felt guilty, there was also a positive side to desensitisation. It helped the nurses to develop a 'thick skin' and the

ability to 'switch off'. This provided a protective mechanism for the nurses that enabled them to deal with their patients' grief and not let it affect them.

Desensitisation does not mean the nurses lack empathy for their patients. Empathy is related to closeness in term of feelings, thoughts and emotions, which in turn is aligned to getting to know the patients and this can be stressful for nurses (Baillie 1996). In this study the nurses described their feelings of empathy and how hard it was for them to deal with this, especially when they saw their patients' reactions when they finally understood the reality of their diagnosis. However, these feelings of empathy were balanced with the need to be 'tough' with the patients in order to empower them to be as independent as possible and to move on in their lives.

Feeling greater empathy for their younger patients than their older patients may influence the nurses' sense of urgency regarding their care and the emotions associated with the patients' lives. The effect of the patient's age on nurses is not exclusive to trauma patients. Similar findings were identified among nurses caring for cancer patients and critical care patients (Alzghoul 2014; Parish 2006).

Moving along in *the passage of care*, nurses were bound to face many challenges. Despite all these challenges, the nurses highlighted that they gained support through working as a team and that they supported each other by sharing their knowledge and experiences. This finding was also reported by Alzghoul (2014), who emphasised the need for peer support when dealing with the challenges. Providing support to family members was challenging and took time. It became difficult for nurses to delve deeper and balance the needs of patients and families. In order to deal with this, the nurses would refer them to doctors or social workers. This concurred with the findings of the study by Bostrom, Magnusson and Engstrom

(2012) who described supporting family members as a difficult task due to a lack of time. In addition, Daines et al. (2013) in their study of nurses' experiences when caring for patients and families dealing with cancer highlighted the fact that nurses struggled to keep a balance between the needs of patients and their families.

Throughout *the passage of care*, the nurses realised that time is the most important thing that they can give to their patients. This realisation came from an understanding of what the patients valued most. The nurses realised that patients' motor and sensory disabilities limited their movement and contact with other people. The transformation from being independent to fully dependent was very overwhelming. Therefore, time spent chatting and providing basic care without the patients asking was considered as a value-added service. An understanding of what patients valued most and delivering it is similar to the improvement technique adapted by the National Health Service (NHS) Institute in one of their quality improvement programmes, known as Lean (NHS Institute for Innovation and Improvement: Lean 2008). Lean aims to understand what patients value and develop a product or design a service to deliver 'the right things to the right place, at the right time, in the right quantities' (NHS institute for Innovation and Improvement: Lean 2008).

Throughout *the passage of care*, it was an undeniable fact that establishing the nurse–patient relationship was fundamental to care. This was a care partnership, where both parties worked on their mutually accepted goals for the ultimate progress of the patient's treatment. In nursing, patients are often considered vulnerable due to the nature of their condition (Holder & Schenthal 2007). Patients may disclose personal information about their feelings, health and concerns and nurses may

disclose their feelings as well. In this study, such disclosures usually happened with long-stay patients and especially when the patients and nurses shared a common background. Any disclosure of personal information by a nurse to their patient has the potential for professional misconduct (Holder & Schenthal 2007). It is therefore important for nurses to be knowledgeable enough to maintain the appropriate professional boundaries. In this study, the nurses commented that these professional boundaries were also essential for protecting nurses from being victimised by their patients. Patients undergoing traumatic events in a spinal unit can be very embittered at times, and maintaining professional boundaries within therapeutic limits was protective for the nurses. Nurses needed to find the balance between a personal and a professional approach. Establishing closeness with patients can create an obligation for nurses to be involved in issues that are outside their professional role (Fegran & Helseth 2009). Therefore, although creating this balance can be demanding, it is essential for nurses.

### **Patients' needs**

The nurses mentioned the importance of respecting and fulfilling the patients' needs, and that these include both physical and psychological needs. This is because depending on the level of the injury, the effects of spinal cord injury may include paralysis and long-term disability and this often requires extensive rehabilitation (Partridge 1994). In this study, the nurses felt that it was important to accommodate the physical needs of the patients, such as by giving support to a body that is dependent on others to fulfil its care needs. The nurses were also focused on stabilising the patients so that they could move on to rehabilitation to preserve and train their physical functional capacity. However, what was unique about the findings

was that despite mentioning physical needs, the majority of the nurses tended to discuss at greater length the ways to accommodate the psychological needs of their patients. This is a unique finding, because spinal cord injury is usually associated with physical disability and care has been predominantly focused on meeting the physical needs of the patient, rather than viewing the physical and psychological aspects of care as interdependent (Dewis 1989; Olson & Ustanko 1990). Partridge (1994) described that on admission to hospital, the patient with spinal cord injury will be in a state of physical and emotional shock. Although sustaining life may be the initial nursing priority, it is also necessary for nurses to provide care for the person's psychological needs. A lack of psychological care restricts a patient's participation in rehabilitation and their community (Cardol et al. 2002).

Reflecting on this finding, the researcher believes it would be interesting to examine this phenomenon from the perspective of spinal injury patients.

### **Hope and grief**

The findings showed that the nurses understood that every loss in life provokes grief, and they see their patients going through the stages of grief, especially when the diagnosis is finally understood by the patient. When an individual feels grief due to loss they pass through the stages of denial, anger, bargaining, depression and finally acceptance (Ross 1973). The nurses observed these stages of grief in their patients' behaviour, which could range from withdrawal to anger or repeatedly asking similar questions. Their grief included a broad range of feelings and reactions that are common after a loss (Dunne 2004). The nurses described this as a very challenging situation for them to deal with; however, they believed in giving hope to the patients even if there was only a very slight degree of hope, since it might help the patients to

move forward in their lives. According to Lohne and Severinsson (2004b) nurses need to learn the skills to foster hope and empower recently injured patients to look beyond their immediate situation and direct their energies appropriately.

In the findings the nurses mentioned supporting their patients by fostering hope; however, one nurse clearly stated that fostering hope is good, but fostering false or unrealistic hope is not. Miller (2007) has a different opinion on this matter; the researcher believes that whether hope is 'false' is based on how we conceptualise it. This is because the researcher's definition of hope permits hope to be allowed at all phases of illness, including at the end of life, when hope is for a good death (Miller 2007). Hope is considered as a crucial alternative to adaptation to illness (Coward & Reed 1996). Therefore, hope is needed by all throughout the life cycle, and especially through the health–illness continuum, including at the end of life (Miller 2007).

### **Nurses' interpretation of the patients and families**

The findings of this study showed that the trauma associated with their injury changed patients' personalities. The nurses categorised patients into three groups based on their personalities: the first group did not want to deal with the reality, the second was optimistic and the last group of patients was in between. In order to deal with these patients, the nurses had to adjust their way of approaching them to help each individual patient adapt to their new condition. This was the case when dealing with family members as well, because different cultures handle the outcome of trauma differently and the extent of the change and trauma to the family members' lives is just as great as that of the injured person. DeSanto-Madeya (2009) suggested that providing social and educational support could enhance adaptation to

spinal cord injury. This was considered important not only for the patients, but also for their family members.

The findings also showed that the family members tended to step into the patient's life and forget that prior to their injury the patient was an independent individual. Instead, family members may treat the patient like a child, and this can be overwhelming for the patient. According to Dickson et al. (2010), the caregivers for patients with traumatic spinal cord injuries seldom received the necessary preparation for their new roles. Therefore, it is essential for nurses to educate the family about the patient's condition, to treat patients as individuals and deal with their trauma at the pace that is appropriate for each patient (Watts & Horne 1994). In addition, nurses need to help families manage these difficult times, and this can be achieved by being present and creating an open and trusting relationship with them (Freeman, Bourbonnais & Rashotte 2014).

### **Study Limitations**

To the researcher's knowledge this is the first qualitative research study to explore nurses' experience of caring for patients with traumatic spinal cord injuries that also have neurological deficits. This study was based on a sample of only six participants. When determining the sample size, the researcher judged the quality of the data collected against the aim of the study. The participants provided rich descriptions of their experiences. Although many strategies were used to maintain the trustworthiness of the findings, one limitation of the study was the inability to generalise the findings; instead, the findings can be transferable to one setting or to similar situations only if they are recontextualised (Lincoln & Guba 1985).

## Recommendations

The findings from this research study contribute new knowledge, and a number of recommendations are proposed as a result of this research. These recommendations have been developed from the nurses' responses in conjunction with the literature, and are separated into recommendation for practice, education and further research.

### **Recommendations for practice**

Nurses that go through *the passage of care* for patients with traumatic spinal cord injuries that have associated neurological deficits must be prepared for the journey. It is recommended that novice nurses or nurses that are new to a spinal unit be educated on the nature of the route that they are going to travel with their patients. The experiences of senior nurses can be shared as part of the orientation programme for these new nurses.

Desensitisation occurs after a few months in the spinal unit caring for these patients. Nurses described feelings of guilt due to their desensitisation, and but also found that desensitisation enabled them to switch off from the confronting feelings raised when dealing with these patients. Having mixed feelings can be stressful for nurses. It is recommended that an ongoing counselling session to be offered to nurses in order to help them ventilate their feelings and ease the guilt while caring for their patients.

Maintaining professional boundaries is important for the therapeutic treatment of patients. The nurse–patient relationship must never go beyond its purpose of meeting the patients' care needs, and nurses need to know how to balance this with



the feelings of empathy they have for their patients in order to facilitate patient empowerment. Therefore, it is recommended that nurses be educated regarding these boundaries and have clear guidelines, which should be kept in the ward for the nurses' reference. It is also important to educate nurses that maintaining appropriate professional boundaries is everyone's responsibility.

Adaptation to spinal cord injury may take time for patients and their families. The majority of the care focus is on the patients; therefore it is essential to provide social and educational support for their family members as well. This is recommended to be done at an early stage in order to prepare them for future life outside the hospital.

### **Recommendations for education**

Caring for patients with spinal cord injuries is challenging, and not only encompasses managing patients' physical needs, but also includes caring for their psychological needs. It is recommended to include a stronger component on dealing with the psychological needs of patients and their families, and particularly on the skills needed to foster hope, in nurse education programmes.

### **Recommendations for further research**

The unique finding in this study was that the nurses were more concerned about the accommodating the psychological needs of their patients than they were about their patients' physical needs. It would be of value to investigate this phenomenon from the perspective of the patients.

Another finding of this study shows that dehumanisation of patients occurs spontaneously. Dehumanisation may decrease the sense of empathy, and this may

have destructive consequences, especially when dealing with patients (Haque & Waytz 2012). There is a paucity of research into this phenomenon, and therefore it would be beneficial to carry out more studies on this topic.

When compared to the literature on nurses' experiences caring for patients with other traumatic injuries, the findings of this study show many similarities. Therefore, the findings of this research could also be used for future understanding of nurses' experience in caring for patients experiencing other traumatic events.

## **Conclusions**

This chapter discussed the major findings that arose from the data collected within this study and in combination with the available research. The recommendations provide ideas to help develop long-term strategies for spinal care nurses in the future.

Caring for patients with traumatic spinal cord injuries that had neurological deficit is a confronting and challenging endeavour. It is essential for nurses who are interested in this specialty to be prepared for the dynamic environment of care and nursing practice.

The fundamentals of nursing care remain unchanged; however, the specific experience, skills and knowledge related to spinal care remain distinct to spinal nursing.

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## APPENDICIES

Appendix 1: Ethics Approval

Appendix 2: Recruitment information flyer

Appendix 3: Participant Information Sheet

Appendix 4: Consent Form

Appendix 5: Confidentiality Agreement

Appendix 6: Interview Question

Appendix 7: Example of interview memo

Appendix 8: Example of Interview summary

Appendix 9: Example of development of selected open codings, categories, sub themes and essential themes

## Appendix 1: Ethics Approval



**Government of South Australia**  
SA Health

Approval Date: 25 March 2015

**Mrs Shareena Bibi Mohd Arif, RN**  
**Master of Nursing Science (Orthopaedic) Candidate**  
**The UNIVERSITY of ADELAIDE**  
**21 Turnbull Road**  
**ENFIELD SA 5085**

Central Adelaide Local Health Network  
**Royal Adelaide Hospital Human Research Ethics Committee**  
Level 4, Women's Health Centre  
Royal Adelaide Hospital  
North Terrace  
Adelaide, South Australia, 5000  
Telephone: +61 8 8222 4139  
Email: rah.ethics@health.sa.gov.au

Dear Shareena,

HREC reference number: **HREC/15/RAH/114**

Project Title: **"The lived experience: Nurses experience in caring for patients with traumatic spinal cord injury."**

**RAH Protocol No: 150321.**

Thank you for submitting the above project for ethical review. This project was considered by the Chairman of the Royal Adelaide Hospital Human Research Ethics Committee.

I am pleased to advise that your protocol has been granted full ethics approval and meets the requirements of the *National Statement on Ethical Conduct in Human Research*. The documents reviewed and approved include:

- **Study Protocol, Version 1, dated 23 March 2015**
- **Participant Information Sheet & Consent Form, Version 1, dated 23 March 2015**
- **Participant Introduction letter, Version 1, dated 23 March 2015**

Please quote the **RAH Protocol Number** allocated to your study on all future correspondence.

### **GENERAL TERMS AND CONDITIONS OF ETHICAL APPROVAL:**

- Adequate record-keeping is important. If the project involves signed consent, you should retain the completed consent forms which relate to this project and a list of all those participating in the project, to enable contact with them in the future if necessary. The duration of record retention for all clinical research data is 15 years.
- You must notify the Research Ethics Committee of any events which might warrant review of the approval or which warrant new information being presented to research participants, including:
  - (a) serious or unexpected adverse events which warrant protocol change or notification to research participants,
  - (b) changes to the protocol,
  - (c) premature termination of the study.
- The Committee must be notified within 72 hours of any serious adverse event occurring at this site.
- Approval is valid for **5 years** from the date of this letter, after which an extension must be applied for. Investigators are responsible for providing an annual review to the RAH REC Executive Officer each anniversary of the above approval date, within 10 working days, using the Annual Review Form available at: <http://www.rah.sa.gov.au/rec/index.php>
- The REC must be advised with a report or in writing within 30 days of completion.

Should you have any queries about the HREC's consideration of your project, please contact Ms Heather O'Dea on 08 8222 4139, or [rah.ethics@health.sa.gov.au](mailto:rah.ethics@health.sa.gov.au).

***You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a SA Health site until separate authorisation from the Chief Executive or delegate of that site has been obtained.***

This Committee is constituted in accordance with the NHMRC's *National Statement on the Ethical Conduct of Human Research* (2007).

The HREC wishes you every success in your research.

Yours sincerely,

*for*

**A/Prof A Thornton**  
**CHAIRMAN**  
**ROYAL ADELAIDE HOSPITAL HUMAN RESEARCH ETHICS COMMITTEE**

## Appendix 2: Recruitment information flyer



We want to learn more about  
Nurses experience in caring for  
patients with traumatic spinal cord  
injury with neurological deficit.

Researchers at the University of Adelaide would like to explore this topic. This research study is for registered and enrolled nurses that work in the Spinal Unit and have had experience in caring for patients with traumatic spinal cord injury with neurological deficit.

Your participation is voluntary

### Who is eligible to be part of this study?

- Nurses currently working at the spinal Unit.
- Nurses with any experience in caring for patients with traumatic spinal cord injury with neurological deficit.

### If you decide to take part in this study, you would be:

- Interviewed individually – in regards to your experience in caring for patients with traumatic spinal cord injury with neurological deficit.

Possible benefits for taking part in the study are;

- Opportunity to have your say and to talk about your experience.
- Contributing to nurses' understanding of this phenomena.

**To take part in this research or for more information, please contact Shareena at 0450 252 008 by 12JUNE 2015.**

The principal researcher for this study is Ms Shareena Bibi Mohd Arif (Master of Nursing- Orthopaedic Student),

Supervisor: Mr Paul McLiesh (Lecturer), Dr Philippa Rasmussen (Senior Lecturer) School of Nursing University of Adelaide.





## Appendix 3: Participant Information Sheet

### Participant Information Sheet



#### PARTICIPANT INFORMATION SHEET

**PROJECT TITLE:**

THE LIVED EXPERIENCE: NURSES EXPERIENCE IN CARING FOR PATIENTS WITH TRAUMATIC SPINAL CORD INJURY.

**PRINCIPAL INVESTIGATOR: Mrs Shareena Bibi Mohd Arif**

**STUDENT SUPERVISORS: Mr Paul Mcliesh**

**: Dr Philippa Rasmussen**

**STUDENT'S DEGREE: Master of Nursing Science (Orthopaedic)**

**This study has been reviewed and received ethics clearance through Royal Adelaide Hospital, Research Ethics Committee (HREC Reference no: HREC/15/RAH/114)**

Dear Participant,

You are invited to participate in the research project described below.

**What is the project about?**

The aim of this study is to explore the nurses' experiences of caring for patients with traumatic spinal cord injury that has neurological deficit at the spinal unit. There are only a few articles that explore the experience of patients with spinal cord injury and the experience of the spouse/ primary care giver in caring for patients with spinal cord injury. However, this phenomenon looking from the nursing perspectives had yet to be explored.

**Who is undertaking the project?**

This research is being conducted Ms Shareena Bibi Mohd Arif as part of a Master of Nursing Science degree from the University of Adelaide, under the supervision of Mr Paul Mcliesh and Dr Philippa Rasmussen.

Version 1.0 dated 23 March 2015!

**Why am I being invited to participate?**

You were invited because you are a registered or enrolled nurse who works in the spinal unit and has had experience caring for patients with traumatic spinal cord injury with neurological deficit.

**What will I be asked to do?**

You will be asked to participate in an unstructured individual Interview, which will last for 30-60 minutes. It will be in place that suits you or the seminar room at Spinal Unit, Royal Adelaide Hospital.

The individual interviews will be audio recorded. Confidentiality will be maintained at all times and participants will not be identified at any stage.

The research will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research, 2007.

**Are there any risks associated with participating in this project?**

There are no foreseeable risks to you associated with participating in this project. However, you have the right to stop the interview at any time during the session if you feel uncomfortable.

**What are the benefits of the research project?**

We cannot guarantee or promise that you will receive any individual benefit from this research however, possible benefits may include having an opportunity to have your say and to talk about your experience in caring for patients with traumatic spinal cord injury. In addition, it would contribute to helping future nurses to better understand human experiences and meaning in order to provide well-tailored nursing care based on the patient's needs. On a broader scale this may increase patient satisfaction and experience.

**Can I withdraw from the project?**

This is a research project and you do not have to participate. If you do not wish to participate there will be no consequences. Also, you may withdraw from the project at any time after you have commenced.

If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; the research team will provide this to you.

**What will happen to my information?**

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any data published will be non-identifiable. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

The data collected will be stored in a locked filing cabinet at the researcher's office or the School of Nursing or in a password protected computer file. The researcher will be the only person to access the data. The supervisors will have access to the data only after it has been de- identified.

**Who do I contact if I have questions about the project?**

If you want any further information concerning this project you can contact the researcher on 045 0252 008 or any of the following people:

**Research contact person:**

Name	Phone No:	Email
Shareena Bibi Mohd Arif, RN, Student, the primary researcher	+61 450 252 008	<a href="mailto:a1640475@student.adelaide.edu.au">a1640475@student.adelaide.edu.au</a>
Mr Paul Mcliesh Research supervisor	+61 8 8222 2991	<a href="mailto:paul.mcliesh@adelaide.edu.au">paul.mcliesh@adelaide.edu.au</a>
Dr Philippa Rasmussen Research Supervisor	+61883133866	<a href="mailto:philippa.rasmussen@adelaide.edu.au">philippa.rasmussen@adelaide.edu.au</a>

**What if I have a complaint or any concerns?**

Royal Adelaide Hospital, Research Ethics Committee has reviewed and approved this study **(HREC Reference no: HREC/15/ RAH/114)**. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator.

If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the Chairperson, Research Ethics Committee, Royal Adelaide Hospital on (08) 8222 4139.

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

**If I want to participate, what do I do?**

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described You will be given a copy of this Participant Information and Consent Form to keep.

The researcher will send you a copy of the information sheet together with the consent form. If you decide to take part in this research, you will be asked to send an email to the primary researcher or to send a text message. You can use the email and the phone number written above. Then you will receive a call from the researcher to arrange for an individual interview. Before starting the interview the researcher will ask you to sign the consent form and have you will have the opportunity to ask questions regarding the research.

Yours sincerely,

**Shareena Bibi Mohd Arif, RN**

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## Appendix 4: Consent Form

### Consent Form

(HREC Reference no: HREC/15/ RAH/114)



RESEARCH NAME: \_\_\_\_\_

INVESTIGATORS: \_\_\_\_\_

This study is to explore the nurses' experiences of caring for patients with traumatic spinal cord injury that has neurological deficit at the spinal unit. There are only a few articles that explore the experience of patients with spinal cord injury and the experience of the spouse/ primary care giver in caring for patients with spinal cord injury. However, this phenomenon looking from the nursing perspectives had yet to be explored.

This research is being conducted Ms Shareena Bibi Mohd Arif as part of a Master of Nursing Science degree from the University of Adelaide, under the supervision of Mr Paul McIesh and Dr Philippa Rasmussen.

You will be asked to participate in an unstructured individual Interview, which will last for 30-60 minutes. It will be in place that suits you or the seminar room at Spinal Unit, Royal Adelaide Hospital.

The individual interviews will be audio recorded. Confidentiality will be maintained at all times and participants will not be identified at any stage.

The research will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research, 2007.

There are no foreseeable risks to you associated with participating in this project. However, you have the right to stop the interview at any time during the session if you feel uncomfortable.

We cannot guarantee or promise that you will receive any individual benefit from this research however, possible benefits may include having an opportunity to have your say and to talk about your experience in caring for patients with traumatic spinal cord injury. In addition, it would contribute to helping future nurses to better understand human experiences and meaning in order to provide well-tailored nursing care based on the patient's needs. On a broader scale this may increase patient satisfaction and experience.

This is a research project and you do not have to participate. If you do not wish to participate there will be no consequences. Also, you may withdraw from the project at any time after you have commenced.

If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; the research team will provide this to you.

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any data published will be non-identifiable. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

The data collected will be stored in a locked filing cabinet at the researcher's office or the School of Nursing or in a password protected computer file. The researcher will be the only person to access the data. The supervisors will have access to the data only after it has been de-identified.

I certify that:

1. The nature and purpose of the research project has been explained to me. I understand it, and agree to take part.
2. I understand that I may (or will) not benefit from taking part in the research.
3. I understand that, while information gained during the study may be published, I will not be identified and my personal results will remain confidential.
4. I understand that I can withdraw from the study at any stage without consequences now or in the future.
5. I have had the opportunity to discuss taking part in this research with a family member or friend.

Name of Participant:

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

(Investigator)

## Appendix 5: Confidentiality Agreement



### CONFIDENTIALITY

We transcribe highly confidential matters on a daily basis for our global clients and have not had any confidentiality problems in our ten years of service. Please find attached hereto our Confidentiality Note for more information on how we ensure the highest degree of confidentiality. We will gladly sign your non-disclosure agreement if you have one for us to sign.

#### Secure Upload

We offer our clients a secure HTTPS site to upload their files to us which is a protocol for transmitting data securely over the World Wide Web. HTTPS provides authentication of the web site and associated web server that one is communicating with, which protects against man-in-the-middle attacks. Additionally, it provides bidirectional encryption of communications between a client and server, which protects against eavesdropping and tampering with and/or forging the contents of the communication. This provides a reasonable guarantee that one is communicating with precisely the web site that one intended to communicate with (as opposed to an impostor), as well as ensuring that the contents of communications between the user and site cannot be read or forged by any third party.

#### General Procedures

We always take the following precautions:

Digital versions are stored on our secure server.

Recordings can be accessed only by Way With Words' bespoke in-house intranet.

Recordings are only available by password entry to server. Each typist has an individual encrypted password, known only to him or herself and management. Each recording is available only to the typist who will transcribe it, not to all typists.

No hard copies of transcripts are produced. Any other sensitive hard copy documents pertaining to client work are always shredded.

Typists are required to delete all transcripts and digital recordings on completion of their transcript.

If the client wishes we can password-protect each individual transcript, and confirm passwords by telephone.

#### IT Controls

Please note that all Way With Words PCs are password-protected, so even in the event of a theft the contents of the hard drives could not be easily accessed. Transcripts are in fact not stored on PCs but on a secure remote server.

We keep a digital log of all activity on our workflow system and secure server.

Please see our WWW IT Security Note for more information.

#### Staff

All Way With Words' staff have signed confidentiality agreements, and we have on many occasions carried out very sensitive work for various government agencies, financial institutions and research marketing companies. We have also transcribed many stock market-related recordings that could greatly affect the value of a company's shares if the information became known prematurely. A copy of the relevant clauses in the contract will be sent on request.

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## **Appendix 6: Interview Question**

**RESEARCH OBJECTIVE: TO EXPLORE NURSES EXPERIENCE IN  
CARING FOR PATIENTS WITH TRAUMATIC SPINAL CORD INJURY  
THAT HAD NEUROLOGICAL DEFICIT**

### **Open Ended Question and Prompt for Interview**

Opening statement:

As I had explained this research aimed to understand your experience in caring for patients with traumatic spinal cord injury that had neurological deficit. We are interested in your experience. And the whole conversation is going to be anonymous. Your experience is very important to us.

*Main question at the beginning of the interview:* “What is it like for you to care for patients with traumatic spinal cord injury that have a neurological deficit?”

OR

“How do you feel, when you care for patients with traumatic spinal cord injury that have a neurological deficit?”

### **Prompts used to encourage participation:**

1. Could you give me an example of that?
2. Tell me more about that.
3. Sorry, I don't understand. Could you help by giving an example?

4. Do you remember how that made you feel? (Assuming there's a reason for a 'feeling' type of question)
5. And how did you feel about that?
6. Go on...could you elaborate more on that?
7. Why exactly do you say that?
8. Why exactly do you feel that way?
9. Could you tell me more about that , please?
10. And what happen after that...

!

## Appendix 7: Example of Interview Memo

### Participant 2 (Colette)

Date: 2 June 2015

Time: 2.15 pm

Location: Private room at the Spinal Unit

Length of interview: 34 min

### Memo

- 23 years of experience at the spinal unit
- Patient now more educated.
- Life changing event
- Put yourself in patient's situation
- It is very hard for young patients.
- Family giving pressure to nurses – “ this is my baby”. Patient get back to be “a child” and now parents is looking after them.
- Always deal with patient first then the family.
- Need to be very subtle and get them (patient and family) involve and educated.
- Some parents can be “in your face”.
- “ That parents is driving me crazy”
- Definition of neurological deficit – you find them loss all their hand, independent, cant scratch their nose, do their face, cant do anything for themselves.
- Empathy – think its probably her own parents and child, talk to patient person to person like u like to be talked too.
- ‘OK This is what I have got something else back, it's a bonus”
- Angry patient – not at nurses but at their situation they are in.
- Categories of patients- people that process it well and look at future, the one that is angry and never dealt with the anger and the one in-between.
- Some nurses take it personal
- Use to affect her when she was younger
- Normal pattern patient go through emotional roller coaster.
- Use sense of humour to feel good at work and lighten all nurses mood abit.
- The troublesome patient or been at spinal unit for long time – she remembered these patients
- Knowledge when started was not as much as the knowledge she have now. Now she is the knowledge source for the other nurses. Educate staff too.
- Nurses celebrate when troublesome patient discharge.
- “If I get back in, I might strangle him” – to ventilate after caring for troublesome patients.

- Different races deal differently with this condition – Aborigines- they don't want technical conversation, " My family live in the middle of nowhere and I cant walk". Asian culture disabilities are not handle the same in their culture. When they go back they not going to get the rehab and care like in Australia. "You are dead to me, you are not my son" eventually father came around but it was hard at first. Background and culture
- Novice nurses forget there is a person attached to the procedure, work only base on worksheet or checklist "Tick, tick".
- Paperwork is a lot now.
- Petrified when firstly join spinal unit.
- Challenging patient that get under the skin
- "I tends to think more before I talk now"
- "They (patient) more positive and you tend to be more positive"
- At the spinal unit prefer a mixture of patients,
- Nurses with experience in life deal batter.
- "if you don't know something, don't say something"
- "Hope is good but false hope is not" because patient cling to every word you say.
- People think like you are going to do a brain surgery. You are here to nursed. You do what you can, if you cant you learn. People skill is important.
- Teamwork
- Brain does not turn off, recall things done or to be at work.
- Problem patient she tries to switch off. "You are not coming home with me, you are staying at work."

## Appendix 8: Example of Interview summary

### Participant 2: Colette

#### **Summary**

Colette experience during the old days, patients did not get a lot of information about their condition, however now they get information everywhere and online and their interaction with nurses become more educated. And this brings many questions from the patients to nurses.

She believes her knowledge is better now and she that she can answer most of the patients questions compare to the time when she newly join in.

She feels that as nurses if "If you don't know something don't say something".

Because Colette believes that giving hope is good but false hope is no good.

Communication with other culture is different because disability is handle differently. As a nurse, she felt that she need to see their background in order to know how to communicate with them. As the researcher I believe communication with these patients is not easy specially when you need to answer their question. Colette's experience shows that it needs skill and knowledge to deal with communication part with these patients.

Looking back during the early days caring for this patient, she was a little like the junior now, where they work like they are using checklist and not evaluating the patients as a whole. She was petrified shifting from orthopedic discipline to spinal. She has to think for herself because there were no super numery (senior nurse) in charge to ask at the shift.

She felt nurses that have some experiences in their life would be good and she believe new nurses at the spinal unit need to ask and it's ok not to know but learn as you are going. Teamwork and people skill is important at spinal unit.

Traumatic Spinal cord injury is a life changing event for patients so as a nurse Colette felt emphatic because she relate it to herself that it can be her in that position and what information that she herself might need if she is in that condition.

She also felt it was difficult to deal with patients and family. Because she felt that, she is not only looking after the patient but the family too. They can give pressure on her emotionally and mentally as well. I believe it is true because it is just naturally hard to communicate and to deal with patients and their families when they are undergoing a traumatic situation.

Family does give pressure to the patient as well and sometime Colette felt like she wants to ask them to back off. The way she deals with it is by talking to the patient first then the family. It need to be done in a subtle way, by keeping the family involve in caring for patients but also give space to patient. However, same family members can be always be "right on your face" and Colette (making "I can't take it gesture") because that get her crazy but she cannot let it get to her. Balancing up with being empathy thinking if it was her child she would have automatically done the same thing (switch the role). When there is older patient admitted with tetraplegia, she think of her parents, from being independent and suddenly their life change.

Based on Colette's experience there are patients that can't accept their injury at all. They are unable to deal with the injury at all even after many years. The anger is demonstrated towards the nurses by being non-compliance to treatment. There are patients that are very focused in their treatment. And there are groups of patients that are in-between this range. As a nurse, she acknowledges the problem and knows that the patients are not angry at her but more towards their situation. As a nurse she believes she has to be professional and doesn't make it personal. It used to affect her but over time she understands the emotional rollercoaster that the patients have been through.

Sense of humor is the way she finds relief and lightens the mood of the situation in the ward.

The patients that are "horrible" or have been in the spinal unit for a long time stick in her mind.

The difficult patients, who are aggressive, spitting in the ward make nurses not want to care for him. Patients would pick up on nurses so the nurses won't talk about themselves in front of the patient. And when the patient is discharged the whole ward cheers. She deals with it professionally, if the patient misbehaves, she would leave and come back later.

Being empathetic is good but sometimes patients' behavior is too vile to limit the care given to them.

Being empathetic also means understanding the patient's situation and talking to them the way you wanted to be talked to.

As for the patients that challenged her behavior or got under her skin, she felt she could probably handle it better (made her reflect at the time) but not always. She thinks a lot before she talks now compared to when she used to.

Patients that say, "I had enough" (after a long time being inpatient). They are the hardest because she has cared for them for a long time.

Patients without neurological deficits are easier to care for compared to the ones with neurological deficits. A mixture of both categories of patients is good because caring for the one with a neurological deficit is mentally harder and physically a lot harder. She felt lucky having a mixture of cases here.

Colette mentions that she still thinks about what is going on in the ward even when she is back at home. "She doesn't turn off" and even her family understands it. However, if she has problematic patients she tries to switch off at home "You are not coming home with me, you are staying at work".

If it was good "Oh! That was good today".

"This is my house, they are at work" then I separate them.

**APPENDIX 9: EXAMPLE – DEVELOPMENT OF SELECTED OPEN CODINGS, CATEGORIES, SUB THEMES AND ESSENTIAL THEMES (The Passage of Care)**

NAME	RESPONSE	OPEN CODING	CATEGORY	SUB THEME	ESSENTIAL THEME
Chris	...whenever they're being transferred to the ward. It's just a matter of trying to explain to them the routine nursing care, the expectation of the ward, also the journey from here to wherever they're going. (P6,L214-218)	It's a matter of explaining to patients the ward routine, the expectation (objective of nursing care at spine unit) and their journey from the spine unit to rehab.	Our mission	Goal	The passage of care
Nate	...there are patients in hospitals that have medical problems as well, but other problems like, we sometimes get new patients, or you can't get the medication you need because pharmacies haven't dispense it or things like that.(P4, L154-157)	Other misc problem in ward	A bad day	Setting	The passage of care

**APPENDIX 9: EXAMPLE – DEVELOPMENT OF SELECTED OPEN CODINGS, CATEGORIES, SUB THEMES AND ESSENTIAL THEMES (Hope and grief)**

NAME	RESPONSE	OPEN CODING	CATEGORY	SUB THEME	ESSENTIAL THEME
Kate	They'll be going through the whole grief syndrome initially, it probably doesn't, the diagnosis doesn't hit, it takes a while for it to sink in. (P5,L193-195)	It takes a while for the diagnosis to sink in	The grief syndrome	The five stages of grief	Hope and Grief
Chris	...but always tell them there's hope even if you think there's no hope, because with nature you never know. Also there's a lot of medical research, some people might try different options, so there's always that small chance that they might get that chance. (P6,L 60-68)	Nurse Supporting patients by giving hope	Essential support service	Hope (real and unreal)	Hope and Grief

**APPENDIX 9: EXAMPLE- DEVELOPMENT OF SELECTED OPEN CODINGS, CATEGORIES, SUB THEMES AND ESSENTIAL THEMES (Nurses' Interpretations of the patients and families)**

NAME	RESPONSE	OPEN CODING	CATEGORY	SUB THEME	ESSENTIAL THEME
<b>Kate</b>	... may have, they may have been an outgoing...it can change their personality as the impact of what has happened and what will happen, impact that they may change totally from an outgoing personality to a very quiet, a very depressed, a very morose, but you're still treating them as that person. You just have to adjust the way you approach them... (P5,L721-727)	Changes in patients personalities.	Dynamic changes	Patient	Nurses Interpretation of the patients and families
<b>Nate</b>	...there are some of them are here longer than other patients. So, you get to know them and their family abit more than you would with patients who...are just here for a few days.(P4, L 187-189)	The longer the patient admitted in the unit, the more you know the patients	Time spent	Patient	Nurses Interpretation of the patients and families

**APPENDIX 9: EXAMPLE - DEVELOPMENT OF SELECTED OPEN CODINGS, CATEGORIES, SUB THEMES AND ESSENTIAL THEMES (Patients' Needs)**

NAME	RESPONSE	OPEN CODING	CATEGORY	SUB THEME	ESSENTIAL THEME
<b>Rick</b>	...in a lot of ways I can remove the emotional person and just look at the physical injuries... and that sort of thing, and then react to the emotional things as, as they arrive.(P3, L 904-908)	Remove the emotional person and look at the physical injuries, then deal with the emotional as they come. (nurse deliver care to patients in need as an individual, removal the title, the incident and all)	Physical needs	Patient's need (Physical)	Patient's needs
<b>Colette</b>	I think I've always sort of done it with a sense of humour... and because you get feedback from patients saying, oh, it's so nice to have a few people that are a bit bright or bubbly or have a bit of a joke, otherwise it's all too serious. (P2, 199-210)	Patients feedback ascertain nurse that humour is the best way to bring cheer in the hospital environment.	Creating cheerful environment	Patient's need (Psychology)	Patient's needs