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

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Outline

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Introduction and Significance

- The spinal cord is a complex system that keeps the body alive by connecting the body and brain.
- It focuses on sensory and motor functions.

Introduction and Significance

- Spinal cord injury usually a sudden, traumatic, unexpected and irreversible event.

- Patients experience major changes due to traumatic injuries – “shattered reality” to overwhelming shock. It represent lifelong challenge as a results of loss of some body functions.

- Involvement of nurses is essential – from admission to rehabilitation.

Initial support and care are very important and it is the nurses role (novice or experienced) to focus on patients’ care – from admission to the transition from acute phase to rehabilitation phase.

The ability of decision making among novice nurses tend to be linear often due to limited knowledge and experience in their job.

Significance

The exploration and understanding of the phenomena investigated in this study will contribute to the body of knowledge for all nurses.

... help novice nurses in preparing themselves to future challenges and decision making while caring for these patients.

Nursing care for patients with spinal cord injuries are different base on the injuries and disabilities. Therefore, it is important for nurses to understand human experiences and meaning to a situation in order to provide a well tailored nursing care.

In larger scale – ↑ nurses understanding, ↑ patients’ satisfaction and ↓ complaints.

To gain a clear understanding on nurses’ experience in caring for patients with traumatic spinal cord injuries that have neurological deficit.
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.
METHODOLOGY

Study Setting: Spinal Unit, South Australia

Population: 27 RN and 12 EN working at the spinal unit. Nurses with a wide range of experience and backgrounds in the field were recruited in order to provide the in-depth information.

Sample: Purposive sampling technique. Six nurses volunteered to participate in the study.
METHODOLOGY: Qualitative hermeneutic phenomenology research design base on Gadamer’s philosophy

Nurses that work in the spinal unit belong to a unique group of nurses.

The nurses remember their experiences precisely when caring for traumatic spinal cord injury patients that have neurological deficit.

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.
Assumptions (Researcher Pre conceived ideas)

- It is hard to give hope to these patients when there is a strong possibility that they will be completely paralysed.
- It is difficult to communicate with these patients and their families.
- When the patients are silent, it may mean that they are afraid or that they have given up.
- These patients are very dependent on their nurses.
Method: Van Manen’s (1997) – the six methodological structure to operationalised the hermeneutic phenomenological human science research.

Van Manen’s Methodological structure
Van Manen (1997)

Thematic Analysis - Burnard (1991) 14 steps approach systematic steps to codify and categorise the interviewed transcript.

Notes are made after each interview

Immerse in the data – read transcript and make notes

Read transcript again and do open coding

Survey List of categories and grouped together (collapsing into broader categories). Remove dross

Each list is worked through with the open coding, categories and final essential themes

Transcript are re read alongside with final list of categories

New list of categories and worked through again

Sort it out - to see the audit trail

Selected respondent was asked to check the category system

Filed up all section for reference when writing up findings

Writing up process begin. Data can be use for commentary that link to examples

Decide: 1st - write up findings and interpret it; 2nd – write the findings alongside references to the literature

FINDINGS

Essential themes:

→ The passage of care
FINDINGS

Essential themes:

- Patients' Needs

- Physical Needs
- Psychological Needs
FINDINGS

Essential themes:

- Hope & Grief

The five stages of grief

Essential themes: Hope and Grief

Hope (real hope & unreal hope)
FINDINGS

Essential themes:

Nurses interpretation of patients and families
DISCUSSION OF MAJOR FINDINGS

It's a rather interesting phenomenon. Every time I press this lever, that post-graduate student breathes a sigh of relief.
Discussion: The passage of care

The nurses were clear about their goal – the patients settle into the ward - medically stable - rehab.

...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)

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)
Discussion: The passage of care

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, Siegert, Levack & Freeman, 2009)
Discussion: The passage of care

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 is when thing 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)

...and if you had a bad day and then you came to work and got abused. (Colette: P2, L341–343)
Discussion: The passage of care

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)
Discussion: The passage of care

Caring for patients with spinal cord injuries that have associated neurological deficit was perceived as being the same as caring for any other patients.

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

It was evident that the nurses perceived their patients in a very mature way. Instead of seeing these patients 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.
Discussion: The passage of care

- 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.

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, 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.
Discussion: The passage of care

- Being exposed to the same environment for months or years had an impact on the nurses.

- The nurses 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.

...I’ve been working in this environment for quite a while now, I have become a bit desensitised, and although I hate that, it’s part of working that you do see it all the time,...(Pink: P1, L18-19)

This made caring for patients with spinal cord injuries that have neurological deficits seem normal.

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)
Discussion: The passage of care

- Positive side to desensitisation - It helped the nurses to develop a ‘thick skin’ and the ability to ‘switch off’.

  ...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, L18-26)

This provided a protective mechanism for the nurses that enabled them to deal with their patients’ grief and not let it affect them.
Discussion: The passage of care

Desensitisation does not mean the nurses lack empathy for their patients.

In this study the nurses described their feelings of empathy and how hard it was for them to deal with it.

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.

...sometimes you have to use tough love with patients... (Rick: P3, L1033–1034)
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.

... 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... (Rick: P3, L859–861, L865–866)

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.

...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)

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.
Discussion: The passage of care

Throughout the passage of care, the nurses realised that time is the most important thing that they can give to their patients.

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’.
Throughout *the passage of care*, it was an undeniable fact that establishing the nurse–patient relationship was fundamental to care.

In nursing, patients are often considered vulnerable due to the nature of their condition.

(Holder & Schenthal 2007)

Patients may disclose personal information.
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.
The importance of respecting and fulfilling the patients’ needs - physical and psychological needs.

Unique:

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, Gam, Beelen, de Groot, & de Haan, 2002)

Reflecting on this finding: It would be interesting to examine this phenomenon from the perspective of spinal injury patients.
Discussion: Hope and Grief

...every loss in life provokes grief, and they see their patients going through the stages of grief...

Their grief included a broad range of feelings and reactions that are common after a loss.

(Dunne 2004)

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)

Very Challenging
Discussion: Hope and Grief

According to Lohne and Severinsson (2004) 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.

*Hope is good, but false hope is not,...* (Colette: P2, L568–573)

Different opinion:

...hope is based on how we conceptualise it...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)
The trauma associated with spinal cord injury changed patients’ personalities.

The nurses categorised patients into three groups based on their personalities:

...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)

In order to deal with these patients, the nurses had to adjust their way of approaching them.
Discussion: Nurses’ interpretation of the patients and families.

- It’s the same when dealing with family members as well, because different cultures handle the outcome of trauma differently.

- The extent of the change and trauma to the family members’ lives is just as great as that of the injured person.

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.

(DeSanto-Madeya, 2009)
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.

The caregivers for patients with traumatic spinal cord injuries seldom received the necessary preparation for their new roles.

(Dickson, O’Brien, Ward, Allan & O’Carroll, 2010)
Discussion: Nurses’ interpretation of the patients and families.

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)
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.

The inability to generalise the findings; instead, the findings can be transferable to one setting or to similar situations.

(Lincoln & Guba 1985)
Recommendations
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 to 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.
Recommendations for practice

Desensitisation occurs after a few months in the spinal unit.

Nurses described feelings of guilt due to their desensitisation, however, 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.

- It is recommended that nurses to 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.
Recommendations for practice

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.
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)

Lack of research looking into this phenomenon, therefore it would be beneficial to carry out more studies on this topic.
Recommendations for further research

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.
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.


REFERENCES


Winters, R & Neville, S 2012, ‘Registered nurses’ perspective on delayed or missed nursing care in New Zealand hospitals’, *Nursing Praxis in New Zealand*, vol. 28, no. 1.
THANK YOU FOR LISTENING.

Do you have any questions?