Mrs Nayana Charles (Sri Lanka)

Experiences of patients with paraplegia: a phenomenological study
Experiences of Patient with Traumatic Paraplegia

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Introduction

➢ Traumatic paraplegia is a partial or complete paralysis of the lower half of the body due to a trauma (WHO, 2015).

➢ Loss of sensory and motor functions influence on patient’s physical activities (Hancock et al., 1993).

➢ It affects on patient’s whole life and the family.
Background of the study

- Most patients are depressed and anxious (Bailey et al., 2016).

- Problems in social adjustment and family burden were seen in Asian countries (Singh et al., 2012).

- Need maximum assistance for activities in lower part of the body (Kalyani et al., 2015).
Justification of the study

- Depending on others – burden on family.

- Increase psychiatric morbidity - 41% depression (Xue et al., 2016).

- Increase suicidal attempts 4-5 higher rate, substance abuse and marital separation (Hagen et al., 2010).

- High frequency of re-hospitalization and increase cost of care.
Significance of the study

Study findings will help to

- Increase knowledge among caregivers, relations and other health care staff members.
- Reduce complications, rehospitalization and government expenditure.
- Enhance occupational ability, adjust to the society, and maintain quality life.
Purpose of the study

➢ Explore the experiences of patients with traumatic paraplegia at National Hospital of Sri Lanka (NHSL).

Specific objectives

➢ To identify physical experiences of patients with traumatic paraplegia.

➢ To identify psychological experiences of patients with traumatic paraplegia.

➢ To identify socio-economical experiences of patients with traumatic paraplegia.
Literature Review

- Inclusion of a body image impact on long term health.
- Poor awareness of possible complications lead to life threatening or prolong rehabilitation.
- Inability to perform functions independently impaired wellbeing.
- Level of physical activity depend on level of injury.

(Bail et al., 2016; Hagen, 2015; Singh et al., 2012)
Literature Review cont…

- Need more psychological assistance.
- Proper attention and care for each patients’ way of dealing with injury are important.
- Accurate analysis of specific psychological problems affect on treatment.
- Coping strategies, personal resources, religiosity, positive reframing and social support contribute social adaptation.
- Profound of all health team members impact on patients’ social experiences.
- Positive interaction impact on social adjustment.

(Aman & Aslam, 2012; Kalyani et al., 2015; Arya et al., 2012)
Methodology

- **Study approach** - Qualitative
- **Study design** - Descriptive
- **Study setting** - National Hospital of Sri Lanka
- **Study population** - Patients with traumatic paraplegia
- **Sampling method** - Purposive sample
- **Sample size** - 16 Patients
- **Time duration** - One to three months
- **Data collection** - Semi structured interviews according to theme guide
Methodology cont....

- Data analysis
- Thematic analysis method.

- Inclusion criteria
- 20 to 65 years old clients with paraplegia.

- Exclusion criteria
- Patients in spinal shock, confusion or psychiatric.

- Ethical consideration
- Ethics review committee of the National Hospital of Sri Lanka
Findings

Experiences of patients with paraplegia

- Life is a mess
- Body Frustration

Psychological Experiences

- Coping Strategies
- Future Plans
- Lake of autonomy
- Worry

Physical Experiences

- Adapting to a New Condition
- Inability to control basic bodily functions
- Pressure ulcers

Socio economical Experiences

- Responsibilities
- Relationship with others
- Livelyhood
- Poor financial support

Inability to return to Pre occupation

Social Contacts
### Findings, cont....

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub themes</th>
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| • Life is a mess                | • Depression  
|                                  | • Fear  
|                                  | • Stress  
|                                  | • Lack of autonomy  
|                                  | • Worry  
| • Adapting to a new conditions  | • Coping strategies  
|                                  | • Future plans  
| • Body frustration              | • Pain  
|                                  | • Discomfort of body  
|                                  | • Inability to control basic bodily functions  
|                                  | • Pressure ulcers  
| • Relationship with others      | • Responsibilities  
|                                  | • Social contacts  
| • Lively hood                   | • Poor financial support  
<p>|                                  | • Inability to return to preoccupation  |</p>
<table>
<thead>
<tr>
<th>Themes</th>
<th>Participants’ experiences</th>
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<tbody>
<tr>
<td>• <strong>Life is a mess</strong></td>
<td>“Oh…mmm I was hurting so much regarding this matter. I’m always remembering children. How can I look after them?. How can I give foods and drinks for them?..my children are small, youngest one is only three and half…(crying). I don’t think that I will be fine..(long pause). Doctors told me that would take a long time to recover and as time went on. (Participant Mr. A)</td>
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| • **Adapting to new condition** | “Initially I couldn't do anything by using my hands after this injury. Now I can handle the spoon and the phone. Gradually I can turn to left and right by using parallel bars in the bed. Day by day I believe I am improving. I want to do small works of mine. (Participant Mr. E)
### Findings, cont....

<table>
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<th>Participants’ experiences</th>
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<tr>
<td>• Body frustration</td>
<td>“I couldn’t bear-up my pain. Most of the time pain come from the upper part of the back. If someone touch me, it is also severe pain for me. I can’t tolerate it. That feeling like a electrocution. Most of the time requested pain killers or sleeping tablets form nurses. (Participant Mr. J)</td>
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<td>• Relationship with others</td>
<td>“In the very first, there are lot of visitors for me…but now…it has gradually decreased. My wife cannot come daily due to travelling problems. Nobody comes to see me…so I can understand the reality…(long pause). (Participant Mr. P)</td>
</tr>
<tr>
<td>• Lively hood</td>
<td>“I am the breadwinner of my family and I haven’t reserved funds. Only thing I have is my job. Now because of this injury I couldn’t do it. My wife must by every things to my children, pay house loan and bills…I don’t know where I can get money anymore. I worked as a driver in a private company. So far I couldn’t do that job. I feel stress….regarding that. (Participant Mr. K)</td>
</tr>
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Discussion

• The study showed that the stress, fear and worry are main psychological experiences same as Singh et al., (2012).

• It also suggested that the future plans abruptly stopped that agree with Kakahel et al., (2012) and Arya et al., (2015).

• Most of patients suffer from loss of independence and lack of autonomy due to need of assistance which agree with Aman & Aslam (2012).

• Depression and suicidal risk also identified as a major factors same as Arya et al., (2015) and Hagen (2010).
Discussion, Cont....,

- Pain, discomfort of the body, inability to control basic body functions and pressure sores are identified as physical experiences as same as the studies of Bailey et al.,(2016) and Hagen (2015).

- Inability to control body functions such as bladder and bowel problems, thirsty, hungry, maintain personal hygiene are mostly experienced which was also identified by Armstrong et al.,(2014).

- Most of the time need assistance for maintain basic body function as same as Kalyani et al.,(2015).

- Sleeping disturbance also identified in this study same as Singh et al., (2012).

- Present study shows a less pressure ulcers, but Aman and Aslam, (2012) highlighted more than 99%.
Discussion, Cont....,

- Patients have support from family, especially from wife, friends and hospital staff that agreed with Araya et al., (2015).

- Patients did not participate in social activities may be due to lack of facilities [Aman & Aslam,(2012)].

- Some patients's social interaction were poor and negative impression on the caregivers and the health staff [Bailey et al., (2016)].

- No ability to get financial support and not enough money to support basic needs which was same as identified by Aman and Aslam,(2012).
Limitations of the study

• All participants were not in same culture or same educational level.

• Research culture were not well established in Sri Lanka yet.

• Result may not be generalized to all paraplegic patients as this is a qualitative study limited to one selected setting
Conclusions

• Patients with paraplegia have psychological, physical and socio-economical experiences in positive and negative ways.

• The study showed that the stress, fear, worry, depression and suicidal risks are main psychological experiences.

• Inability to control body functions such as bladder and bowel problems, thirsty, hungry, maintain personal hygiene, pain and discomforts are mostly experienced as physical experiences.

• Patients have support from family but having poor social interactions. Socio-economically not stable.
Recommendations

• Need positive support to enhance their negative experiences.

• Family members, caregivers and health care staff must be educated, therefore awareness programmes must be introduced for them.

• Conducting counseling and awareness programmes about complications is important.

• Governmental and non-governmental support must be provided for financial security at least acute stage.
References


References cont....,


Hancock, R.H.(1985). Some guideline for the phenomenological analysis of interview data. Human studies, 8(3), 279-303


THANK YOU