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## HOPELESSNESS EXPERIENCE PATIENTS OF TRAUMATIC SPINAL CORD INJURY (SCI) SURVIVORS IN JAVA TRIBE, A STUDY OF PHENOMONOLOGY

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### ABSTRACT

*Hopelessness is a negative assessment towards result to be achieved and powerlessness against an expectation. Hopelessness can occur in traumatic spinal cord injury survivors because of disability due to neurological deficit and a long time in healing. This condition can lead to mental disorders or emotional or act of suicide. Therefore the description of the experience of hopelessness traumatic spinal cord injury survivors discussed in the study using descriptive phenomenology qualitative research to 6 participants. The result showed seven main themes: (1) Physical changes as result of the response of hopelessness, (2) Response of lost as the stressor of hopelessness, (3) Dysfunction process of the family, (4) Loss of meaning in life, (5) Support and self motivation as a source of coping to face hopelessness, (6) Spiritual value behind hopelessness traumatic spinal cord injury survivors and (7) Have a better life. The study suggests the development of nursing care standards of hopelessness and provision for family support and also family psychoeducation for traumatic spinal cord injury survivors.*

**Keyword :** Traumatic spinal cord injury survivors, Hopelessness, Phenomonology.

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### INTRODUCTION

Patients disability of post traumatic spinal cord as a result of neurological deficits required a long healing time and affected the psychosocial condition of traumatic spinal cord injury survivors. Psychosocial changes, such as low self esteem, feeling unlucky, wanting to have the capability back, sorrow, fear and hopelessness are manifestations of hopelessness, and even a sign of depression. According to Abramson, Alloy and Metalsky, (1989) hopelessness was essentially a precursor in the course of depression. Result of study in India stated 35.29% traumatic spinal cord injury survivors experienced depression (Srivastavaet al., 2010).

Traumatic spinal cord injury survivors who have prolonged illness, low selfesteem, will lead to the conditions of hopelessness, depression and even suicide action. Teasdale and Eingberg (2001) described traumatic spinal cord injury survivors has risk taking suicide in the first 3 years of his illness. This condition put the traumatic spinal cord injury survivors who have hopelessness with highly risk getting mentally emotional disorder.

In the other hand traumatic spinal cord injury survivors with hopelessness need long-term treatment for developing adaptive coping mechanism and prevent the growth of disability stressors to become maladaptive condition.

Anticipation efforts to reduce number of mental disorder was to manage risky patients with mentally emotional disorder so that he would not experience the problem, as traumatic spinal cord injury survivors's patients with hopelessness. Based on this phenomenon, need to do in-depth study on traumatic spinal cord injury survivors with psychosocial problem of hopelessness. Therefore, the study wants to answer the question "How does the hopelessness experience of traumatic spinal cord injury survivors in Java tribe?"

## MATERIALS AND METHODS

The design study used qualitative descriptive phenomenology research. Participants of the study were traumatic spinal cord injury survivors's patients with medical history of more than 3 months, mid-adults (40-60 year-old), had experience of hopelessness mid-level categories being measured by Beck hopelessness scale (BHS) and had cognitive vulner ability being measured by Mini mental State Examination (MMSE). The number of samples were taken from six people. The location of the study took place at *Puskesmas (Health Center) Tulangan's* work area of *Tulangan Village*, Java tribe, and implemented in September to November 2014.

Data collected by indepth interview and field notes. Data analysis used Colaizzi steps, by making a verbatim transcription, reading transkrip repeatedly, collecting significant statements, determining the meaning of each important statements, gathering keywords, classifying data into categories, then compiling and classifying into themes result of the study.

## RESULT AND DISCUSSION

Participants in the study were three males and three females of traumatic spinal cord injury survivors's patients who married and aged between 46 to 52 year-old. The education level of the participants consisted of High School and Diploma III. The duration of traumatic spinal cord injury suffered were between 6 to 12 months, including five participants had vulnerability in their lower extremity, urinary retention constipation and one participant had vulnerability in his upper and lower extremity. In overall, participants of traumatic spinal cord injury survivors had experience of mid-level hopelessness and had good cognitive. It was obtained various experiences of traumatic spinal cord injury survivors to face hopelessness in seven major themes.

### Physical changes as result of hopelessness

Physical changes stated as result of hopelessness is fatigue feeling as limp and powerlessness as it was expressed by following participant:

*"It was when I am down as powerlessness, felt my weak hands and feet were getting weaker ....."*  
(P1)

Other participants felt tired and lose physical working ability as described in the following expression:

*"Honestly, I felt my body lose its energy, my hand and right foot getting weaker when I lose my spirit or down"* (P4)

Result of hopelessness also felt in digestion and sleep disorders, as described in the following expression:

"Usually I get starve in the morning and take any breakfast and drink water, but at that time when I was down, I did not feel hungry and lose my appetite so my wife got angry." (P4)  
Sleep disorder was expressed as below:

"..... honestly when I got attack again, the feeling of hopelessness appeared caused me awaken all night and not sleepy at all up to 2 days, when I am going to sleep I always think that now I am being troublesome" (P5).

Hopelessness also result in cerebral perfusion with dizziness as described in the following expression:

"When I am in condition of low spirit, I feel lazy (spinning like going to faint) and also dizzy." (P3)

### **Response of lost as the stressor of hopelessness**

Response of lost as it was expressed by participants with distrust or bargaining was described in the following expression:

"Why after 7 months my leg is getting heavier." (P4)

Response of lost was tried to overcome by pressing(suppression) problems faced as described in the following expression:

"I will not tell my wife because I don't want her to be worried." (P1)

In addition participants also expressed anger overcondition:

"Sometimes I punch my hand and myright into bed while murmuring why I'm not getting well, angry at myself." (P5)

Depression behavior like low of spirit, sad, and worry were expressed as follows:

"I have baby while I can not work, I just like to give up."(P4)

"Is this the feeling of sad, worry, and I got lazy to do anything, justcrying." (P3)

### **Loss of meaning in life**

Disability in achieving goals of life was defined as loss meaning in life, and even came the desire to end life as described in the following expressions:

"I am a woman with working husband. I used to work to help my husband, clean our house and cook, but now I become burden for my husband." (P3)

"I have thought that it will be ok if I die because my husband and my children will not be bothered again". (P5)

### **Dysfunction process of the family**

To experience family dysfunction which was caused by inability to perform selfroles and inability of the family members to give respect for each members, as described in the following expression:

"My wife ever told me that she felt guilty, I told her to not saying that or I will slap her or even kill her, but I am still conscious, frankly speaking". (P1)

While inability to give respect between family members was described in the following expression:

"Sometimes when I ask my daughter to help me boil water for bath she did not do it directly until I

*asked her several times, it was like she did not respect her mother." (P3)*

### **Support and selfmotivation as source of coping to face hopelessness**

Source of coping for traumatic spinal cord injury survivors came from family support, environment, positive belief and motivation for activity. Source of coping from family's core was described as following expression:

*"When my son not going to college or gets holiday, he and my husband always accompany me in my room and motivate me, well, everytimemy son and my husband did this my spirit arise again." (P5)*

Beside the family support, there was positive belief from traumatic spinal cord injury survivors as described in the following expression:

*"The most important is self spirit, I remember some day when I parked my car, when the parking guy gave me change, it was dropped because my right hand could not functioned normally, he mocked me, but even I do not care about that I still remembering it". (P2)*

### **Spiritual value behind hopelessness traumatic spinal cord injury survivors**

Traumatic spinal cord injury survivors got spiritual values or wisdom of rebirthing through the process of redefine spiritual values in the powerlessness condition and also redefine meaning of life as described in the following expressions:

*"I am grateful,Imight have been guided to the lighter path and gave great blessed for the opportunity to worship to improve my quality of life". (P3)*

*"Since I have fallen and made me down until now I am able to work, learned me how to be more patient." (P4)*

### **Have a better life**

The meaning behind hopelessness of participants encouraged them to willing to have hope become healthy again and recover, perform the function ofself roles, as described in the following expression:

*"I hope to recover, can work smoothly to collect junk as usual, and hope all my children stay healthy." (P4)*

### **Participants Characteristic**

Hopelessness in the course has still debatable in terms of the cause, the study showed manifestation of hopelessness occured in traumatic spinal cord injury survivors with *hemiplegiadextraon* four participants. Study by Robinson said that there was relationship between lesions in the frontal lobe, sub-cortical and basal ganglia with occurrence of depression post traumatic spinal cord injury with central hypothesis that lesions in left hemisphere was the main factor caused depression post traumatic spinal cord injury(Meifi and Agus, 2009).

One participant experienced lower extremity hemiplegia that showed hopelessness was not only caused by organic factors but also psychological reactions factor as clinical consequence due to traumatic spinal cord injury. Study by Chen(2011) stated that motoric weakness suffered by post traumatic spinal cord injury patients was an important factor to cause depression. It was stated 61.3% of respondents who had badmotoric function suffered from depression post traumatic spinal cord injury, while 38.7% of respondents with good motoric function suffered from depression.

Participants' characteristic of the study had yet described the hopelessness experience of individuals who did not have supporting system such as husband, wife or experience being left by people who loved.

### **Physical changes theme as result of hopelessness response**

Physical changes as result of hopelessness were fatigue, anorexia and insomnia. Fatigue experience was expressed by participants as extremity weaker and sluggish powerlessness feeling. According to Naess, Lund and Brogger (2012) fatigue was associated with pain and depression suffered by post traumatic spinal cord injury patients. Its study stated there were three manifestations that frequently appear on the patients, namely depression 19%, fatigue 46% and pain 48%. Based on the correlation between depression and fatigue it showed strong relationship, while between pain and depression showed mid level relations.

To experience pain of traumatic spinal cord injury survivors was not found in the study according to researcher it was possible due to the influence of cultural factors. In Javanese culture especially East Java, to reveal pain on other people can significantly interfere him. Another factor that might influence was age. According to Kozier, Erb, Berman and Snyder (2011) adults could ignore pain because acknowledged pain considered as a sign of weakness or failure.

### **Response of loss as hopelessness stressor**

Traumatic spinal cord injury patients suffered the loss of functional ability because disease can change his physical appearance. In this condition, traumatic spinal cord injury patients got stressors that caused him to have negative expectations and powerlessness appeared against it. It was in line with study on chronic diseases such as breast cancer that stated 80% of patients worried about their future and 30% felt fear (Gumus, Cam and Malak, 2011).

Result of the study revealed that the response of loss suffered by traumatic spinal cord injury survivors was not at the stage of denial, but entered the anger stage which could be manifestation of frustration with the powerlessness condition in carrying out his role. Anger that expressed by traumatic spinal cord injury survivors was actually a form of coping. Besides anger, traumatic spinal cord injury survivors did coping with suppression that hiding his problem from others. Increased number of stressors could cause the stage of loss taken longer time to reach the condition of acceptance. The experience was supported by study conducted by Jones and Morris (2012) about the experience of traumatic spinal cord injury in adults and parents' career that expressed a theme of feeling useless and loss.

### **Loss of meaning in life**

Inability to run self roles brought a sense of powerlessness was perception that his life changed situation could not influence the results wanted to be achieved so that the meaning of life became meaningless. It was supported by preliminary qualitative study conducted by Kariasa, Sitorus and Afiyanti (2009) on post stroke patient's perception of the quality of life in the perspective nursing care that revealed post stroke patients had suffered and changed in meaning of life. The study stated the changes in meaning of life occurred more due to unrespected feeling, unnoticed and useless. The condition was actually a powerlessness revealed in the study. The study added findings that post traumatic spinal cord injury patients suffered from useless feeling which emerging idea or desire to end life. The desire to end life was supported by a study conducted by Towfighi (2013) stated that traumatic spinal cord injury survivors in United States as much as 7.8% had suicidal thoughts.

### **Dysfunction of family process**

Result of the study revealed the existence of conflicts between family members and inability to give respect towards family members. It was caused by the effect of role changed and self respect of traumatic spinal cord injury survivors that family became unable to perform affective function. According to Friedman (2010) affective function was internal function of the family as the basic force of the family. It was associated with mutual love, mutual support and mutual respect between family members. The overview results of the study was also supported by a study conducted by Clark et al (2004 in Gillespie & Campbell, 2011) stated that dysfunction of family in the first nine months of post traumatic spinal cord injury, 32% because of the inability of family to perform its functions and 66% due to family's conflicts.

### **Support and self motivation as source of coping to face hopelessness**

Source of coping that became primary choice of traumatic spinal cord injury survivors in hopelessness condition was family support, in this case from family's core like wife, husband and children. Significant other was considered meaningful and significant to foster traumatic spinal cord injury survivors with hopelessness. It was supported by qualitative study result conducted by Jones and Morris (2012) about the experience of adults's stroke survivor and parent's career that obtained themes for study "significant parent" which described that most natural support during nursing were parent's mother, father, children or their spouse.

Traumatic spinal cord injury survivors's attempted to keep the spirit was carried out through efforts to grow positive belief and motivation to get active and free from his hopelessness. This positive belief also called self efficacy. According to Bandura (1997 in Stuart & Laraia 2006) self efficacy was the capability of individual's self confidence. Individuals who have high self efficacy will give effect to his thought, motivation, mood and physical health, thus stressor considered as challenge. Study by Albal and Kultu (2010) described relationship between self efficacy coping and social support against depression patients, where the patients had low scores of self efficacy.

In the study also found that social support had been helpful to overcome hopelessness. Panzarella, Alloy and Whitehouse (2006) described social support as part of adaptive in ferential feedback (AIF) which effective to reduce sensitivity of depression cognitive by lowering negative conclusion of individuals, while also lowering maladaptive behaviors result of negative conclusion from experience that caused hopelessness.

### **Spiritual value behind hopelessness traumatic spinal cord injury survivors**

According to Bastaman (2007) the meaning of life could be found in every pleasant and unpleasant condition, happy and unhappy, as in the expression "meaning in suffering" or "blessing in disguise". The meaning of life for traumatic spinal cord injury survivors was obtained through redefine process towards spiritual values for himself. The study revealed difference with preliminary study on chronic diseases conducted by Sasmita, Hamid and Daulima (2011) where the spiritual values was obtained at the stage of acceptance, while traumatic spinal cord injury survivors who suffered from hopelessness got their meaning of life when the stage shifted to acceptance. The experience was manifestation from stages of loss as described earlier that every individuals had different process of loss. Some might directly able to reach acceptance, while some need long time and even months to finally accept the pain (Joseph, 2009). Another study conducted by Wachholtz and Pearce (2009 in Lewis & Peterson, 2013) explained that spiritual role in chronic disease and disability could encourage patient to find positive feelings to himself.

### Have a better life

As explained previously that powerlessness traumatic spinal cord injury survivors was able to get the meaning of life, so that they had hope for better life. Hoped for get well and run their role was ideal self identity for traumatic spinal cord injury survivors.

According to Snyder (in Cheavens., et al 2006) hope was positive motivation to achieve goal. In theory of hope, one of premise mentioned people normally think for goals. In this condition, Snyder, Feldman, Taylor, Schroeder and Adams (2000 in Cheavens., et al 2006) described four categories of the goals, to get desired results, to have purpose to hinder or postpone unwanted desire, to maintain or defend status quo, and to boost purpose to increase positive results.

In this context, hope and hopelessness were two different things, but related because it was useful to set target between hopelessness and hope in the psychotherapy construction. Cognitive therapy to overcome hopelessness could be done by digging thoughts of hope in his life (Cheavens., et al 2006). Study conducted by Curry et al (1997) in Cheavens et al (2006) also explained that high expectation of adults could increase self esteem. Thus, it was concluded that traumatic spinal cord injury survivors with hopelessness and high expectations were motivation to achieve wanted results. It was benefit for traumatic spinal cord injury survivors because it could improve self esteem.

### CONCLUSION

The study showed that the impact of hopelessness for traumatic spinal cord injury survivors were physical changes as a result of hopelessness response, occurred loss as hopelessness stressor, dysfunction of the family process, as well as loss meaning of life. The study, in result stated that loss meaning of life added to the findings of a new experience, the desire to end life and could be important domain in determining the quality of life for traumatic spinal cord injury survivors in terms of psychological being particularly self control.

The occurrence impact of hopelessness, traumatic spinal cord injury survivors did choice and strategy of coping like getting support from family and environment. Family's core support was the significant others to face hopelessness. Meanwhile efforts to grow positive belief and self dependency for traumatic spinal cord injury survivors also became sources of coping options to face hopelessness.

Despite hopelessness, traumatic spinal cord injury survivors got spiritual values from the meaning of life which obtained by redefine the powerlessness condition. As an individual, beyond hopelessness there was hope to recover, hope the attack would not happen again and hope to be able to perform self roles and want to have motivation and good health service from health workers.

The results of the study also described that the experience of hopelessness of traumatic spinal cord injury patients were closely related to the adaptation process when he got stressor, either physical or psychological stressors. The process involved several functions, among others physiological functions, self concept, role and interdependence which could be interpreted as support system.

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