CHAPTER 1

INTRODUCTION

This first chapter describes the background and significance of the research problem, purpose, specific aims and research questions. Definitions of the terms used in the study are also given in order to clarify their meanings.

Background and Significance of the Research Problem

Nearly 200-300 Spinal Cord Injuries (SCI) occur every 3-5 years in Thailand. Of these spinal cord injuries, 39 % involve paraplegia. The main group affected are males (83%) ranging from 18 to 39 years of age (55.4%). Most of them are young men who engage in high-risk activities, are unskilled laborers and the main income earners in their families (Intensive Care Unit of Orthopaedic's statistic, 1996-1999; Pajareya, 1996). Paraplegics have devastating experiences of trunk and leg paralysis; loss of ability to walk; and loss of bowel, bladder, and sexual function (Zejdlik, 1992). After medical stabilization, paraplegics receive inpatient rehabilitation for several weeks to several months. Most return home, some are transferred to long-care facilities.

In their real life situation, beside physical paralysis, they also suffer from secondary symptoms and conditions such as pain, spasticity, pressure sores, urinary tract infections, and autonomic dysreflexia (Pruitt, Wahlgren, Epping-Jordan, & Rossi, 1998). Moreover, paraplegics inevitably encounter additional changes; that is, change of body image, change of self and change of daily roles (Bozzacco, 1993; Quigley, 1994). These changes result in feelings of hopelessness, helplessness or powerlessness, distress, depression, anger, grief and anxiety (Walsh, 1999). The impairment of both physical and psychoaffective function has been shown to have negative consequences on employment opportunities (eg. premature exit from the employment sector, income disadvantage), social stigma and marginalization, disabled rights, and other opportunities (eg. discrimination, psychological well-being and quality of life) (Gignac & Cott, 1998). Hence, they suffer abrupt life changes, from living in a state of independent functioning to one of living in dependency with a disability (Dewis, 1989), social isolation and borderline poverty (Oliver, 1997). To achieve maximum physical independence, they need to manage the best they can. The ability to manage these aspects of their living is dependent on many factors that may inhibit or facilitate management (Widerstrom-Nago, Felipe-Cuervo, Broton, Duncan, & Yezierski, 1999). Paraplegics must learn a variety of new behaviors to manage their physical impairment and environment barriers and out of necessity spend much time in continuing efforts to reclaim what has been lost. They must master day-to-day activities in order to survive. They may go through a series of trial and error attempts to adapt to the situation instead of moving smoothly forward and accomplishing a goal. (Danielson, Hamel-Bissel, & Winstead-Fry, 1993).

To understand the whole context of managing everyday life among Thai men with paraplegia, a number of authors have examined how individuals with SCI or disability managed their personal and social world (Ray & West, 1984; Yoshida, 1993; Dewar & Lee, 2000; Chuenklin, Phantusena, & Songwathana, 2000). Ray and West (1984) have examined how paraplegics cope with SCI. The authors conceptualized the results through three domains of research questions: social relationship, sexual performance and relationship, and personal adjustment. With social relationship and sexual performance and relationship themes, the authors described in detail the strategies for dealing with other people and their attitudes, and sexual adjustment, but lack a conceptualization into obvious strategies. In contrast with the personal adjustment theme, they conceptualized emotional reaction into strategies including suppression, denial and repression, resignation and acceptance, positive thinking and independence and assertiveness. These strategies seem to be an hierarchy consisting of emotional reaction as has been argued by stage theories. Furthermore, this study specifies only social relationship, sexual performance and relationship, and personal adjustment. It fails to cover all aspects of a paraplegics' life in which paraplegics may perceive difficulties confronting them.

Other authors have attempted to delineate coping or adaptation with SCI. Yoshida (1993) conducted grounded theory to explore how individuals reconstructed their lives after SCI. The author believed the adaptative process post-SCI was the reconstruction of self and identity. The process of identity reconstruction was conceptualized as a pendulum which has a directional process that swings back and forth continuously between five dominant identity views; the former self, the supernormal identity, the disabled identity as total self, the disabled identity as an aspect of the total self, and the middle self. These identity views are influenced by the experience which transforms the individual in a significant way in which the individual perceives and takes action. This finding supports Mead (1934) and Blumer (1969) who identified the centrality of the self in social interaction as the medium through which people interpret situations which guide human behavior. However, the result of this study focused on the consequences of experiencing illness for creating self and identity rather than concentrating primarily on the practical struggles of managing life with paraplegia. Furthermore, the sample in this research has a wide range of age , from 22 to 56 years. Therefore, it lacked specifics in relation to any developmental task.

Recent work on coping with disability literature can be organized into a "process" framework. With respect to process, Dewar and Lee (2000) examined how individuals with catastrophic illness and injury managed their personal and social world by using grounded theory method. The authors described how individuals with catastrophic illness and injury experienced three phases in bearing their situations: finding out, facing reality, and managing reality. In the managing reality phase, individuals employed three strategies: protecting, modifying, and boosting. While this process on bearing illness and injury described a variety of strategies to cope with catastrophic illness and injury, it probably less represents coping with SCI because there are only fives SCI informants from the twenty-eight informants in this study. In addition, this participant group also has a wide range of age which does not provide any clear result of the strategies used in a young adult group.

Finally, the study of lived experiences as being paraplegic patients. Chuenklin et al. (2000) conducted a phenomenology study of lived experience as being paraplegic patients. The authors have illustrated the meaning, feeling, experience of living as a paraplegic, and caring need. Patients described their experience of living as paraplegic patients which were conceptualized into the important themes that follow: 1) the early period: living as lying only and under the supervision of the caregiver;

2) the transitional period: several themes emerged, including hoping to seek alternative treatment, confronting complication and unpleasant symptoms, learning how to live, provision of facilities for living, being independent to decrease the family burden, and being isolated from the society; 3) living with paraplegia period: stop seeking alternative treatment, be able to take care of themselves, return to be part of society and contributing benevolence to oneself.

The result of this study provided better understanding of the lived experiences as paraplegic patients in both genders, especially in the context of southernmost Thailand. However, it lacks knowledge about managing everyday life among Thai men with paraplegia through social interaction and their reality.

In Thailand, most of the previous studies concerning paraplegics have focused on management of activities of daily living (ADL) in hospital by health care provider (Ounprasertpong, 1983; Lertpoonwilaikul, 1983; Songwathana, 1988; Sukwinya, 1993). No study was found that explored paraplegics'long-term post-recovery management skills. These studies have shown that there are no significant differences in the incidence and onset of urinary infection between clean intermittent catheterization and sterile indwelling catheterization (Ounprasertpong, 1983), the effectiveness of the method of using soap solution with oral laxative were better than the method of using tap water, and normal saline with oral laxative (Lertpoonwilaikul, 1983). In addition, no pressure sores were detected in any paraplegics where relatives were prepared for new paraplegics home care prevention of pressure sores (Sukwinya, 1993). Although the research cited above has increased the knowledge necessary to care for paraplegics, it has emphasized that health professionals assume responsibility for the management of the problems for those individuals with paraplegia. Therefore, the question arises whether the ADL program provided by health professionals is appropriate for, and conforms with, the lifestyle and needs of each person. This is due to individual differences, people with paraplegia and their circumstance (Carpenter, 1994). Gage, Cook, and Fryday-Field (1997) reported that patients and health care providers had different perspectives about what was important in a successful transition to community living. Health care providers emphasized management on the day of discharge, whereas patient concerns related to the adjustment process once in the community.

While there is substantial literature in this area in Thailand, there are a number of omissions and assumptions. First, there is an absence of a follow up study of paraplegics in their home-based situation. Related to this concern is a preliminary survey at the rehabilitation OPD in Maharaj Nakorn Chiang Mai, which found that many paraplegics have urinary tract infections and pressure sore problems which are not severe enough for admission. Second, in 1999, a preliminary study was done to explore post spinal cord injury life after 2-3 years of paraplegia of five young men and two young women in their home-based situation. It was found that these people had several problems in managing their everyday lives, such as pain, decreased control of bladder and bowel, not being accepted by others, limited access to community resources and not being able to go out of their house by themselves. Despite this, these paraplegics who were supported by the family were able to manage everyday life better than those who lacked family support systems. There is, however, little explicit work that reveals what paraplegics really experience in their community life and how they manage it, based on Thai perspective. Therefore, this study attempts to address a holistic study in the aspect of their perspective on their daily life, and explore their management from a Thai cultural perspective.

Purpose and Specific Aims

The purpose of the study was to gain a deep understanding of perception changes after paraplegia and the process used by Thai men with paraplegia to manage everyday living.

The specific aims of the study were:

1. To explore and describe the perception and everyday life management among community-based Thai men with paraplegia.
2. To develop a substantive theory that identified the core problem facing these men, and the core processes used to deal with the problem.

Research Questions

Research questions examined:

1. How do Thai men perceive changes after paraplegia ?.
2. How do Thai men with paraplegia manage everyday life?.

Definitions

1. Everyday life management refers to ways that the individual handles their life in term of physical dysfunction and secondary complications as well as family and social management in the context of their environment in daily life.

2. Paraplegia refers to physical disability which is experienced as paralysis, with no sensation and movement of their lower limbs and loss of autonomic control, especially , no control over bladder and bowel (Trieschmann, 1986).

3. Disability refers to any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (Manciaux & Romer, 1991).

Summary

Many Thai men sustained paraplegia through accident, as a spinal cord injury. As the number of Thai men with paraplegia increases over the next few years, nurses and others health professionals or persons and institutions concerned with persons with disability will need information regarding the problems they face and how they can cope with living with paraplegia. This study aims to explore the paraplegic person's perception of their changes and to describe the process of managing everyday life as they interpret their experience of being paraplegic persons and their interaction with others. The next chapter will present a review of selected literature that is relevant to this study.