

## **CHAPTER 4**

### **FINDINGS**

This chapter presents the findings generated from grounded theory analysis for understanding the management of everyday life among Thai men with paraplegia and research questions for this study. The chapter is organized into three sections: (a) the first section presents the characteristics of the informants; (b) the second section present diagnosis and characteristics of SCI treatment; (c) the third section presents analytic finding including the theoretical explanation regarding to the paradigm model of grounded theory and the qualitative data relevant to research question 1 and 2 regarding perceived changes after paraplegia and how Thai men with paraplegia manage their everyday life.

#### **Characteristics of the Informants**

In this section, the personal or background characteristics, i.e. demographic information and information related to paraplegia are described. The demographic characteristics of the informants are presented in Table 3, while the paraplegic characteristics of the informants are shown in Table 4.

### **Demographic Characteristics of the Informants**

There were 14 informants in this study. The demographic characteristics include information about their age at the time of injury, age at contact, duration of disability, educational background, marital status, type of family, working status, and household income.

**Age at time of injury / Age at contact.** The informants were between 20 to 35 years of age (Mean = 26 years, Median = 30 years) at the onset of Spinal Cord Injury SCI. At the time of the study they were 25 to 39 years old ( Mean = 31 years, Median = 24 years, SD = 4.92). Seven men (50%) were in their early adult age (25 to 31 years old). The rest were in their late adult age (32 to 39 years old).

**Duration of disability.** The duration of disability ranged from 2 years to 8 years, with a mean of 4 years and a median of 4 years as well. Eight men (57%) had been disabled for less than five years, while six men (43%) had been disabled for five to eight years.

**Education background.** The majority of the informants (58%, n = 8) were high school and college graduates. Three men (21%) attended only primary school, whereas the others completed secondary school.

**Marital status.** Fifty percent of the informants ( $n = 7$ ) were single, whereas forty-three percent ( $n = 6$ ) were married or living together. Only one informant had separated from his wife after SCI.

**Type of family.** Ten informants (72%) lived in extended families, whereas four informants (28%) lived in a nuclear family, living with their spouse. Of those living in extended families: one of them was living with his father and mother; one of them was living with his parents and his spouse; one was living with his parents and elder sister's family; two of them were living with their mother; one of them was living with his mother and younger sister; two of them were living with their younger brother's family; and one was living with his mother and elder sister's family. Only one informant stayed in the household of his elder sister.

**Working status.** The current working status of the informants was classified into two groups: self-employed and unemployed. The most of the informants (64%,  $n = 9$ ) reported themselves as self-employed, working at a rooster farm, as a lottery ticket seller, grocer, repairman (electronic, motorcycles), at a VDO game shop, as a musician, at a rental book shop and eyeglasses shop. The unemployed group consisted of five men (36%) who were in the categories of "not being able to get a job", and "not wanting to work". Of the three men (22%) who were in the category of "not being able to get a job", one reported that he could not find a job where he could work so he focused on work training. Another thought that it was difficult to, go

outside his house, so he helped with his wife's job instead, whereas another still wanted to work yet he could not find an appropriate job for himself. The "not wanting to work" group included two men (14%). One wanted some time to stay in his house since he had just returned home from the hospital and had deep vein thrombosis. Another was not allowed to work by his parents.

**Household income.** The statistic survey of household income in the northern part of Thailand found that household income average is 10,231 baht / month (Particle Data Bank and Information Dissemination Division, 2544). In this study eleven men (79%) lived in a family of under average household income (1000 to 10000 baht / month). Only three men (21%) were from families of higher-than-average household income (>10000 baht / month). All of the informants did not receive disability pension from the Disability Act (B.E. 2534) because the disability budget is limited and some of the disabled did not request for it. There was only one informant who was covered by social insurance from his former office. Also, four informants received private life insurance benefits every three years and stopped paying money back to the insurance company.

**Table 3****The demographic characteristics of the informants (n = 14)**

Demographic Characteristics	Frequency	Percentage
Age at time of injury		
20-29	10	71
30-39	4	29
Age at contact		
25-31	7	50
32-39	7	50
Duration of disability (years)		
< 5	8	57
>5	6	43
Educational background		
Primary school	3	21
Secondary school	3	21
High school/ College graduate	8	58
Marital status		
Single	7	50
Married	6	43
Separated	1	7
Type of family		
Extended	10	72
Nuclear	4	28
Working status		
Self-employed	9	64
Unemployed	5	36
Household income (per month)		
1000-5000	7	50
5500-10000	4	29
>10000	3	21
Financial resources		
Social insurance	1	7
Private insurance	4	28
Not received any benefit	9	65

### Paraplegic Characteristics of the Informants

Paraplegic characteristics include information regarding the cause of accident, level of paraplegia, type of lesion, and physical complications.

**Table 4**

#### The paraplegic characteristics of the informants

Paraplegic Characteristics	Frequency	Percentage
Cause of accident		
Car accident	11	79
Falls	3	21
Level of paraplegia		
Upper thoracic (T1 to T7)	7	50
Lower thoracic (T8 to T12)	7	50
Type of lesion		
Incomplete	1	7
Complete	13	93
Physical complication		
Pressure sores	10	72
Spasticity	13	93
Pain		
Neurogenic pain	11	79
Non-neurogenic pain (back pain)	5	36
Urinary tract infection	5	36

**Cause of accident.** In this study, car accident exceeded falls as the cause of SCI. Automobile and motorcycle accidents, and being hit by a car together accounted for 79% of all car accidents because of the high use of automobiles and motorcycles in Thailand. Falls while working (from elevator, tree, and well) accounted for 3%.

**Level of paraplegia.** The level of the spinal cord lesions ranged from the first thoracic vertebra (T1) to the twelfth thoracic vertebra (T12). Upper thoracic paraplegia accounted for 50% (7 informants) and lower thoracic paraplegia accounted for 50% (7 informants) of all informants with SCI.

**Type of lesion.** According to the American Spinal Injury Association (ASIA) scale utilized to rate the lesion as to the degree of the incompleteness of injury, one informant (7%) was classified as having incomplete paraplegia, and twelve (86%) as having complete paraplegia.

**Secondary complications.** In this study, physical complication accounted for in between of study, approximately 1 year. The findings revealed that the informants experience physical complication sequelae frequently and long period of time. These issues reported by informants include pressure sore, spastic, pain, and urinary tract infection.

**Pressure sores.** Pressure sores occurred in 72% of all informants. The severity of pressure sores ranged from stage 1 ulcer of the epidermis or into dermis, to stage 4, bone at the base of ulceration. One informant who had the most severe pressure sore, stage 4, had an operation during the time of study.

**Spasticity.** All informants were asked whether they currently experienced spasms, and if so whether the spasticity constituted a significant problem. Most of the informants (93%) reported that they had spasms, out of whom 7 informants (53% of

those with spasticity) reported their spasms to be a problem which restricted the activities of daily life, caused accident or pain.

**Pain.** The majority of the informants (79%,  $n = 11$ ) reported that they had a neurogenic pain which was described as a burning pain, tingling, sharp and shooting, throbbing, tight, pressure or diffusely below the neurological level of lesion in the lower part of the body. Some of the informants could not specify the site of the pain, but some could detect it in the abdomen, both legs, knees, calves, feet, sole of the feet, waist, buttock and as pressure on the body area.

Five of the informants (36%) stated that they had back pain. This pain was related to long periods of sitting, spasm when sitting, or at the injury site.

**Urinary tract infection (UTI).** During the 11 month period of the study, thirty-six percent of all informants ( $n = 5$ ) developed UTI. Two of these informants talked about the cause of UTI which came from his contamination, or his ignorance to eliminate at sometime of the day. All of the informants reported that they have known a sign or symptom of UTI because of having experienced it before.

### **Diagnosis and Characteristics of SCI Treatment**

SCI, if complete, causes permanent paralysis below the level of injury which results in multisystem physiologic dysfunction. Therefore, persons with SCI are at a high risk for medical complications all of their life. As shown in table E1 (Appendix E), the diagnosis and characteristics of the treatment in 14 informants are described.



Following the patients' medical records, the majority of the informants (seven informants) had sustained a fracture from thoracic level 8 to lumbar level 3-4, while five informants had sustained a fracture from thoracic level 1 to 7. Only one informant had sustained a fracture at cervical level 7, however, another one was found to have no spinal fracture. Comparing with the neurological diagnosis, seven informants were diagnosed with a neurological level of lesion higher than their spinal injury level, whereas six informants were diagnosed with a neurological level of lesion in the same level of the spinal injury. Only one informant who had no spinal injury could not show a relation between diagnosis.

The treatment of SCI has to begin at the time of injury continuing to long-term follow up. Therefore, the characteristics of SCI treatment should be divided into three phases: acute, recovery, and chronic. In the acute phase, the major aims of treatment are life preservation and spinal stabilization. The average duration of the acute phase is 2 to 3 months. In this phase, eight informants underwent spinal surgery compared to six informants who received conservative treatment. Two informants who had other concurrent injuries also received emergent surgery. Bedside physical therapy to maintain range of motion and prevent atrophy was needed for all informants because of their paralysis and immobilization in the bed. All of them also were inserted with an indwelling catheter because there is no sensation of the need to void and distention occurs easily. Similarly, all of them received bowel care by manual evacuation or a cleansing enema 3 days after admission. Once the bowel has been cleaned and the informants are eating, all of them began bowel training.

The recovery phase or rehabilitation phase begins as soon as the informants are stable. This phase continues for 2 to 6 months after SCI. The goal of the

rehabilitation phase is to assist persons with SCI in achieving their maximum potential and avoid complications resulting from disabilities. Therefore, during this period all informants receive a full rehabilitation program including physical therapy and occupational therapy in which thirteen informants wore orthosis, a Jewette or Taylor brace, and two of them wore a long leg brace during ambulation or upright mobility. All of them started bladder training and continued with bowel training from the acute phase. Many complications concerned with SCI or not concerned with SCI developed in this period such as spasticity, urinary tract infection, pain, pressure sores, hypertension, deep vein thrombosis, tuberculosis, and depression.

Five informants were treated with antispasmodic and minor tranquilizer medication for spasticity. Four informants developed a urinary tract infection while they were bladder training and they received quinolone medication. Only one informant experienced neurogenic pain and received neurogenic medication. Two informants who developed severe pressure sores from the acute phase were treated; one was treated by surgery whereas the other was treated by wound dressing because of a medical problem. Another informant who had hypertension was treated with antihypertensive medication. Another one experienced deep vein thrombosis, a rare SCI complication in a Thai person, and tuberculosis. He was treated with anticoagulants and an antituberculosis agent.

In the chronic phase, a phase of follow-up or re-hospitalization is continued in the first six months of the post-discharge year and at yearly intervals thereafter. The aim of treatment in this phase is to up-date the management of the problem related to SCI, with added benefits of providing preventive health maintenance. In this phase, all informants received the provision of comprehensive life-long follow-up services with

outpatient clinics for periodic evaluation such as an urology check-up, and other assessments such as the patient's current neurology, genitourinary, gastrointestinal, skin, and skeletal system, as well as other medical problems and treatment of inter-current problems in the hospital.

The experiences of re-hospitalization due to an urology check-up were reported by twelve informants. Six informants had further urology investigation with cystometry, cystoscope, voiding cystogram, cystourethrogram, and intravenous pyelogram, because of the finding of an abnormality in their urinary tract system. With the results of the investigation, five informants were diagnosed as having a spastic bladder and dyssynergia bladder (the bladder contracts and the sphincter will not open), and they received antispasmodics and muscle relaxants. One informant experienced a ruptured urethra and was treated with an internal urethrotomy and supra pubic cystostomy, whereas another one had the complication of a vesicle stone. He had to be treated with cystolithotomy and lithotripsy. In this phase, recurrent UTI was found in eleven informants and some of them were re-hospitalized the first time and self-treated by taking antibiotics from the hospital or drug store the next time.

Nine informants developed pressure sores both in the chronic phase and continuing into the rehabilitation phase. Pressure sore treatment included wound dressing, antibiotics, operations (flap coverage, STSG) and one informant had to have a colostomy because of a severe pressure sore at his buttocks and legs.

Nine informants developed spasticity in this phase and since they were in the rehabilitation phase were treated with minor tranquilizers and physical therapy (therapeutic standing) while re-hospitalized. One informant who experienced back pain was evaluated with a radiograph and received analgesic medication, whereas four

informants who also experienced back pain and neurogenic pain were treated with an anticonvulsant and minor tranquilizer from the pain clinic. In this phase, three informants were diagnosed with depression and were treated with antidepressants.

Since it is a long-term phase, some informants might develop physiological problems such as phimosis, allergic dermatitis, and heterotopic ossification and were treated as per their symptoms. Two informants who had an indication of a slipped or loose implant were operated on to remove the implant. Finally, two informants who had neurological recovery, received gait training with a walker, however, the effort to walk was not justified.

### **Analysis Findings : The Theoretical Explained**

In grounded theory, many categories are linked to one core category by means of the paradigm model- phenomenon, causal condition, context, intervening conditions, action/interaction strategies, and consequences (Strauss & Corbin, 1990). The analysis followed a symbolic interaction perspective. The basis of this perspective is the idea that the self is established, maintained, and altered through communication. All of the paralyzed informants developed an awareness of their body by the experience of living in that body. However, because the body in which the person lives is visible to others, it is the object of social attention and public appraisal. Social interactions provide persons with critical data for knowing their body. That is, the self-perception occurs continuously while they live in everyday life.

In this study, Thai men's perception of their self and life alteration after paraplegia was seen as a causal condition leading to the phenomenon of making the

best of paraplegia. With the perception of the change, paraplegic persons tried to manage their situation within the context as much as they could. A context is the specific set of conditions within which the action/ interaction strategies are taken to manage, and respond to a specific phenomenon (Strauss & Corbin, 1990). These conditions include self (personal consideration, personal attributes, physical condition, and past experiences), and environment (setting, lifestyle, and access to resources).

Learning self-care, learning the system of care and support, and learning to live in society, are identified as action/ interaction strategies that are dynamic processes, and that are also influenced by intervening conditions. These conditions, the broader structural context pertaining to a phenomenon (Strauss & Corbin, 1990), consist of hope, norm, and sociocultural attitude. The last condition of a paradigm model is consequence, which is the event that happens as a result of action / interaction strategies (Chenitz & Swanson, 1986). In the consequences of making the best of paraplegia, the problems were not resolved but the attempt of the informant's management resulted in limiting the amount of physical and emotional suffering, which made them able to live in society. These major findings are summarized in Table 5.

Table 5

The relationships of categories to their causal condition, context, intervening condition, context, intervening condition, consequences and the properties of categories.

Causal condition	Context	Intervening conditions	Categories / Phenomenon	Consequence	Properties / Characteristics
-Perception of self and life alteration	-Self -Environment	-Hope -Social norm -Socio-cultural attitude	Making the best of paraplegia	-Physical function aspects -Psychological aspects -Lifestyle/behavior modification -Social participation	-Self interaction and social interaction -An effort to manage the best as one can. -Try to manage by self with or without help from others, and have a goal.
-Perceived physical function alteration	-Personal consideration -Physical condition -Past experiences -Setting -Lifestyle -Resources	-	Learning self-care -Maintaining physical functions -Controlling and preventing physical complications	-Physical function aspects -Social participation -Lifestyle / behavior modification	-The cognitive and behavioral strategies required an effort to manage physical dysfunction and complication. These strategies are done regularly throughout the rest of one's life. -Action learnt from health care providers and other disabled people. -Actions were rigorous methods or modified to conform own lifestyle. -Action concerned preventive action and physical care, and physical observation
-Perceived being dependent on others -Perceived decreased working capability	-Personal consideration -Physical condition -Resources	-Hope -Socio-cultural attitude	Learning the system of care and support -Seeking and accepting necessary support from significant others -Seeking governmental support -Seeking alternative treatment and professional suggestions	-Psychological aspects -Lifestyle / behavior modification -Social participation	-The cognitive, and behavioral strategies described as an effort to seek and accept support to replace the one that they lost capability of to meet life demands. -Actions required an effort of self and family to tolerate, adapt, and attend to manage. -Action concerned seeking and accepting support in aspects of basic needs, finance, job, and more physical treatment.
-Perceived inferiority -Perceived discrimination from society -Perceived changes in relationship with significant others	-Personal consideration -Personal attributes -Physical condition -Past experiences -Resources	-Hope -Social norm -Socio-cultural attitude	Learning to live in society -Avoiding having a sense of inferiority -Controlling negative behavior -Managing stress -Protecting dignity	-Psychological aspects -Lifestyle / behavior modification -Social participation	-The cognitive, affective, and behavioral strategies described as physical and social skills to protect against harm to the self, and assert self-value. -Action concerned social skill, adapt behavior, take care of the mind, and use remaining capability. -Action was performed frequently or sometimes varied by degree of stress. -Action described as passive or active / performed by own self or depend on other.

### Making the Best of Paraplegia

Making the best of paraplegia emerged as the central phenomenon, which refers to people with paraplegia trying to manage as much as they could in perceived alteration due to their paraplegic situation. The attributions of making the best of paraplegia include: 1) making an effort to attentively and carefully take care of the self; 2) trying to seek and accept supports as much as they are capable; and 3) trying to maintain normalization. The attempt to manage their life the best as they could was also explicitly expressed in data.

*I tried to do my best. I tried to keep and prevent my body from any damage. When it's cold, I sought clothes to wear, and wore socks to prevent chapped feet. I don't let any wounds appear on my legs (2:13).*

*I went every where for seeking treatment. I met the doctor or practitioner in every nation and every kind of treatments. I went to all...I went to a lot of places (9:20).*

*I can't do things as ordinary people can. If I do as an ordinary people, I will be in misery or pain. However, I tried to do my best or tried to do the thing that was closest to what the normal people can do. I understand my capability. I'm now happy on one level (8:20).*

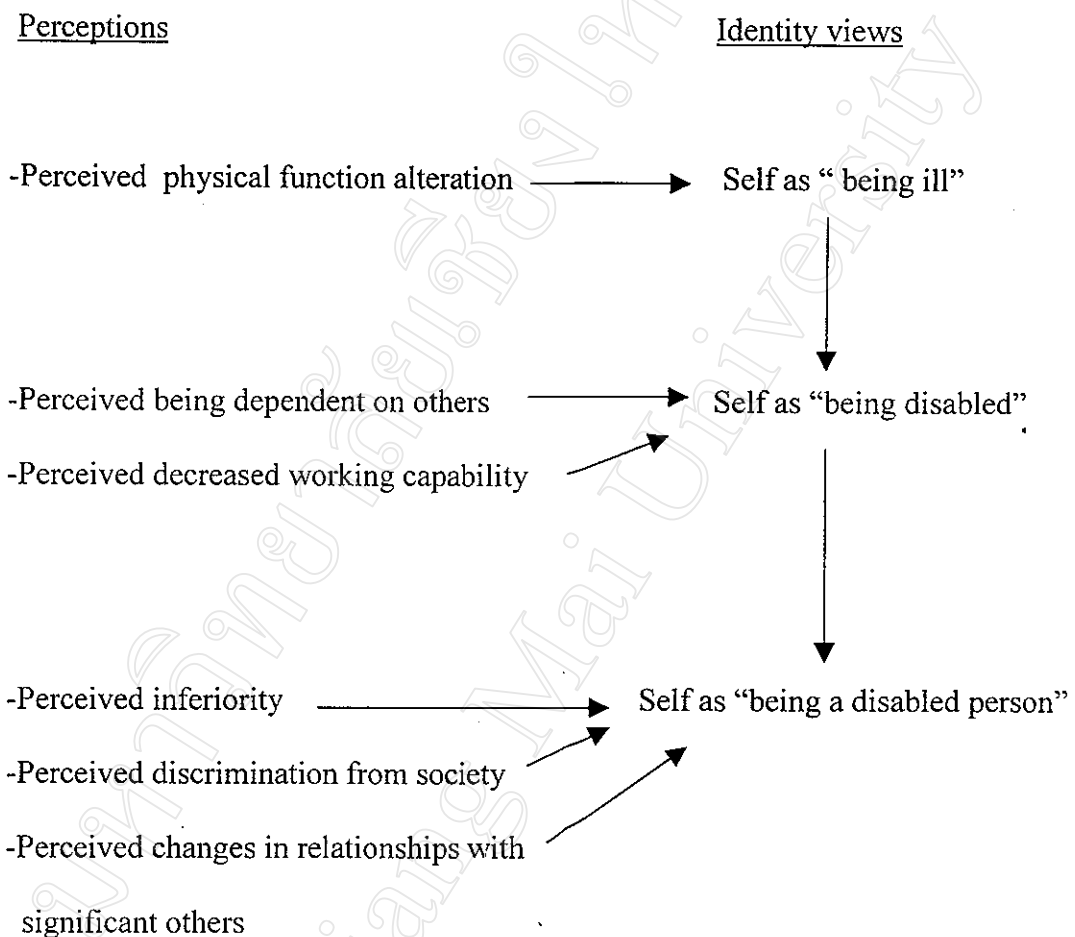
Making the best of paraplegia means that the informants do or seek the best thing for managing their problem. The strategies were being developed with an extreme existing capacity of own self, as their supporting resources and under the conditions specific to their context. Making the best of paraplegia involved both self-interaction and social interaction by means of cognitive, affective, and behavioral strategies. The informants performed these strategies by having their own goals, with or without help from others. These efforts can be expected to leave the informants better off physically and psychologically after employing them.

To relate to making the best of paraplegia, the informants perceived life change after paraplegia. Their perception varied from person to person depending on the situation they faced, self-perception, context in term of resources and supports. Most of them perceived physical function alteration, being dependent on others, decreased working capability, self-inferiority, discrimination from society, and perceived change in relationships with significant others. These perceptions have three attributions: cannot do as before paraplegia; can do but not the same, and can do but not equal to other people. These perceptions of life alteration caused “self” alteration into three identity views which emerged from the interview study. These are: 1) perceived physical function changes which led to perceived self as “being ill”; 2) perceived being dependent on others and perceived decreased work capability, which led to perceived self as “being disabled”; 3) perceived inferiority, perceived discrimination from society, and perceived changes in relations with significant others, which led to perceived self as “being a disabled person”. Since the informants perceived their life depending on the conditions and context around them, the self after paraplegia may change progressively among these identity views (Figure 3).

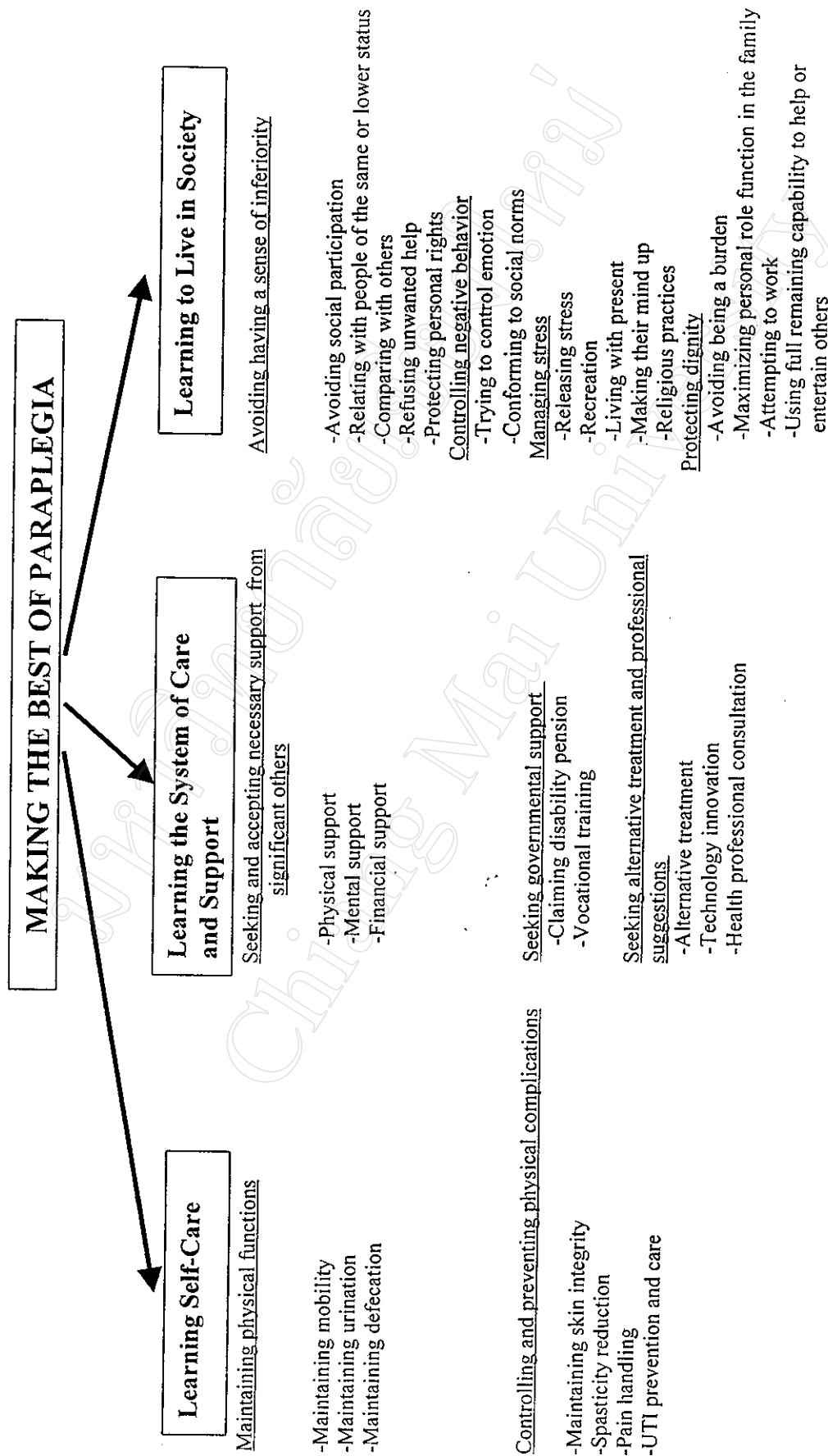
The “phenomenon of making the best of paraplegia” is concerned with the strategies of learning self-care, learning the system of care and support, and learning to live in society (Figure 4) which responds to the alteration of self during paraplegia as follows: 1) perceived self as “being ill” led to the strategy of learning self-care; 2) perceived self as “being disabled” led to the strategy of learning the system of care and support; 3) perceived self as “being a disabled person” led to the strategy of learning to live in society. The consequences of each management became a



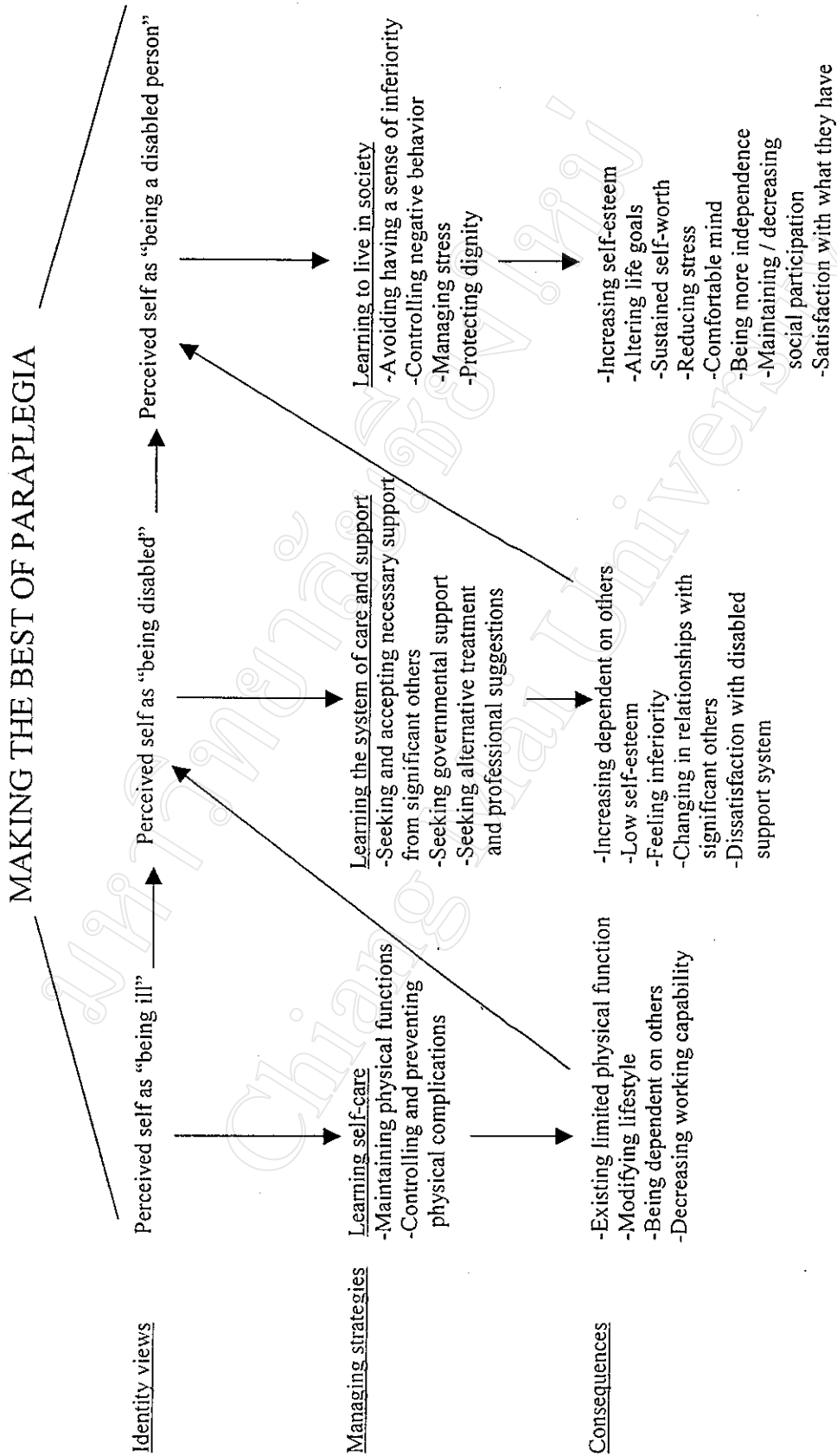
condition of the next strategy. Therefore, the phenomenon of making the best of paraplegia represents a cycle continuous moving process (Figure 5).



**Figure 3.** Perceived self-alteration among young adult Thai males with paraplegia



**Figure 4.** The basic social process of making the best of paraplegia.



**Figure 5.** The relationship between self-perception, managing strategies, consequences.

### **Perceived Self as “Being Ill”**

Perceived self as “being ill” was developed in the first period of paraplegia and was perceived throughout their life time when they faced physical deterioration due to secondary complications. Disability condition, pain, pressure sores, and urinary tract infection may be on and off symptoms and so severe that the persons with paraplegia were able to think of themselves as still “being ill”. The informants may also feel that treatment in hospital is not enough in first period of paraplegia. This situation may affect a informant’s self-perception. They would perceive their self as “being ill”.

To continue their own life, the informants tried to do their best by learning self-care physical their dysfunctions and secondary complications. Learning self-care refers to a cognitive and behavioral strategy that the person with paraplegia used to take care of their body in order to maintain physical function and prevent physical harm. The informants learnt this strategy from health professionals and from other disabled patients in the hospital. Then, they could adapt it for themselves. Some informants used this strategy rigorously which they learnt from the hospital, whereas others could modify self-care to conform with their lifestyle. The characteristics of this strategy consist of the method of caring, preventing, and observing physical function. The strategy of learning self-care is composed of two strategies: maintaining physical functions (maintaining mobility, urination, and defecation), and controlling and preventing physical complications (maintaining skin integrity, spasticity reduction, pain handling, and UTI prevention / care). These strategies were performed by the informants when they perceived self as “being ill” and perceived

physical function alteration including: not being able to walk, urinate and defecate, having spasms, pain, pressure sores, and having urinary infections.

### **Not Being Able to Walk**

All of the informants perceived “not able to walk” as a common area of concern for them. The changes of motor function below the injury level caused them to be unable to walk. They have to use a wheelchair and mobilization depends mostly by use of their hands instead of their legs for the rest of their life. Most of them had to reside in their house because it was difficult to travel outside their house due to the road condition and inconvenient transportation in rural areas of Thailand. The impairment of mobility limited the way of movement in their daily life and affected their mind, job, and social relationships. A 26 year-old paraplegic man described his life after paraplegia.

*I can't move my legs at all (2:5). I've to use my hands instead all the time. My lifestyle has changed. Previously, I could go anywhere with my friends easily, but now my friends can only visit me here. I could go outside for working as I needed. I have to stay home and do nothing much. I felt things are getting worse (2:3).*

A statement of a 33 year-old who sustained complete paraplegia T12, lower paraplegia level, indicated that he used to walk with a walker after acupuncture treatment at one private hospital, however, he spends the majority of his time in a wheelchair.

*It has been one year since my injury and that I went to the hospital to remove the instrument from my back. Then I was treated with acupuncture for 15 days. That time, from being unable to walk, I could walk with a walker, but needed some help from others when I got on the sloping way. Now, I do not walk any longer, because it is slow. I feel tired. I could walk approximately less than 3 meters. Most of the time, I use a tricycle wheelchair in my daily life (14: 1-2).*

The result of not being able to walk may seem an insurmountable problem in daily life. In order to maintain physical functions, the informants tried to manage this problem by learning self-care by maintaining mobility.

### **Maintaining Mobility**

To be able to engage in activities in daily life, the informants tried to maintain their mobility both inside and outside their house. They used this strategy depending on health belief, family / social supports, and resources (building and transportation). Inside their house, the mobility strategies included: using a wheelchair, using hands instead of paralysed lower extremities during transfers, moving along the floor, standing with long leg braces and bar, and exercises. They used these strategies with or without assistance from others. Two informants described the wheelchair as an important piece of equipment in assisting mobility and having activities of daily living.

*Regarding my movement, I would use my hands most of the time because my arm are strong enough. My left leg may be useless but my right leg can lift a little bit. I use my hands for moving to the bed or the toilet (4:6-7).*

*I have to use a wheelchair all the time, otherwise I couldn't move from place to place. Even for getting my drink, I have to go by wheelchair. I couldn't move along the floor (5:2).*

Although one had high paraplegia, he wanted only to have a chance to stand for improving physical function and for feeling physical progress. At the last interview, he had a chance to stand with long leg braces and support from his family member in his house.

*I want a braces. I have to ask the doctor. It affects my mind. I will use it for standing up. I must be able to do it. I would like to stand up to improve my blood flow (7:17-18). I could stand with braces 5-10 min per day. I try to do it everyday (7: 30).*

Another who had a vital complication, deep vein thrombosis, would like to stand.

He believed that standing might help him to move easily.

*I wanted to stand up but he (the doctor) forbade me from standing. He was afraid of me getting deep vein thrombosis. I would like to be able to stand up. It will be easier to move from a standing rather than sitting position (11:25).*

Moreover, some informants assumed that the more physical therapy they received, and the harder they exercised, the more they would regain physical function.

They believed mobility with exercises would compensate for the useless parts of their body and increase the rest of physical potential.

*I don't have much problem moving around for I don't move much (8:4). From here to the bed or to the bath room to take a bath. In the evening before going to bed, I would exercise by push-ups for 30 times, back extension and push the elbows for 50 times a day. Then raising my feet, and move ankles to prevent stiffness of the joints (8:18). I did the exercise in order to maintain muscle strength., If I don't do any exercise, my muscles will become powerless (8:35).*

*I rarely do the exercise, but pushing the wheelchair was like an exercise. I sweat a lot. I push the wheelchair by myself, never allowed others to push it for me. I push the wheelchair inside my house for 200 meters or more per day (2:10).*

Mobility outside their house is mentioned as one particular experience which made informants able to participate in a wide range of activities such as being able to go outside for working or increase the potential for maintaining their social function. The informants tried to maintain their mobility outside their house by getting the help from others, choosing accessible places, and independent wheelchair usage. This method may make them able to go outside but limits the time and place.

Because of inaccessible buildings and transportation in rural areas, some informants who did not drive themselves, or have high paraplegia, have to rely on

family or friends to actually drive their cars for them. Going outside often has to be arranged around the times when drivers are available. Some informants complained of the difficulty depending on others for assistance but some had no problem.

*If I want to visit my friends, I would ask my nephew to take me there (7:20)... Sometimes I felt lonely, if my friend happens to come by, I would ask him to drive his car to his orchard, in the evening or day time. When I reached there, I sat inside his car and took a look at his orchard (7:23-24).*

*When I wanted to go anywhere, I had to wait for him to have free time. Sometimes, he had to finish his work before taking me out (12:5).*

An inaccessible place, such as their friend's house, the road in the village, or a travelling place may be a barrier for the informants to travel and work outside their house. Therefore, for maintaining mobility, one informant had to select the place where they could perform independently whereas another had to depend on his sister for going outside.

*If I want to go anywhere, I would go, but I had to select the accommodation. For example, when I went to the sea, I would stay in the room with a raised seat toilet (13:1).*

*I rarely go out of my house because it is difficult to cross the bridge. Someone suggested that I sell lottery tickets. Where can I sell it? I couldn't go outside even if it is in this area (4: 41). I disliked to travel in my village because of the bad roads. I liked to go to the department store with my sister because it is more convenient (4:7).*

The last strategy is going outside alone with a wheelchair or their own car. The informants who have potential independent mobility, may have sustained paraplegia for more than 5 years, or have car ownership. They could have gone outside wherever or whenever they wanted. This strategy was done everyday or some days. With this strategy, they can maintain social activities with neighbors as usual.



*When I went outside, I drove my own car to travel. Most of all, I went to my cousin's house or visited the neighborhood (14:14). I thought my capability had become developed. I told my friend, "you could go before, and then I would follow". I don't depend on others now. I can go everywhere by my own self (14:52).*

### **Not Being Able to Urinate and Defecate**

The loss of control over elimination, both bladder and bowel dysfunction, was a profound concern for the majority of the informants. These were two kinds described as "urine and bowel retention", and "urine and bowel incontinence". Unable to urinate and defecate affected their lifestyle, had psychological aspects, and financial issues such as the cost for bladder and bowel accessories or medication. Of these issues which were more complained. About, a 33 year-old man who had paraplegia at the upper thoracic level and had urine incontinence, said:

*I can feel when I need to urinate, however, I cannot control it. Urine will leak all the time (12: 3). Now my financial status is worsened because I have to spend a lot of money on enemas, urine bags, and condoms. Sometimes I have to ask for them from Health Center (12: 7).*

Some people had paraplegia at lower levels. Another had upper thoracic level but they received medication for spastic bladder treatment. These informants had urine retention except it had a high volume of urine. Certainly, the need of bladder management engendered their concern because they had to do catheters prevent urine leakage. A 26 year-old paraplegic man said:

*I, now, cannot urinate by myself. I have to use a catheter because it does not come out. Except when it had filled the bladder, it would be incontinence (2: 7). I actually could go anywhere but I'm worried about my habit of urination. I want it to be normal. If it is normal, I may be able to go and work in the distance and to help other people (2:20).*

A 27 year-old paraplegic man stated:

*Since the doctor gave me the medicine, my bladder can hold more urine. Previously, I had a leakage problem. Now, it can hold as much that it would leak only when the bladder had overflowed. However, I have to get the urine out by catheter eight times a day (7: 10).*

“Not being able to defecate” was like bladder dysfunction, Yet most of the informants seemed to be more concerned. Since all of them not only had no sense of fullness but also no control over it anyway. This bowel problem included: incontinence of bowels, and constipation. Incontinence bowel, especially creates enormous problems such as limited working capability, decreased social participation, and psychological disturbance. A 26 year-old paraplegic man said:

*I can't feel it when I need to defecate. Sometimes it comes out, sometimes it does not. Some days I had diarrhea without having any causes. After having diarrhea, I had constipation for weeks. I thought my bowel system was bad. In every day life, I do not dare to go away from my house. I couldn't go far away for working. I'm afraid, I may have problems with my excretion system outside my house. Sometimes, if I had a lump on my abdomen, I would hurry back home. If I stayed there, I would have shame certainly (2: 17).*

A 33 year-old paraplegic man explained:

*Some days I had diarrhea without any causes. Some days while I stand, I can feel I am having a stomachache and suddenly, I excrete. In the day time, while I was on lying the bed with a good mood, suddenly I feel like I want to excrete, then it will come out. This destroys my mood. It makes me feel very depressed and I do not want to speak with any body for a whole day (4:14). I cannot go out partying or having fun with my friends like I used to do because I am worried about the excretion which could occur any time. I feel lousy (4: 8).*

Not being able to urinate and defecate was a profound concern for the majority of the informants. Most informants can no longer feel when their bladder and bowel need emptying. Since these functions are essential for survival, the informants attempted to learn self-care physical function by maintaining urination and defecation.

### Maintaining Urination

All informants had to learn urinary care to maintain urination which included: catheterizing, tapping and expression, and using condoms. Some informants employed the method of catheterizing and tapping and expression after they predicted the sign of elimination from observing body signals. However, all techniques might be modified according to individual needs, physical condition, capability to adopt, lifestyle, past experiences, and financial supports.

The informants chose the strategy of catheterizing because they had no urine leakage. Some who had a spastic bladder and took medication for enlarging the bladder, as well as another who was afraid of kidney complications also chose the strategy of catheterizing. They used this strategy with emphasis on their safety, doing as the hospital routine did, or at their comfort, and also conforming to their lifestyles. Catheterizing may be managed by informants, with or without help from family members. In addition, the strategy of catheterizing would use different techniques depending on their setting (inside or outside their house). The adverse effect of catheterizing consists of urinary infection, urethra injury, and lifestyle disturbance.

Some informants emphasized the rigorous, formal program of bladder management that is practiced in the rehabilitation ward. Since he had a urinary complication experienced with his own self or another, or he was just discharged from the hospital less than 2 years, he recognized that strict urinary care had to be done. He had to modify his life in the way that enabled him to achieve his self-care.

*I do five catheterizations a day at the same time they did for me at the hospital +- 30 minutes. I had to wake up at mid night for catheterizing. I drink not more than 2 liters of water per day as advised by the doctor. I didn't push it because*

*she (the health care provider) told me that pushing can cause urine reflux to the kidneys (11:9).*

On the contrary, one informant who sustained paraplegia 8 years ago, used this strategy conveniently by seeking a private place along the side of the road for catheterizing.

*When I go outside, I have to attach a catheter set with me. If there is a bottle or plastic bag, I would catheterize along the side of the road, for I keep going forward constantly (14:10-11).*

Most of the informants did not control water consumption and did not catheterize at a regular time. They also described a sense of voiding after bladder distension while urine began to flow urgently. Therefore, they have to learn to interpret by feeling their abdomen, observing bladder distention and a cool body. They may develop techniques to empty it before they have a sense of voiding. By observing body signals, it helps to determine the time to empty the bladder. This technique may be convenient to use both inside and outside their house, and help to prevent urine leakage.

*I know the time for urination. I felt my abdomen, if it is distended, then I will tap and press it out (12:12).*

*It is uncertain when to catheterize. If I drink too much water, I will catheterize several times. When I feel my abdomen and it is convex or distended, then I will catheterize (14:9).*

Many informants chose the strategy of catheterizing and condom because of urine leakage. Although they received medication for enlarging bladder volume, they still had urine leakage. Therefore, after catheterizing, they had to use condoms to prevent urine leakage.

*The doctor told me that my bladder had contractions. When it contracted the urine refluxed to the kidneys. So I had to take the medicine to enlarge my bladder. I catheterized 4-5 times a day and I used the plastic bag to prevent incontinence (8:3).*

*I have to catheterize in the morning and evening. Sometimes I had a sense of voiding but I couldn't hold it and the urine would flow out. I used a condom and a plastic bag after catheterization both at home and outside (5:4).*

Some informants used only condoms for maintaining urination. They described that they have less residual urine from the last follow up and the other reason is an occurrence of urethra injury led to a decision to change the strategy to maintain urination.

*I don't leak urine, but I couldn't suppress when I have a sense of voiding. Thus, I have to use a condom. I was examined by Dr..., he told me that residual urine of about 80 ml. was retained in my bladder (15: 8).*

*They (the health care provider) allow me to catheterize. I've catheterized for 3-4 days when I felt pain in the urethra, I stopped it (10:10). It is urine incontinence which flows down the plastic bag. I have no problem about that. If I drink more, it will flow more. If I drink less, it will flow less (10:5, 10).*

The last strategy is tapping, expression or strain. At the present, this strategy is not recommended to patients for bladder management in Maharaj Nakorn Chiang Mai Hospital because it may increase bladder pressure which pushes urine reflux to the kidneys. However, this strategy was used carefully five years ago. From this study, there are five informants who have experienced this technique. These informants have used this strategy in addition to condoms or catheterizing. They gave the reason for using this strategy as not having much urine and this strategy saved time.

*I catheterize in the morning and at mid night. During the day, I drink a little water (2:7). Thus, I don't catheterize at noon because there is only a little urine. I use the abdominal squeezing technique or strain it out in the toilet on the first floor. I don't go up to the second floor to catheterize (2:34).*

*Actually, the doctor told me to catheterize but I didn't do it because I had to work at the company. There was not enough time. I finished my work and got back home around 8.00 pm., I had to wake early and get to work starting at 07.00 am. So I had no time for catheterization (12:12). I just let it incontinent, and use the condom and the bag (12:2). I know the time for urination. I felt my abdomen, If it is distended, then I will tap and press it out (12:12).*

### **Maintaining Defecation**

Most informants could not feel when they have a sense of fullness. If unable to defecate, the informants have to require mechanical assistance including: unison enema, press on their stomach, stimulate around anus, and manually evacuate. From the interview data, they used two strategies together for maintaining defecation including: strain with manual evacuation, or stimulus around anus with manual evacuation, or enema followed by manual evacuation. They gave the reason that if they used only one method like strain, unison enema, or stimulate around anus, they always experienced of bowel accident, constipation, and autonomic hyperreflexia. However, if they added the method of manual evacuation after that method, they felt confident that they would not have a complication like that. Therefore, fear of complication, and past experiences were considered as the factors which influenced the selection of the strategy for maintaining defecation.

Manual evacuation is a strategy that many informants used to empty their bowels. After using this strategy, they felt confident that their bowel was empty. They may use only this strategy in the morning or evening at a regular time everyday or every second day. Moreover, they also used this strategy for checking empty bowel before going outside their house to prevent bowel accidents.

*About defecation, I have to remove it manually every day. If bowel does not move today, I have to remove it manually the next morning. Otherwise it will be very uncomfortable going outside of the house (5:6).*

Strain, stimulate around the anus, or enema followed by manual evacuation is a strategy that most informants selected to use in their daily lives. Some used only strain or stimulate around the anus for bowel movement but when they have constipation, manual evacuation was combined. They described that they used an enema before the method of manual evacuation because the effect of the enema provided feces softening that made it easier to manually evacuate. The time of the bowel movement procedure was the same as the above strategy.

*Normally, I use strain method for bowel movement. However, I had constipation sometimes. I tried to take vegetable soup and use a manual evacuation method. With this method, I could remove feces easily (10:22).*

*I had to do enema with unison 10 ml. After I did an enema, I had to remove it manually. If I do only an enema, it won't empty the bowel. And the next day it will be as hard as solid. I think, I have to pay attention to it. If I don't remove the feces until clear, I will have abdominal distension, headache, and sweating (8:7).*

*I normally evacuate at a regular time, around 11.00 pm. I take a bath on a raised seat toilet and evacuate at the same time. I wore gloves and stimulated around the anus. Sometimes, it passed out. In case of constipation, I had to remove it manually (15:8-9). I also checked the bowel manually in the morning before going out (15:9).*

Although having no sense of defecation, they noticed the elimination in daily life by observing abdominal features and feeling for it. They suspected that it would eliminate when their abdomen displayed symptoms such as abdominal distention, and a lump on the abdomen. This observation would help the informants know the time of elimination and they had to stay in their house to avoid the situation of bowel movement outside their house.

*If I'd diarrhea, I would know. There is a lump in the abdomen at the left side of my abdomen. I would have to hurry back home. If I still stay outside of my house, I will be humiliated certainly. If there is a lump on the abdomen when I stay at home, I won't go anywhere. I will only wait at my home (2:17).*

*Sometimes when I felt about the abdomen, there was...like a wave...lots of wave. I felt abdominal distention. It could be bowel movement. It is the time to go to the toilet (4:11).*

The consequence of learning self-care by maintaining physical functions included: maintaining mobility, maintaining urination, and maintaining defecation where the informants could be able to self-care with or without dependency on others, existing limited physical function, limited physical complication, and decreased working capability. Moreover, modification of their lifestyle and maintaining social participation were also the results of this strategy.

In addition, the informants perceived they had secondary complications, such as spasm, pain, pressure sores, and urinary infection. They needed to learn self-care in their daily life to control and prevent physical complications by spasm reduction, pain handling, maintaining skin integrity, and urinary tract infection prevention and care. They tried to control physical complications for health protection from the harm of the secondary complications that require a life-long process of management. These complications will likely diminish the overall health status and quality of life in the person with paraplegia.

### **Having Spasm**

Most of the informants perceived they had leg spasticity. The characteristic of spasticity is different in each individual, flexor spasm or extensor spasm. In general, changing position and coughing stimulates spasticity. In the time since injury,



infection (wound infection or urinary tract infection) may also influence the severity of spasticity. Severe spasticity causes the informants to feel discomfort, interrupted normal sleep, or it throws some of them from the wheelchair. A 31 year-old paraplegic man who has been paraplegic 8 years and often has pressure sore infection, reported the severe discomfort from spasticity:

*Some days my legs are tense all day. Some days it happens 4-5 times. When I lie down, both legs would be tense and pulled up to my chest. I feel like having cramps. It is rapidly gusts out and I want to cry and scream out loud. It gusts out like a crash of television. I feel exhausted like I am having fever (14:6). When I cough, the tension of my muscles will spread through my back and abdomen. I feel tight at the abdomen, waist and back. (14: 7-8).*

A 27 year-old paraplegic man who is a high paraplegic stated that he used to fall from his wheelchair because of spasticity:

*Regarding severe muscle tension, I was injured by falling from a flush toilet 3 times in two and a half years. That happened when I forgot to lock the wheel of my wheelchair while I moved on the toilet. Then it slipped, my legs got tense, and they pushed against the wall. My wheelchair was pushed away. I fell down and got a cut on my foot by the pedal of the wheelchair. (7: 26).*

The informants perceived the severity of spasticity differently. Some experienced mild spasticity (as they said it did not disturb activities of daily living), while others experienced severe spasticity (as they said it was interrupted normal sleeping or caused an accident). Therefore, they tried to control this physical complication by learning self-care with spasticity reduction.

### **Spasticity Reduction**

The informants tried to deal with their spasticity on their own by both preventing the occurrence and caring to alleviate the severity of spasticity. They selected the

strategy for reducing spasticity depending on their physical condition, and setting (time). For spasticity prevention, they tried to deal by carefully changing body position, and taking medicine. In the case of severe spasticity, they could not prevent it from occurring by these strategies. They used the method of binding their legs with ropes attached to the bed before they slept in order to prevent their legs from spasm and legs rubbing together which caused them pain and disturbed their sleep.

*Some days I got a very bad spasm. At night I got spasm once or twice every 3-4 days. The spasm was so severe I felt that I had a fever (4:3)...If I don't take any medicine, the spasm will be worse. However, if I take the medicine, it will be a mild spasm(4:5). When I lie down, I have to sit and then carefully lie down on my left side. Otherwise, it will be a severe spasm that my knees flex close to the chest and I will feel back pain (4:24).*

*When I was sitting in the same position for a long time. I would develop spasm continually (12:1-2)...Regularly when I lie down, I have to tie my legs to the bed. For when it becomes spasm, my legs will pinch together. I will feel hot between my legs. I must separate my legs when I lie down (12:15).*

Some informants have spasticity both from frequent spontaneous spasticity or induced only by stimulation such as coughing or changing body position. They tried to manage their symptoms by massaging, exercising, flexing the feet, and stretching the body. The result of care caused spasticity to subside, and they could bear it.

*I've spasm but it doesn't disturb me much. When it occurred, I would exercise by pedaling a bicycle. Most of the times, I would pedal a bicycle three times a day, in the morning, afternoon, and evening (10: 4).*

*When I first got up or start to get on the wheelchair, my joints may be stiff. They jerk a bit. Spasm also occurs when travelling. However, it doesn't disturb my daily activities. If it often occurs, I would massage, pull tip my feet, flex and rotate them. I will become better (13:2).*

*When I lay down, it would spasm by pulling up. I had to do like this ( bent body down and stretched his legs) and wait for a while, it would subside (14:5).*

Some informants knew the time their spasticity would occur. They knew by observing the physical symptoms and recognized the severity of spasticity caused

them to fall from their wheelchair. In particular, one informant persisted in their attempts to observe their symptoms which caused them to avoid accidents.

*I rarely confronted an accident from spasm because I would know before it occurred (12: 2). Before spasm occurs, it will start at chest muscles and gradually downward to the legs. My legs will be extended....then I have time to be prepared by holding the arm rest of the wheelchair firmly (12:12 ).*

### **Having Pain**

Most informants perceived pain as a significant problem. They have experienced pain at the back and the lower part of the body. Few informants perceived they have back pain. Back pain affected their lifestyle, wishful occupational training, and working outside their house. One informant described spinal injury and trunk muscle paralysis caused him back pain with prolonged sitting. A 26 year-old paraplegic man stated:

*My back seems to be crooked(2:6) and out of control(2:18). If I sit all day, I have a backache. I have to lie down in the day time. (2:3). Because of this, I couldn't attend an occupational training. The reasons are they had no break at the day time, and the trainees had to sit in a wheelchair all day. I couldn't do like that (2:6) I also couldn't sell lottery tickets as my cousin had persuaded me (2: 22).*

Back pain may also be associated with spasticity and caused one informant to stop all voluntary activity. A 33 year-old paraplegic man said:

*When my legs are tense and pulled up to my chest, it caused me a sudden pain like I am being poked by needles at my back (4: 24). This muscle tension causes me pain and made me feel bored of myself when I go anywhere. So, I decided not to leave home (4:31).*

Additionally, thirteen in fourteen of the informants reported that they had an experience of pain below the level of paraplegia, that is phantom pain or dysesthesia. They described the feeling of this pain like burning, numbness, tingling, cramps, stinging, or needles at the lower part of their body. Common sites distal to the lesion

included legs, buttocks, abdomen, and waist. The informants perceived that this pain occurred all the time. Some felt suffering but others can tolerate it. Nonetheless, it would exacerbate while their legs were exposed to cool wind or cold weather. Severe pain affected psychological condition, sleeping and lifestyle. A 33 year-old paraplegic man revealed:

*I felt a numb pain at the left side of my body. Though I felt normal on my right side, I can feel weakness in it. I felt like my body is separated. It makes me feel stressed and bored. (4:1-2). I didn't want to go to village fairs because of this pain (4: 30).*

A 31 year-old paraplegic man confirmed:

*I felt pain at night more than day time, especially, cold weather at the time of rain boosts this pain. Normally, I feel pain in both legs. I felt like stinging. I felt cold pain at night like I dipped my hands in cold water. It would be like that all the time. When it hurts, sometimes it makes me unable to sleep. Thus, I have to sleep in the day time instead (11: 14).*

Although some one had experienced stressful pain, a 39 year-old paraplegic man was able to deal with it.

*I felt burning pain at the waist, bottom, and below it. I felt it more at the waist, and that makes me feel uncomfortable. It hurts all the time, both day and night, but I could tolerate it (6: 32).*

Most informants in this study who had pain experienced both phantom pain and back pain. They tried to learn self-care by controlling pain symptoms with pain handling.

### **Pain Handling**

Each person managed pain differently depending on health information, setting (time) and whether it showed results. Regarding back pain, the informants perceived

back pain associated with spasticity while they had prolonged sitting or when lying down. Back pain was also related to their spinal lesion. The method of reducing back pain included lying down during the daytime, taking medicine and pressing on the pain site. Using the method of lying down during the daytime, the informants believed that it could prevent spasticity occurring which it was followed with back pain. Whereas other informant tried to use the later two methods for caring after back pain.

*Supposing I lay down, my legs will be flexed up. I felt back pain as well. It is like needle pain inside. I took two tab of antispasmodic drug. It still has the same symptom (4:24). If I don't take it, it will be a lot of spasm but if I take it, it will be normal pain and spasm (4:5). When I had prolonged sitting, my legs would be spasm, move up and down. It caused me back pain and discomfort. Therefore I had to lie down during the daytime (4:26:27).*

*When I'm sitting all day, I felt shooting pain at the back...at the broken bone. I would lean back down, sometime I let others press on my back. It would be relief. If pressed on affected site, it will be better (12:15).*

The other type of pain is phantom pain. The informants attempted to deal with this pain by physical management, taking medicine, and tolerance. These strategies were sought by themselves and the health care provider. The strategy which informants tried to use for self-treatment was physical management. This strategy included exercises, opening legs and bent down (stretching), lift-up, lie down on top of the pain area, and rub the pain area with cool water. They decided to use these strategies because medicine was not working.

*My pain is like numbness. This pain causes difficulty to turn position. I felt tense all over my body. I still have pain now. When I exercised by pedaling a bicycle 2,000 rounds a day. It may be pain for a while. After finishing it, I felt a lightened body and ligament isn't tense.....I felt better (10:1).*

*Sometimes, I felt pain until I had to groan with pain. I felt pain downward all through legs. I tried to find out the pain's site by pressing on legs. It is a pain like a cramp, and tingling. Sometimes I opened legs then bent down for a while, it would be better. When I lay down on a side position, we had to turn on the top of the pain area. It would be better. Thus, my position changed all the time (14:6-7).*

*I felt burning pain start from the waist both sides down to the buttock. I feel discomfort now. I have to lift-up. It would be better. At night time, I also had burning pain and it's pain like needle pain. I tried to move back and forth and rub waist area with cool water. It didn't recover, but I wanted only coldness providing numbness on the skin (6:32).*

One informant could tolerate it during the daytime but he had to have medicine for reducing pain in the nighttime. With managing pain differently, he described that he felt severe pain in the nighttime because his body had more contact with the bed, including his head, back, buttocks, legs, and feet, whereas during the daytime, his sitting position allowed the body to contact or press on the wheelchair only at the buttocks, and soles. The more the body area contact with an other object, the more he felt pain.

*Regarding pain, I use a tolerating method every day. During the daytime, I could tolerate with it because I feel pain only on the pressure area, especially, buttocks area. However, at night when I lay down, it has much of the tactile area, so it is more pain than usual. Thus I would take valium sometimes at night (15-6-7).*

### **Having Pressure Sores**

Eight out of fourteen informants reported that they have pressure sores while three informants used to have pressure sores and three informants perceived they had potential to have pressure sores. Most of them were the most concerned about pressure sores, because of their experience having pressure sores that took a long time to heal or they have seen from other patients in hospital. A 31 year-old paraplegic man stated:

*I used to have wounds caused by pressing when I was in the hospital for 8 months. Now, it is nearly healed but the skin still isn't firm. I'm rather afraid of a pressure ulcer, because of difficulty in healing. A cure took so much time until it developed a dry scab. I spent 8 months for curing it (11: 11).*

A few informants described that the causes of pressure sore came from forgetting to lift the body up, being injured from the toilet, and having shearing force on the floor of the house. Pressure sores usually occur at the lower part of their body, for instance; buttocks, coccyx, under upper legs, ankles, and toes. At the first time of observing, most of them saw blistering. When the skin broke down, it may be too late for them. Moreover, the impact of pressure sores on the informants involved psychological effects, occupation and lifestyle. Meanwhile, occupation itself created an opportunity to develop pressure sores. This consideration was reflected in a statement of a 36 year-old paraplegic man:

*I used to have a pressure ulcer after I came back to stay home in the first year. It is difficult to cure. I'm afraid of having pressure ulcer the most(5:16). Last week, I had a blister under my legs. So I stopped to go out selling lottery tickets. After it was broken, I thought, it might be healed. So I went back to sit for selling lottery tickets again. Only one day of long sitting, I saw my skin scratched at the broken blister. A day later, it became a hole and developed as a more than 1 cm. wide pressure ulcer (5:20).*

In this study it was evident that pressure sores are a significant problem for all the people with paraplegia. They needed to be aware and careful to prevent it from developing and also care when it occurs. Thus, the informants attempted to learn self-care by controlling and preventing this physical complication through maintaining skin integrity.

## Maintaining Skin Integrity

Maintaining skin integrity is a controlling and preventing physical complications strategy which has to continue throughout the lives of paraplegic persons. This strategy is composed of preventing and caring. The ability to maintain skin integrity depends on the context of past experiences, health information, physical condition, and setting (time and place).

Few informants who never had pressure sores, or used to have pressure sores, described how to prevent the development of pressure sores both at the day and night time. During the daytime, the strategies compose of awareness, lifting-up, shifting body weight, and applying skin with body lotion. To maintain skin integrity in the night time, the strategies consist of setting the alarm clock for turning the body with or without help, and bony prominence support.

*Sometimes I enjoyed working and forgot to lift up. When I realized it, then I lifted my body up. I have no pressure sore (8:9). I know that I have to be more aware of sitting, transferring, watching out for an ant on the bed (8:2). Regarding the skin care, I would touch my skin after taking a bath to see if it is dry. If it gets dry, I would apply body lotion over my skin (8:35).*

*I have no pressure sore. At night, I turned my body at the same time each night by setting an alarm clock (3: 5-6). I lie down on my side, and place a soft cloth between my knees and ankles. I am depending on my wife's assistance in turning my body. However, I could turn to prone and lie flat on the back by myself. I lift up around 4 times a day, less than one minute each time because I am heavy. If I feel discomfort with prolonged sitting, I will shift the body weight instead (3:16).*

Many informants perceived they have pressure sores on their buttocks and it occurred from forgetting to lift the body up during working or it may result from skin injury in the toilet. They described pressure sore requiring a long-term to cure, with the method of no prolonged sitting, dressing wounds, good ventilation on wound,



taking medicine, lifting-up, shifting body weight, turning body, prone position, checking buttocks with a mirror, preventing wound from being wet.

*I used to have a bit of pressure sore at the buttocks. I spent some time to take good care of it. I didn't sit too long. When I finish my daily activities, I will rest. Then I will dress the wound until it is clean and provide it with good ventilation and take an antibiotic. Moreover, I have to lift up once every 1-2 hours. If I travel a long distance, I will move my body, to the left and right. Sometimes, I used the mirror to examine my buttocks (13: 2-3).*

*At present, I have a pressure sore on my left buttock. It was a wound injury from a flush toilet's seat cut the skin. It is not healed yet. My sister and my girl friend dress the wound in the morning and evening for me (7:9). I had to take a bath every other day to prevent the wound from being wet (7: 12). I tried to take good care of myself. Now, it is nearly healed (7:24).*

### **Having Urinary Infection**

One of the complications which most of the informants perceived repeatedly is having a urinary infection. Some informants noticed that they had a urinary infection several times after being discharged from the hospital. They described the signs and symptoms including abdominal discomfort, cloudy or red urine, bad smelling urine, and having much muscle spasticity. They described urine retention and improperly doing catheter is a cause of infection. A 26 year-old paraplegic man stated:

*I assumed that I got a urine infection when I noticed a cloudy, smelly urine. My stomach felt like it had something stabbing inside it. I was in pain and suffering. I had a urine infection 3 times after I went out of the hospital. I thought the cause of infection may be from my habit of going out traveling. I often traveled not far from my house and didn't come back home at noon for urination. I would skip it. Urinary infection may be occurred. Now I have to be more careful about myself. (2: 8, 29).*

A 29 year-old paraplegic man, who observed a lot of muscle spasticity while he had a urinary infection, said:

*Since I left the hospital, I have had urine infection once. I knew it might be from the fact that I didn't wash my hands before catheterizing. I got a mild fever and had a lot of muscle tension. While I lied down, I felt a sharp pull in my muscles. Then I felt abdominal pain, and pain at the bladder. My urine was also cloudy (13: 6-7).*

One informant who had frequent urinary infections reported that urinary infection affected his emotions and earning income and it usually happens in the summer time.

A 36 year-old paraplegic man said:

*If I have an unclean catheter, it will cause frequent infection .If I have a fever for 2-3 days, my urine becomes red. In the summer time, it is easy to get a fever. I don't know why (5:2). While I had a fever and lied down, it made me think so much about anything. I thought what should I do for my life. Why I had much complication. I felt discouraged and depressed. I felt useless and worthless (5:14).*

Having urinary infection is a serious complication. It disrupted the physical and psychological health status and other aspects of life. For maintaining health status, the informants tried to control and prevent this physical complications by learning self-care with urinary tract infection (UTI) prevention and care.

### **Urinary Tract Infection (UTI) Prevention and Care**

The prevention and care of UTI was a strategy used by the informants and their family members to maintain health. Most informants had UTI experience before the time of study. Therefore, past experience and health information would influence them in selecting the strategy to deal with UTI or preventing UTI. UTI prevention included observing the appearance of urine, drinking a lot of water, and catheterizing carefully. The method of prevention was rather effective.

During the time of study, some informants who used to have severe UTI experience, described the method of UTI observation for prevention.

*I used to have urine infections one time when I had a bladder stone after my first discharge from hospital (8:4). After that I had never had urine infection (4:25). It may be careful catheterization which led me to have no urine infection. I would be careful when I held the catheter and didn't let it touch other places. I would let it touch only my urethra (8:24).*

*I thought I haven't had a urine infection and no fever. If I've infection, the urine will become cloudy and a red color. Most of all I used to have cloudy urine, but no fever. I used a method of drinking a lot of water. I brought a canteen attached to myself all the time. When I saw cloudy urine, I would drink 2-3 glasses of water. My bladder seems to be small, after I drank water for a while. Urine will flow out. It likes to treat by itself (12:13).*

Some abnormal symptoms were not easily recognized by the informants. Exceptionally, he monitored his own physical over an extended a period of time, asked the health care provider, or read from a handbook. He could predict urinary infection by observing another symptoms. The benefit of this observation body signals helped to cure it immediately.

*Normally, we read a handbook....If spasm occurred, it showed that something went wrong. We know from the handbook what was the cause. It is no good to delay. I told her (his cousin-health care provider) about it. She said take this medicine and I didn't have to admit at the hospital. I used to have urinary infection only once (13: 7).*

Because of having UTI frequently, some informants talked about an attempt to seek the way to treat themselves with or without assistance from a health care provider. The process of urinary care started with the informants observing the color and smell of urine, and assumed that it might be an infection. If it is cloudy and has a bad smell, they will try to treat themselves by taking an antibiotic which is bought from the drug store and stopping to work for rest. If the result of self-treatment fails, they will decide to treat in the hospital. This management usually got support from

their family members for buying medicine or taking them to hospital. UTI might occur many times in some informants. Therefore they learnt how to care for their urination.

*I assumed that it was urine infection. I observed that the urine is cloudy and had a bad smell. I let my mother buy medicine from the District Health Center near my house. I took paracetamol but it didn't recover. Then I went to ...the District Health Center (The large center), I got and took a highly effective medicine. I would recover but turned to be fever again. Lastly, I decided to cure at...hospital. The doctor prescribed antibiotics. I took it and recovered (2:8-9).*

*I used to have fever from bladder infection (5:2). The first time of infection is a normal fever. When I took paracetamol, it had recovered but incompletely. I began to know, it was infection approximately 2 days later. I would be cold and shivering. If I've antibiotic drug (he always keep medicine at home), I will take it and stop working for rest. I cured myself until it was recovered (5: 35). Unless fever is subsided, I would meet the doctor (5:20).*

The consequences of learning self-care through controlling and preventing physical complications by spasm reduction, pain handling, maintaining skin integrity, and urinary tract infection prevention and care were limited physical harm and decreased working capability.

After getting spinal cord injury and being paraplegic, the informants had to face with permanent physical dysfunction and secondary complication for the rest of their life. This situation caused them to need to learn self-care by maintaining physical functions, and controlling and preventing physical function in order to survive and be able to live in daily life. Although the outcomes of learning self-care were limited physical complications, maintaining social participation, and some were able to self-care without dependence on others, most of the informants still had limited physical function which caused them to be dependent on others for self-care, decreased working capability, and modification of their lifestyle. That is, this negative

consequence became a part of the next life perception which caused self-alteration from the self as “being ill” to the self as “being disabled”.

### **Perceived Self as “Being Disabled”**

With physical dysfunction and having complications, the informants perceived themselves not only as being dependent on others concerning physical, emotional, and financial supports but also perceived a decrease in their working capability which led them to financial hardship. These situations caused them to recognize that they could not help themselves at all. They perceived themselves as a metaphor for being unable to do anything as before and dependency like the self as “being disabled” as the general culture perceives the idea of disabled. The perceived self shifted from the self as “being ill” to the self as “being disabled”. For maintaining their living, they tried to learn the system of care and support to meet their needs. Therefore, the perception of the self as “being disabled” which directly influenced the strategy of learning the system of care and support is perceived as being dependent on others, and perceived decreased working capability.

### **Perceived Being Dependent on Others**

Although activity of daily living (ADL) achievement is a criteria for discharging paraplegic patients from a rehabilitation ward, most of the informants were faced with inaccessibility in house and community, complication such as pressure sores, severe spasticity, and unemployment, and having to depend upon significant others to meet their basic needs. They perceived being dependent on significant others in physical

care, bringing them to meet the doctor when they got ill (having urinary infection or having pressure sores), and financial resources. Family and public's attitude also stimulates this perception. This situation places enormous stress on the informants whom have taken responsibility as the worker role of the family. Their life changed from an interdependent role between family members to dependence on family members.

A 39 year-old paraplegic man who stayed with his wife talked about his situation that made him stressed.

*My life....I feel bad now. When I got up in the morning, my wife cooked for me and went outside to work. I'm unable to do anything and waited for her to help me (6:7). Sometimes I want to die to escape this problem (6:10).*

Realizing that dependency causes a reassessment of self worth as a person and can lead to uncertainty about accepting support from his cousin when some day they may lose of support from his mother, a 26 year-old paraplegic man recalled:

*I have not planned about my life. If my mother dies, I will die with her. Today, I live only for my mother. (2:28) I am able to stay alone, but I felt uncomfortable. When I wanted something, or needed to take anything, it is hard. It is such a pain. It may be difficult to ask my uncle for help and I felt that I don't want to bother him. I can depend on my uncle, but I'm afraid that he hates and is displeased with me (2:37).*

The worries about dependence were often compounded by fears for the future. A 33 year-old paraplegic man who lived with two sisters who were willing to help him, spoke about such concern:

*I could hardly do anything. If I had no sisters what would I do?. When I defecate and need to wash dirty clothes, who will help me?. I always think, if some day they were not with me anymore, what would happen to me? (4: 16).*

### Perceived Decreased Working Capability

Perceived decreased working capability was apparent in all informants. The perception of decreasing working capability caused them not only to be unable to continue to their previous job, but also unable to get a new job. They reported that barriers to returning to get a job included: physical limitation, inconvenient mobility or travelling, inadequate assistance from institutes, uncertainty about a job, family overprotection, lack of information about employment opportunities, and get less income (financial disincentives). These reasons caused them to lose a job and led them to have financial hardship. Consequently, family members or their wives have to have responsibility for earning income.

A 39 year-old paraplegic man used to work as a mason and farmer. Now, he does not work and stay in the house waiting for his wife to earn for the family. He expressed how his capability of working was decreased.

*After I got into an accident, I could only stay and watch the house like this. I couldn't work as before. I couldn't go far away from my house. My wife and my cousin were concerned about me getting harmed. I did not know a job for me to do. I was unable to think of it (6: 21). Everyday my wife goes out for working but I have no job. I am not responsible for anything (6:17).*

The kind of previous job is difficult to return again. A 39 year-old paraplegic man whose previous job as a construction employee, complained of no job and no assistance from the government.

*Previously, I used to work as an employee, working as a construction worker. In evening, around 17.00 o' clock, I would leave home seeking for small frogs, crabs, and fishes for selling (10:17). After I got in an accident, I was in trouble. My finance is in crisis. I've no job. I lived like this without any body or organizations to help me (10:1). My wife had to go to work as a construction employee instead of me (10:30).*

A 25 year-old man who had high paraplegia and worked as a company officer before, described how his life reversed itself after he got in an accident.

*My daily life has changed. Normally, I'm a salary man. I graduated at a higher diploma level (vocational school). I had a permanent job, and had high income. That is, I worked in a stable company. Suddenly, when I got in an accident, I changed from a person who had a job and income to a person who had nothing, except income from social insurance (7:3).*

A 36 year-old paraplegic man recalled his work life before his accident compared to his current situation.

*At first, I was a salesman in a famous drug company. I had authority over two areas, Central part and Northern part (15:3). What has changed now is I lost my job. In reality, there are many things which I could probably do but I lost those opportunities because of difficulty in traveling (15:14).*

With a perception of self as "being disabled", the informants tried to secure themselves by learning the system of care and support. They required physical, emotional, and financial assistance from significant others in order to sustain their life with less threat and a fulfilling life as much as possible. With hope for life better and recovery, they tried to seek care from alternative treatments, technology innovations and health professionals. They also needed a job and financial assistance from the government. This management of life was moving out from emphasis on self to their family, health care system, and society around them. The strategy of learning the system of care and support means a cognitive and behavioral strategy which was management of life changes by seeking or accepting supports to replace the ones that they lost the capability to get to meet life demands. The properties of this strategy are composed of seeking and accepting supports in aspect of basic needs, job and finance, and physical treatment from other resources. The informants used this strategy by themselves with and without significant others' assistance. This strategy required an



effort of the self and family members to tolerate, adapt and attend to manage. The strategy of learning the system of care and support involves seeking and accepting necessary support from significant others, seeking governmental support, and seeking alteration treatment and professional suggestions.

### **Seeking and Accepting Necessary Support from Significant Others**

When the informants treated themselves as “being disable”, most of them expected and accepted support from significant others without asking all of the time and / or believed that significant others should know what a person with disability can and cannot do. The factors that influenced their consideration to seek and accept support from significant others is sociocultural attitude, financial resources, and family support. Some informants felt their acceptance of support responded to a family member’s concern towards them. However, the possibility that a family member may have to obtain more employment and take on additional roles, while at the same time their caretaker burden has increased, may make the informants feel extremely guilty, and feel low self-esteem. The strategy of seeking and accepting support from significant others included physical support, emotional support, and financial support.

**Physical support.** Although most of the informants were able to be independent in activities of daily living, many of them needed physical support. Physical support refers to the care of the physical, meals, clean clothes, and activities of daily living from family members. The reasons that caused them to seek and accept physical

support is the need to prevent physical complications, hope for recovery, and an inaccessible house. The family members understood their situation and continued to provide support with an open mind.

One informant who lived with his wife, has accepted physical care, and the serving of meals from his wife. Although he felt a burden for his wife, sometimes he felt he received love from his wife and had value in the family.

*I would call her every three hours for turning position at night. She also emptied my urine out in the morning. She was a good wife and didn't complain about anything. Previously, I said to my wife "go away, you needn't to stay with me", but she didn't go, she might love me. We have stayed together. If we've something to eat, we will eat together. If we have nothing, we won't eat together (6:34).*

Similarly, one informant emphasized Physical Therapy because he recognized the benefit of Physical Therapy. His family understood his need and provided support for him in almost everything.

*Previously, I was able to walk after out of hospital for 10 days (4:1). But now I couldn't walk after a long time lying down in the hospital for treatment of pressure sores (4:2). Now, I stay with my two sisters (4:11). My sisters have helped me with everything such as going outside, help for walk training (9), washing soiled clothes (4:16).*

Another informant who lived with his parent, expressed the necessity of accepting physical support from his mother for protecting him from complications or accidents.

*Sometimes my mother had to help me transferring to the bed. Sometimes my wheelchair would probably slide, my mother must support me. She didn't leave me alone (5:1).*

Since one informant lived in an inaccessible house, he had to seek and accept physical support from his sister.

*At night, I catheterized by myself, but I needed my sister to prepare the equipment of catheterization and help me clean my hands. In reality, I could do this but my house is narrow and it was difficult to do it all by myself (8:11).*

**Mental support.** When the informants were unhappy and discouraged, or hopeless concerning their physical disability, they accepted mental support from significant others. These people made them more comfortable in their mind by providing positive opinion, consoling them, and explaining the worth which they had to the family.

One informant who felt worry and hopelessness about his disability became happy and had a hope after accepting mental support from his friend.

*When I came back early from the hospital, I told my friend I could not walk again. One of my friends said that you had to walk again because your legs are not missing. You have two legs that you can see. Amputated legs means unable to walk but you still have legs. I agreed, I have legs I can see, at least. One fine day, I may walk again. I felt in a better mind (7:17).*

Another informant believed that he was rapidly recovering (mental recovery) and had morale because of his wife's assistance.

*I thought my wife is partly important for me. She was my morale and being a person to hold my mind. If I have some problem which caused me unhappiness, I would consult her. I thought I was able to go forward because of her help. I thought I was able to live because of my wife (9:18).*

Similarly, one informant talked about mental support from his cousin when he was feeling unhappy. This support made him believe he still had love from his cousin.

*Most of all, my cousin took part in mentally supporting me, when I was discouraged and depressed. They would observe and know if I was unhappy. They consoled and encouraged me that made me forget unhappy matters. I thought that I have a cousin who loves me, at least (8:11).*

**Financial support.** The informants had to seek and accept financial support from family members because they could not work from physical limitation, inaccessible transportation, and family member concern. The strategy of seeking and accepting financial assistance may cause them to feel guilty, and increase their dependence on other, inferiority than other and perceive changing in relationship with significant others.

One informant who was the youngest child living in an extended family talked about the parents' attitude and the reason for accepting assistance from them.

*My mother gave me 20 baht a day. If I run out of money, I will request more. Mother had also bought trousers for me (14:22). Now, I didn't think about a job. I stay like this everyday. If I do something, my mother forbade me to do "don't go to work, you needn't do anything, you have eaten". She feared for me being in trouble and uncomfortable. My father has also thought the same (14:39).*

Another informant depended on his wife, and sometimes his cousin especially, for financial support, until he felt inferior to his wife and low self-esteem.

*Everyday I'm not responsible for anything. I only stay at home and wait my wife to come back from working. I thought I was a burden on her (6:10). It was compared with "a fledgling is waiting for his mother to feed rice". Previously I was a leader, like men were compared to the front-legs of an elephant but now, I'm the tail of an elephant. I saw myself like the breath of an other, able to live because of others support (6:17). My financial is in trouble (6:34). Sometimes my elder sister visited me she gave me 100-200 baht for buying some food (6:15).*

Similarly, one man who sustained paraplegia one and a half year ago, employed most of his time to think a lot concerning his own self and was depressed. He felt guilty and had low self-esteem, and sometimes uncertainty about his sister because he had a dependent relationship with his sisters in everything, especially, financial.

*I have stayed with my two sisters (4:11). I could not do anything and only sit and lie down here everyday. Previously, I never made any body trouble like this. I could earn income for the family, but now, my sisters have to be responsible for all my expenses. I have no money (4: 18). Sometimes my sister left me 3-4 days for her business. It made me think a lot and have an uncomfortable mind (4:41).*

Another informant who was unemployed and stayed with his mother in a high and narrow house, described that he accepted financial support from his mother and his brother. After receiving a lot of support, he planned to earn income for his family. However, after consulting his mother, he found that his mother did not trust his capability like before. It showed that their relationship had changed.

*I have to depend on my mother for everything now. Everyday she has to work as an employee, and cook, wash clothes for me (12:9). She could earn income but not much in daily living. My brother sent his salary of 3000 baht per month to our. Sometimes I would like to work outside for earning income. When I consulted my mother, I found it was difficult to approach her to trust me 'I can do'. Sometimes we quarreled together about working (12:20-21).*

The consequence of the strategy of seeking and accepting necessary supports from significant others was being dependent on others, low self-esteem, perceived inferiority and changes in relationships with significant others. However, the informants still had a comfortable mind, and maintained self-worth, morale, and hope.

### **Seeking Governmental Support**

Five informants were not employed during the time of the study, and it is recognized that their financial consequence may be deleterious. Some of them were the head of the household, while others were living in households where other family members had sources of income. Living on limited income, most of them have tried their best to seek governmental support. Seeking governmental support is the strategy

of seeking the way to obtain an income through claiming disability benefits, and through vocational training, to replace the loss of income after paraplegia. The conditions which influence one to use this strategy are disabled supporting policy, physical condition, resources (training information, transportation, and financial resources), and parents' attitude.

**Claiming disability pension.** Most of the informants perceived that they have to depend on their family for the cost of living because of their unemployment. These informants tried to seek financial resources by claiming disabilities pension with assistance from family members. This method depended on the disabled supporting policy and family support. In this study, it was found that four of the informants were not receiving disability pension after they proposed a document for pension. They were told that there was limited and inadequate budget for disabilities. Ten informants were not claiming disabled pension because they ignored or did not know about the information. However, there were only two of the ten informants receiving work pension (social insurance) and four of them received unemployment benefits from an insurance company every three years.

During the time of the study, three of the four informants gave up claiming, whereas one of them still waited. Only one informant who had applied for a disabled pension for 3 years, pointed to the system of claiming benefits. He is expecting to get a disabled pension this year.

*My mother told me that I may get a pension this year. The first year, the district health volunteer was surveyed and District Administrative Office was surveyed again. Then, they sent my documents to the District Public Welfare office and Provincial Public Welfare office in the third year. I expect that this year I will probably get a pension (8:8).*

Others reported major delays in the process. The process of claiming causes difficulties for the informants and their families. One informant said:

*It has still been quiet for 4-5 years (I4-45). I was informed that the District Administrative Organization (อบต.) would provide money, or pension for the disabled. They notified that I should give. I applied for it last year, and I still haven't got it now (I4:19). I never got anything, after I applied for it.*

Not only the lack of budget about disabilities benefit but also the delays and uncertainties of the legal process may create profound personal and family boredom. One informant who proposed documents for benefits two years ago, has still not received a disability pension but received an unwanted wheelchair replacement.

*My sister applied for assistance from the Provincial Public Welfare office. They told us that there is a pension of five hundred baht a month, but now they have no budget. We did not mind because we knew about the bureaucratic system. Like, the District Administrative Organization, they told us that they would help us. It caused us turbulence...they wanted many documents. I applied for it...4-5 months it was quiet, and one year, it was still quiet. With no progress, why did they request many documents? They made us waste time and boredom (4:19). Despite asking for it, I still get nothing now (2 years later). They gave a big wheelchair for me, but it wasn't appropriate for me. I told them I couldn't use this wheelchair (4:39).*

There was also a problem about the basis on which decision regarding entitlement to particular benefits are made. One informant who had applied for loan investment 3 years ago found:

*I applied for a loan 3 years ago and now I've not received notification. I also applied for a disabled pension but they refused it. They told me that when you got a loan, you wouldn't get a disabled pension. Now, I don't get both a loan or a disabled pension (6:13).*

**Vocational training.** After paraplegia, all of the informants perceived they lost their job and it was more difficult to get a job, keep a job and to obtain the kind of jobs they desire. Many informants tried to seek support from institutes by looking for

retraining programs at vocational training centers. At Yardfon Vocational Rehabilitation Center for the Disabled Chiang Mai Provide, there are four sections for vocational training including: computer usage and repairing, radio and television repairing, clothes making, and artistic work (such as drawing). Each course involved six months to one year for training. During this study, two informants applied for training already, whereas four informants had a plan to train but one of them had no information, and three of them were forbade by their parents and wife.

Despite applying for vocational training already, one informant explained the reason which prevented him from retraining.

*Previously, I applied for retraining at ....center. They told me they would call me back...but now they still haven't notified me...I applied again at ....center. I applied for retraining already. They asked me the place I wanted to go. However, I thought, I didn't learn any more, because that center didn't permit to lie down in the daytime, and I had to sit in a wheelchair all day. I couldn't do like that. My back didn't like it. I felt it had a curve (2:6).*

Similarly, an other informant who worried about his family, described the reason which was a barrier to vocational training.

*The most important thing is "I would like to work" but I didn't want to work outside. If my house had not any body there, I won't go anywhere (10:7-8). I used to apply for training in television or radio repairing at.....center. However, it was too long a time for training. During that time, my wife had to stayed alone(10:12). I was worried about some cousin who was addicted, that he would assault my wife (10:25).*

The results of the strategy of seeking governmental support was that most of the informants had still not received disabled compensation, and had no chance to practice in vocational training. They were also dissatisfied with the disabled support system.



### **Seeking Alternative Treatment and Professional Suggestions**

The strategy of seeking alternative treatment and professional suggestions was initiated at the first discharge from the hospital until now. This strategy was used by the informants with or without help from family members and his friends to increase hope for recovery and correct dysfunction. During this study, half of the informants had a hope of cure and hope for their physical condition to get better or someone ever had a hope for full recovery. These informants and their family tried to seek alternative treatment and professional suggestions which could assist them to reach their goal. Some informants who had a hope for pain diminishing or hope that nothing got worse, also used this strategy. Some said that they did this strategy in order to reduce stress from feeling useless and helpless. They sought support resources from alternative treatment, technology innovations, and health care professional consultation, as it was believed that these resources provided extra assistance for them. They used these strategies under the context of health belief, health information, financial support, social / family support, and hope for life and for recovery.

**Alternative treatment.** After being discharged from the hospital, some informants were faced with uncertainties regarding their recovery. Most informants and family members attempted to seek treatment for their chronic condition, and still hoped that they would find a cure from alternative therapies. Alternative therapies generally employed in this study included: traditional Thai medicine (herb, holy water, tread on the body), traditional Chinese medicine (acupuncture), and Yore. The

informants in this study described the obvious reasons that they employed alternative therapies: the current medical therapy can not help, performing as a various advice, paying less, and family member requirement. Alternative therapies were intensely utilized in the first one to two years after paraplegia occurred and gradually declined until they ceased to seek it. However, some of them still sought it continuously.

Some informants talked about how to use herbs and they used herbs continuously because they felt better, or better than doing nothing.

*My sister bought herbs one hundred baht a pack from... (district) hospital. Took it steam and then compress with hot pack and massaged on my legs.... If my sister doesn't go anywhere, I will do it everyday... I felt it's better, although it wasn't effective one hundred percent. When I had spasm, I compressed with an herb hot pack. It became warmer. My sister massaged and raised my legs. Actually, I didn't know what is effective, but I thought that it is better than lying idly. I didn't know what to do. When I went to the hospital, the doctor only prescribed medicine and gave me an appointment note (4:32-33).*

*During the first one to two years, my mother sought an herb for compressing on both legs. Sometimes, my mother soaked my feet in warm water. Now we rarely do this because she has no time (8:38).*

One informant has employed many kinds of alternative therapies since the first day of discharge from the hospital until now. Although later he knew the nature of his disability and did not want to seek alternative therapy, he complied with his father who wished him to continue treatment by seeking alternative therapies for him. His father believed that his son has gotten better.

*Initially, when I went out of the hospital. Other told me that there are, a treading upon legs" at..... I went out of the hospital and continued to go there. He (Alternative practitioner) trod on hot iron and then trod on my legs. It wasn't better. I felt I had better from acupuncture. During that time I could walk with a walker (14:38,1 )..... (Father) I took holy water from a well at.... I waited for a half of a day. (Informant) I didn't want to do it anymore, it wasn't better. (Father) Although it wasn't much better, it was gradually better... I didn't know which one is good otherwise you couldn't walk like this (14:33).*

However, after many informants and family members attempted to treat with alternative therapies over a period of time, they ceased these therapies. The reasons they ceased alternative therapies were the doctor telling them to, or uncertain about which one caused the body to feel better.

*The first time the doctor told me to try to wait 2-3 years for recovery. That time, I sought and met many practitioners; traditional practitioners, and modern medicine. After the doctor told me, I was unable to walk again, I would stop seeking other treatment (3:19).*

*I went to many places. I met many practitioners, many methods, many places....When I went to...hospital, the doctor let me Tum Jai. He told me like that. Now, I stopped to seek other treatments (9:20).*

*After I was out of the hospital, I stayed at Bangkok for a while and went to Surat Thani to meet a Chinese practitioner. After that I went back to Chiang Mai for acupuncture here. I couldn't tell which is good. It wasn't different. That is, I couldn't differentiate because I'm familiar with it, then it felt better, or it was because of acupuncture (15:2).*

**Technology innovations.** The expectation of technological innovation is also a strategy of seeking alternative treatment which the informants have used as a resource of hope regarding their progress. They expected that the progress of medicine and technology in the present or in the future, such as put a microchip inside the body, tissue from cloning, and omentum graft at spinal cord, can extend the capacity of their body until they can walk again. All of them knew technological information from some media, academic journals, and conversations between their friends.

After one informant felt discouraged from his condition, he was more encouraged by the new technology medicine for one superstar's treatment.

*My spinal cord was torn already, this point caused me hopelessness. However, now I may have more encouragement, I may be can walk again. I hope with the doctor whom Superman talked about. He told that he may walk again in 5 years, because he put a microchip inside his body. I saw from TV. Thus, I thought that I may use a microchip (2:27-28).*

One informant had a diagnosis of a spinal injury with no fractured spine. He graduated with a bachelor's degree in political science and is now living with his younger brother who is a doctor. He accepted that he has hope for recovery, whereas he has tried to follow the information of technology medicine.

*In deep reality, I believed that every body (disabled person) though.....I followed for reading "Spinal cord" journal all the time. It is real. It could be an experiment in animals for both putting in a microchip and doing a spinal cord omentum graft (15:13).*

In a conversation between one informant and his friend, technology medicine was one issue for discussion. He said:

*My mind is better now, but I still feel bad because I don't know the time when I will recover. I always argue with my friend about new issues. We followed information concerning recovery. My friend tried to tell me about cloning. I thought, it probably has a spinal cord transplantation because it comes from the same cell (7:21).*

Another informant imagined that his body could be taken over by technology, like a robot.

*I thought about future technology, and then I have a hope. Some one may create a robot and then put our body inside a robot and control it by remote control for walking. Even television has a remote control for controlling it (8:37). I hope to walk again. I hope the method lets me walk (8:40).*

**Health professional consultation.** The informants sought how they could deal with their physical problem from health care providers as they believed that health care providers were the only ones who knew about their problem and could help them. Especially the informants who had a cousin or friends who were health care

providers, had a high chance to consult about their physical problems. The outcome of consultation led to one not needing to go to the hospital whereas another learned how he should practice.

*I used to have an infection one time. I knew from a handbook ...it was spasm, showing...may be something wrong. I told (his cousin - health care professional). She suggested me to have this medicine. I didn't need to go to the hospital (13:7).*

*My friend is a nurse at....hospital. She often has visited and suggested how I should to do...what I should take for medicine, or why I should take more valium (7:6).*

Of those interviewed, only two informants sought about sexual information. One was preparing to marry, whereas another lived with his wife. These informants said that they had a chance to meet a foreign male doctor, leading them without a sense of shame and able to have a more open mind. They could get access to information about sexuality and knowledge about the effect of a specific disability.

*I used to meet Dr.....He is a foreign practitioner. We were able to have a more open mind, being the same male, it was easy to talk about this topic. Frankly speaking, this topic is pretty important as well. However, we could resolve this issue less than one hundred percent. I tried to do but it couldn't work like a normal person (9:19).*

*I spoke with ...(disabled person) and Dr....I believed it is a normal matter. I spoke with Dr...If I know some one who had been like this, I will suggest to meet you. He is a rather up-to-date doctor. I met him at a later time. He told me about the innovation of medicine which was discovered in Egypt (15:26).*

The outcome of the strategy of seeking alternative treatment and professional suggestions was the informants felt better than if they did not perform anything. They had a hope for recovery but one decreased hope that nothing would get worse and he would be able to work again. Moreover, they could have more self-care after professional consultations.

The perception of the self as “being disabled” caused the informants to try to learn the system of care and support by seeking and accepting necessary support from significant others, seeking governmental support, and seeking alternative treatment and professional suggestion in order to maintain their living. The consequences of these strategies were not only creating a comfortable mind, morale, maintaining self-worth, maintaining hope, and increasing self-care capability, but also increasing dependence on others, low self-esteem, feeling inferior, changing relationships with significant others, and being dissatisfied with the disabled support system. The latter group of consequences would become part of the next conditions that led the informants to perceive the self as “being a disabled person”.

### **Perceived Self as “Being a Disabled Person”**

Due to a settlement with their spinal cord injury, the persons with paraplegia were able to re-enter outer society which allowed them to organize their social group around their paraplegic needs. Throughout these situations, the informants perceived themselves as still being dependent on others, and being a burden to others. This condition also added the prejudiced social attitude towards disabled people. They may be seen as useless, and dependent on others. This attitude caused others to discriminate against the person with paraplegia. The others’ attitudes do appear to have a significant influence on their self-conception of the informants interviewed. They perceived a negative view of the self as their physical and capability was different from normal people which led them to perceive a change in relationships with significant others. This included the opportunity for parenthood, marriage, and

friends were decreased or lost. They thought that they were unable to achieve a “normal” life as before paraplegia. Therefore, it was easy to recognize themselves as “being a disabled person”. In this period, the perception of the self as “being disabled” change to the perception of the self as “being a disabled person”. This identity view was manifested when they perceived inferiority, discrimination from society, and a change in their relationships with significant others.

### Perceived Inferiority

The perception of inferiority was a view of their self toward their own self. It was engendered from the feelings of worthlessness, and being different from others. They perceived worthlessness when they were unable to do anything, lost their job, or suffered from complications. The result of this feeling caused them to be bored and discouraged which led them to sometimes have suicidal thinking.

A 39 year-old paraplegic man who had lost his job as a consequence of the accident, also feels that he was written off.

*Since I had an accident. I can't work. I've been at home everyday. What can I do ? (10: 7). I want to work but I can't. Sometimes, I tried to do things but I couldn't do it (10:8). I feel bored of myself. I saw myself as 'useless' and 'worthless'. I'm afraid my family will not accept me. I want to die to be free from this misery (10:7).*

A 36 year-old paraplegic man talked about his suffering from having a urinary infection frequently.

*Sometimes I was discouraged, and despaired about living. I had been like this, and had a lot of diseases. Why did it happen to me?. Sometimes, I feel discouraged, and feel worthless. I told my friend to get his lottery tickets back. I didn't want anything in this life anymore. My friend said, 'if you committed suicide, I will not come to cremate you' (5:14).*

A 39 year-old paraplegic man who depended on his wife for everything said:

*I couldn't do anything. I saw myself as worthless already. I felt pity for my self and my wife (6:9). Sometimes I would like to die. I was living as being a burden to my wife. She looked after me like her children (6:10).*

The informants may have felt inferiority when anyone asked questions about the disability and in this way communicated one's feelings about the disability to the person. It is visibility that makes intrusion easier, an intrusion that the informants may feel more powerless to control. A 26 year-old paraplegic man who has been paraplegic for 6 years, said:

*I thought that others may look at me in a rather bad way. They have already seen me as disabled. (2:5) When I attended my friend's wedding, I felt outstanding in the ceremony. It seemed like others are insulting me, looked down upon me. I could see it from their eyes. (2:25). When there is a village fair, I had no interest in it. If I go there, I will be inferior. I didn't like others to ask me in a ridiculous or satiric way. I could catch from their voice, 'You have been like this, what will you do next?' 'It was such a pity! person like you have to lose your future.' I felt terrible. I didn't want to hear it (2: 25).*

Most of the people with disability might be sensitive to the sight and voice of other people while they have social interaction. The perception of inferiority may occur from the change in body image which was different from other people. The difference created the feeling of inferiority. This evidence was confirmed by a 36 year-old paraplegic man who said:

*When I visited Night Bazaar. I had to face with the eyes which could be understood that I was different from other and didn't belong to this society (15: 20). I disliked to go outside (15:21).*

A 30 year-old paraplegic man whose family was rather rich in the village and had a job as a policeman before, stated:

*This village had only a few persons who are like this. Everybody stared at me as if they are saying 'you freak', like I was a strange man. Some societies are good, such as, at the airport. Such people didn't stare at me like this (9:23).*



### Perceived Discrimination from Society

The perception of discrimination from society was a self-perception that came from the informants interpreting others' reactions to them. It may happen when the informants have to face with the attitude of other people, who impose on them stereotypes which inappropriately define their capacities and attributes. The perception of discrimination from society is related to the inability to control the situation and maintain meaningful relationships. They may find themselves receiving condescending looks, being ridiculed or teased from the neighborhood. It was evident in a statement of a 39 year-old paraplegic man who stated:

*Some villagers spoke to me with abuses. It looks like they are insulting me. When I pushed my wheelchair passed them, they shouted and insulted me. Some people liked to look down upon others. I want to work. I want to have money (10:28).*

Although living together in a family, a 33 year-old paraplegic man experienced being looked down on from his mother when he consulted her about his career.

*My thought had been changing all the time in these eight years. Sometimes I thought I would sell something. Yet when I thought about it and came to consult my mother, she said, "you couldn't do it, you are a 'cripple'. How will you do?. You'll never be able to do it. Who will you ask for, if you need someone's help. When I heard it, my thought about that disappeared (12:19). She was not thinking only because she worried about me but also she didn't think I had capability to do it (12:20-21).*

Other people's reaction toward the informants that is similar to looking down on them and that can be viewed as being offensive, is pity. Pity can also take the form of practical efforts to help the informants. A 27 year-old paraplegic man stated:

*They saw me as I had seen the disabled person before. They saw me as a pitiful person. I can tell from their eyes. I am not that kind of person. I told myself that I have a capability. I don't understand why they look at me like that. They asked me, 'are you recovered', or 'do you feel better'. Then they gave me 100-200 baht. I don't like the way they treated me. (7: 21).*

### Perceived Changes in Relationships with Significant Others

Paraplegia affected all aspects of personal life, including relationships with significant others. Persons with paraplegia tend to decrease this relationship or finally cease their relationship with significant others. The conditions which affected their relationships with significant others include their physical function, personal attributes (developmental task, male value), access to resources, and sociocultural attitude.

For the married informant, physical limitations caused him to be unable to fully help himself and he had to modify the activities of everyday living as well as an alteration or reversed role from the breadwinner to a dependent person. Since he could not earn as before, the financial situation in his family tended to be worse. Certainly, it was a strain on his male values (strength and independent person). While his wife may feel burdened because she has to take care of her child at the same time. These situations may place a great strain on marital relationships and end up with divorce. A 36 year-old paraplegic man revealed how their marital relationship broke up with emotional pain :

*At first, she separated to stay with her sister. I didn't say anything, OK. I accepted she may want to take care of our baby. I was no problem. It seemed to be good at first, she always visited and took care me. That time, I couldn't do anything. I didn't know what to do. I kept on thinking. At last she rebuked me. The problem couldn't be resolved. She spoke too much, implied divorce. When I woke up in the morning, I went to see her and we decided to divorce. I didn't care for this matter. I'm a man. I accepted, I couldn't do anything. I couldn't take care of her as a husband. Then, I let her go away (5: 6, 11).*

Seven of the fourteen informants were single. Although being a young adult, five of them stated no intimate relationship had ever been established. Some refused to have an intimate relationship because the suffering from pain prevented him from

thinking about love matters. Another also gave the reason that he was still dependent upon their family for basic survival needs.

A 26 year-old paraplegic man used to have a girlfriend, but both of them were not serious. After he got in an accident, she still visited him at the hospital and at his house. However, in the long run, she disappeared. Now, although he is anxious about the shape and condition of his body, he tried to develop an intimate relationship with his employee but his mother was an obstacle.

*About women, I don't care. She may think "this man had bad legs and has not a good thing". I don't care that she had gone away (2:15). Now, I feel unhappy because I have fall on in love with one woman but our relationship was difficult. It may be impossible, because my mother forbade me to meet her. She said "no body truly loves you" (from letter).*

A 36 year-old paraplegic man who had past experience about his love after he got in an accident and now he is uncertain about the new intimate relationship. He described a typical experience when he visited the girlfriend's family.

*When I was 28, I had a marriage project. However, when something changed...it lost all including my girl friend she has gone (15:3). Now, to be frank, I have already had a girlfriend who worked as .... here. This caused trouble too. Our relationship may be affected in the aspect of her sibling or her family. I have been to her house but they, I thought that deeply, it is hard. If it is you, as you are a mother of a daughter, what will you think? (15: 14).*

Another major aspect of being paraplegic is the distance of relationships with their friends. Many informants commonly reported that they had lost their friends after they had been paraplegic. They claimed that their friends tend to keep more distance from them because of having no mutual activities together. Whereas others gave the reasons that they couldn't meet their friends because of the long distance to meet their friends, difficult transportation, dependent on others to go with

them, and anxiety of bowel incontinence. These reasons have led to a distant relationship with their friends.

A 24 year-old paraplegic man described the causes of being unable to join with others which led him to have a less friends:

*I couldn't be involved with others, because I couldn't go to meet them. I had to wait for them to meet me at home. It caused a distance in the relationships. Most of my friends lived in the town. Therefore, it was difficult for me to see my friends. If I want to see them, I've to pay for a taxi with an expensive passenger fee (8: 11).*

A 33 year-old paraplegic man also lost his friends. The reasons for this appear to be social and physical isolation, his mental state, and fear of bowel incontinence. He talked about his relationship with his friends.

*If there were any festivals or fairs near my house, my friends persuaded me to go there. I didn't go because it was not convenient for me. If I go there, I had to use a wheelchair and found the old place, the same atmosphere where I and friends used to enjoy drinking together. Yet, I couldn't do like that anymore. Going to those places could destroy my mind. It caused me pain. I cannot get back to be like that again. Also, sometimes I might excrete accidentally. So I refused to join them. Even sometimes, I felt alone because there's no one to come to visit me. (4: 8).*

In perceiving the self as “being a disabled person” permanently, the informants tried to manage their situation with the strategy of learning to live in society. Learning to live in society refers to a cognitive, affective, and behavioral strategy which involved physical and social skills to protect against harm to the self, or assert self-value. This strategy required an effort to adapt their self, and interaction with others in daily life. The characteristic of this strategy is comprised of a choice of social associates, adapting one's own behavior, taking care of the mind, and using remaining physical skill. This strategy may be characterized both passively and actively. The informants performed this strategy by their own self, except some who needed to go

outside their house. The frequency of performing this strategy varied by the degree of the stress situation they encountered. The strategy of learning to live in society involved avoiding having a sense of inferiority, controlling negative behavior, managing stress, and protecting dignity.

### **Avoiding Having a Sense of Inferiority**

Most of the informants experienced dependence on others, perceived inferiority, and perceived discrimination from society. These situations were disliked by most of the informants in this study because these situations threatened to the young adult Thai males' values, such as equality and freedom, self-esteem, social recognition, and concern for success in life. The avoiding having a sense of inferiority strategy was aimed to manage negative feelings of being inferior. This feeling can be avoided by avoiding social participation, relating with people of the same or lower status, comparing oneself with the same or lower status, refusing unwanted help, and protecting personal rights. The informants used this strategy under the condition of the developmental task of young adults, physical condition, recognizing one's own ability, past experiences, resources, and sociocultural attitude.

**Avoiding social participation.** Avoiding social participation is a strategy that the informants use to avoid participating with both ordinary people and disabled people. Some avoided participation with ordinary people because it caused them to feel different and inferior.

One informant described the reason causing him to avoid participation with others in a villager fair. He avoided others who asked questions because such conversation showed the curiosity of neighbors which indicated a ridiculed feeling. He was also annoyed by this phenomenon which tends to grow irritating, because the result of interaction gave him a mark of inferiority, a skeleton to be hidden.

*When I went to a funeral, I didn't join with my other cousins. Some one asked me like...taunting...ridicule. I could catch from their voice. 'You were like this how do you do. It was a great pity person and lost the future already'. I felt bored, I didn't want to hear this matter (2:25).*

Another avoided meeting his cousin because he felt suffering from the hostile and condescending interaction. He tried to avoid participating with his cousin while travelling on a village public street.

*Someone seem to look down on me. So I would like to work and have money. This is an important thing. He wasn't a child, he was an adult and older than me. When I pushed my wheelchair past his house. He was shouting sometime like rebuking. So I didn't pass this way and went another way and didn't go that way (10:28-29).*

A few informants also avoided joining in neighborhood fairs because their disability stops them from helping others. Assistance in the village fair is a northern Thai tradition, especially in villages where it has been continuously performed for a long time. Thus one who joined in the ceremony but was unable to help others, unable to do like others, may feel different, and inferior which causes them to have an uncomfortable mind. This avoidance affected their cousin or social relationship.

*When we went to join in an important fair, like grandfather's or grandmother's funeral, I couldn't help the others. I never have participated with others. I only saw and never had an opportunity to help others. Thus, sometimes, I didn't join with a fair. This may affect the relation with my cousin (9:17).*

*I thought that I couldn't help others. I thought that I didn't want to bother others. When the neighborhood had a fair, I wouldn't go there (5:18).*

On the contrary, one informant avoided participation with disabled people or joining organizations for persons with disabilities. He did not want to be recognized as a disabled person.

*I thought that almost one hundred percent of disabled people did not like the word "disabled person" (15:21). So I didn't register because I wanted to show that I could live normally without registering and asking for assistance. I would perform to show that I have done everything by myself (15: 23).*

**Relating with people of the same or lower status.** Another social skill while resuming social relationships in the community is to relate with individuals of lower or equal status. This strategy involves seeking out social situations where the demands are not beyond their current level of competence. The informants tended to avoid associating with people who were superior to themselves, and chose to associate with persons who had mutual activities and were familiar with them, or people who had ordinary status such as villagers. The reason for this strategy was that it was easy to gain acceptance from ordinary people or those less different between status. The informants described:

*I'm a normal person and able to associate with normal villagers. I would rather not associate with high status people. I would like to join with normal people who understood each other or who were able to laugh when joining together...I have one friend who liked cock fighting as well. He has visited me frequently. My house raises cocks. We always exchanged cocks (2:27).*

In addition, they also have chosen to join with persons who were in the same position, spinally injured people. Within the context of peer interactions, they could be emotionally expressive, high in self-disclosure, and have activities together which understand each other. It is evident that supportive interactions among those people are protective against the consequences of life stress.

*I never got anything as I hoped, I felt sorry. I have joined with my friends in order to cease discouragement. Friends who had been the same and had sold lottery tickets together. I felt, it was a good thing that I have a group of friends who had gone everywhere and joined together. I felt a comfortable mind (5:28-29).*

*I felt discouraged....sometimes, when I had no job or I would like something but I couldn't get it. I would like to do something but I couldn't do it, and I couldn't go anywhere, I felt discouraged. There is a network which helped me, that is association. If the association has activity, she (disabled person) persuaded me to join in the activity (12:8).*

**Comparing oneself with others.** Comparing oneself with others indicates that the informants tried to use social skills by holding the worst situation in reserve. On the other hand, the comparing oneself with others strategy is an effective way to improve feelings and protect a declining sense of self-esteem. By attempting to select viewing only certain aspects of one's circumstances, the informants are able to endure the present. They compared themselves with others in two major ways: comparing themselves with normal people, and comparing themselves with others who had disability.

By comparing their present state of status behavior, emotion, and capability with normal people, the informants confirmed that their present situation was preferable.

*Comparing with a normal person, some were more miserable than me. They were still worse off than me...more trouble than me. Acting as a dissipated or distrustful person has caused social problems. For me, I haven't been making trouble to society and others (9:10).*

*I could have travelled but others couldn't have travelled. Although I've been like this, I could have gone anywhere...everywhere. Others could walk but they couldn't have travelled like me (14:18). I have to compare with one who had more than me. Sometimes they couldn't do something, they had to ask me. Sometimes they asked me about a car. They didn't know, I had to tell them and sometimes I had to repair a car for them....I felt good because a normal person couldn't do it (14:48).*



The informants compared themselves in supportive resources, physical condition, and capability dimensions with others who were suffering a similar or different disability. Even a profound informant believed that he had more supportive resources and that others had worse circumstances to bear. One informant compared his own self with other disabled people.

*My mind condition is better in everyday life because I have a family, surrounding environment, friends, and a girlfriend. I have everything that a lesser person could have like me. That is, I'm better than every person who thought their own self better. I got a pension at least. Some persons didn't get a pension. Some persons had to reside in the foundation (7:17).*

One informant saw himself as having a worse physical condition than other disabled people, but he was behaving better and had more capacity to work.

*Sometimes I thought why I have been like this. I thought and compared my self with others who were much inferior than me. I would compare with a blind man. I still can see anything. I'm better than those (8:38).*

**Refusing unwanted help.** Many informants have experienced unwelcome social advances that seem to be related to their disabilities. Some people assumed that the persons with paraplegia would have more sympathy and pity for their problems. This feeling often makes people try to help them. Family members wanted to help them with activities in daily life. Other people may give things, money, offer assistance, or give suggestions.

One informant lived with two sisters in a small house and he was unemployed. He rarely went outside. He always lied down in front of his house and waited for neighbors to come back from their jobs to talk with them every evening. He said that he disliked others who provided help to him, so he refused to accept such help.

*I thought society around accepted me. They expressed that they sympathize with me, and humored me as well. They said 'would you like to travel?'. They would take me to travel. 'What did you want to eat?' Sometimes they bought some food for me. However, it made me have an uncomfortable mind. Although, they did a good behavior to me, I didn't go with them. I thought that formally they didn't do like this with me but I'm being like this now. I thought that I might be inferior to others (4:36-37).*

One informant who used to work as a company officer and had a high salary, asserted that he disliked it when others gave him money. He found that it was difficult to refuse it at first. However, he resolved this problem by avoiding to go outside.

*I met someone, who knew my family, in a department store. He showed he pitied me, and said 'When will you recover?' 'Are you better?' They insisted to give me money 100, 200 baht for buying sweat meats. I disliked it. Why did they give me money? I wasn't a beggar. However, I couldn't refuse them. Now, I avoid it by not going to shop in department stores (7:20-21).*

Another informant who used to be a policeman and used to have high status in his village, faced the difficult situation when others offered an undesired suggestion. This situation created a feeling of tension in the informants. He described that he had the capability to resolve his own problem when the time passed. Therefore he refused the undesired help and thought the suggestion from an other is not necessary.

*I could resolve the problem by myself. Time helped me to adapt. I didn't need other suggestions. The more others suggested to me, the more I felt an uncomfortable mind. I didn't believe it. Thinking by myself gave me a more comfortable mind and I was able to do more than the other suggested. The good intention of others is a two-edged sword for me (9:16-17).*

**Protecting personal rights.** With protecting personal rights, the informants made every effort to ignore the possibility of an unwelcome social situation or staring from the public and they attempted to "act as usual". Trying to protect personal rights allowed them to sustain self-worth.

*When I went to my friend's marriage ceremony at a hotel, many people stared at me...let it be. I didn't beg for your money for eating. My friend said you didn't care about them....I didn't also concern about that. Where others could have a dinner, I could go there as well. I didn't think anything. Where others could enter to travel, I also could travel there as well (14:54).*

*Some one didn't want to be close with me, and didn't attend to me. Sometimes we had to join together because of a task. Yet we only communicated by phone. I'm not sure what they thought...Sometimes I may think in advance. However, I didn't care about them, because I didn't beg whose rice for eating at least (12:7).*

In addition, to manage the social pressure while having social interaction in public, the informants exerted by themselves. They had to contend with their own self about their right as people in society.

One informant described his situation while under pressure to yield to others in a social interaction because of his disabilities. However, his effort to protect his own right was realized when some one invaded his self.

*The first time, I yielded to others in everything. However, now, if it wasn't wrong and an other admonished me wrong, I won't yield. If I was wrong, and an other admonished me, I would accept it. I yielded sometimes (5:40-41).*

Another informant recognized by facing with the fact that he was disabled already. He recognized that this fact was unchangeable and beyond his control. Since he knew all his neighbors in the village, he didn't mind the others when entering to social activities.

*I'm not ashamed because I have been already. Why are I ashamed? (10:11). About society, I didn't think anything. If it is necessary, I will go anywhere, (10:16).*

The outcome of using the strategy of avoiding having a sense of inferiority had two aspects: one aspect is decreased social participation, and the other is the informants felt a comfortable mind and sustained self-worth.

### Controlling Negative Behavior

After their paraplegia, the informants have a chance to depend on others or family members for help with tasks that could not be done. This situation always occurred in the first period of paraplegia and still remained while they had social interaction in the community. The informants tried to learn to live with this situation through attempting to control their negative behavior. Controlling negative behavior is a strategy which they tried to do, forced themselves to do, or concentrated on doing. It was not their previous behavior but they tried to do it in order to be able to live in society. They attempted to control their negative behavior by trying to control their emotions, and conform to the social norm. They tried to control their behavior under the condition of social norms, and sociocultural attitude.

**Trying to control emotions.** Many informants described how their dependence on others caused them frustration from unsatisfied emotions when they could not anticipate the help they needed it. Some informants had expressed dissatisfaction about the supportive resources when they did not receive help immediately. This situation caused them not to receive help back. They learned how they should respond to others, at least as the social norm. To be able to live in society, they attempted to maintain the status quo, tried very hard not to get angry or tried to calm their feelings.

*Previously, I felt a lot of frustration when I called others to help me but he was delayed. Sometimes, nobody was here, I couldn't immediately get it. It caused me frustration the first time. However, I would be better later. I thought I was already. If I call an other and they've a business. If I am hot tempered, I will*

*never get it. Some one may be frustrated and didn't meet me. Thus, I have much a cool-temper for getting the thing I need (12:18).*

*At the former time, if my parents said something that caused me to be unsatisfied, I will argue with them. I was easily frustrated. I try to adapt by not being fussy about anything and don't argue with them now. Similarly, if my cousin said something, I won't be interested in it. If I argue with them, some day I have to ask them for assistance. They will talk "do as you can". I tried...tried much to comply with them (5:40).*

*I have a normal mind now, that is not troubled. I am more cool-tempered than before. I was hot-tempered before my injury. I was gradually cool-tempered. It might come from going to hospital. I had to wait for others. I saw other's condition. I was better than others. It was useless to be hot-tempered. They waited and I also waited. This caused me to be cool-tempered (8:29).*

Because of his entertaining occupation, one informant tried to control his feelings by presenting happy emotions in front of his audience.

*I thought, if I make myself happy, the audience around me will be happy as well. If I can't make myself happy, why will others sit to see me (13:16).*

**Conforming to social norms.** In order to be able to stay with other people in society, the informants tried to control their negative behavior by conforming to the social norms which included: having behavior as a peer group, exchanging social support, quitting drinking alcohol, and avoiding addiction.

One informant talked about his attempts to enjoy himself with his peer group and to abolish drinking alcohol in order to avoid the rebuke of others.

*In the same group, they didn't think anything, enjoyed themselves and were in a joyous mood. We couldn't act strained. They didn't think anything, why did I still think?. They were being like me. They remained joyous, why I still have surly face. Thus, I began to openly talk and enjoyed being with them, it led me to release stress and have a comfortable mind (5:42).... Previously, when I went anywhere, I drank alcohol. Although the doctor didn't inhibit me to drink, I was like this, I have never been drunk. If I drink, the neighbor will disparage me 'you got in an accident because of alcohol, you are still unaware'. So I was abolished (5:29).*

Similarly, another informant who tried to reciprocate the good manners of his friend by visiting his friend's family at the hospital.

*A friend visited me, and also took his family members to visit me...let me know his family. Sometimes, his wife gave birth in the hospital. Although I was ill, I had to visit them. I would visit them at the hospital (7:20).*

To maintain his relationship with his uncle, another informant had to avoid addiction as his uncle requested.

*My uncle was head of the village, he absolutely ordered me to avoid addiction. If I got involved in addiction, he will sever my family ties. I have never been involved in addiction (2:24).*

Consequently, the strategy of controlling negative behavior provided evidence that the informants modified their behavior, had a comfortable mind, and were able to maintain social participation.

### **Managing Stress**

The informants in this study described that repeating activities in daily life, being unable to do anything and being dependent on others, no job, and staying only inside their home can easily become a source of loneliness, and sometimes stress. They also talked about how the problems from physical dysfunction and the secondary conditions, psychological issues, lower social status and decreased relationships with significant others gave them stress. In an unsatisfied situation in daily life, they tried to learn to live in everyday life by managing their stress to prevent themselves from a harmful environment. Managing stress is the strategy which focuses on distracting and adapting one's psychological condition in order to alleviate the emotional stress. This strategy needed effort to be done in their situation which could not be changed.

Managing stress involved; releasing stress, recreation, living in the present, making up their mind (Tum Jai), and religious practices. They used this strategy under the conditions of past experience, personal attributes (male value), physical conditions, religious belief, resources (transportation / building, financial resources, social / family support), and hope for maintaining life.

**Releasing stress.** The strategy of releasing stress found a way to release the accumulated tension which wasn't resolved. Informants released their intense tension by hitting the toilet wall, singing loudly, staying with an animal and talking to themselves. With this strategy, they felt their stress flow out of them and felt better. They said that it is the best strategy to release stress but it was not often used because they seldom had intense stress.

*An accumulated stress is simultaneous stress from the job and other stress, such as my finances, buying things (accessories for his work), and then, the insertion of other matters until I couldn't discriminate. Stress would be demonstrated by being easily angered when others spoke, discomfort in the mind, and being unsatisfied with others spoke...I assaulted my own body but not severely. I went to the toilet, and hit my palm on the toilet's wall which was made of hard wood. I hit against it until I had red palms, pain and numbness. After I did it, stress would decline and I felt like it was releasing. I learned this method from friends while in re-admission(8:40).*

*Sometimes, when I was under intense stress, I would stay with my cocks...held it up and wiped it with water. It helped me feel better. Sometimes, I spoke with my cocks. If I stay alone, I will speak with myself (2:25). The best releasing thing is I had turned the radio on the loudest, and was singing along as well...the loudest singing. If I shout with a loud noise...shout the loudest, I feel a comfortable mind, feel better. My body would cool down with sweat and I felt better(2:25-26).*

In seeking a way of releasing stress, one informant chose imagery as a diversion from stress. He used the strategy of reading to distract his attention.

*Our mind had thought continuously...used to go here and there....used to work, then I thought....I never thought, I was like this. Sometimes, I was angry. I had many emotions. I used the method of reading. Seeking the old book read...read ...read for deferring to its (4:11).*

For stress which came from their job, some informants used the strategy of leaving or avoiding the cause of stress, and sought self-control in a quiet place. They would return to continue their work after releasing their stress.

*I have worked repairing radios and televisions. Sometimes, I couldn't solve a problem. This was a stress. I would stop to do it for a while...stopped it...didn't continue the stress. The more I was stressed, the more I was angry. I stopped it and went to do other things, it let me quiet and clear my mind. Then I would seek information. When I got it, I would be back to work again (8:29-30).*

*While I prepared lottery tickets, if the wind blew, it blew them open. I couldn't catch it then I got angry, sometimes I often made a loud noise, and was stressed. If I can control my mind, I will continue to work. Sometimes I wouldn't like to do it because of stress. I would cease it, and wait to have a good mood. After that I began to think and did it again (5:9).*

When one informant who was able to drive a car felt an uncomfortable mind, he released his stress by driving his own car along the road and didn't want to meet anybody.

*When I felt discomfort, sometimes I drove my car to travel in Chiang Mai or went to Doi Saket. When I had a bad-temper, I didn't like to meet my friends. I would like to stay alone. It wasn't a long time I would find relief, then I could meet my friends (15:15).*

**Recreation.** Most informants performed recreation more than usual after paraplegia because they had more free time and were bore. They described that the methods of their recreation also changed after injury. The former recreation might have been active such as playing a sport, travelling, or going to the movies. Now, although some were able to go outside or some could have active activities in their house, most of them stayed at home and performed passive recreation such as



watching television, listening to music or lying down. Recreation are activities that help the informants relax and get rid of frustration. It also prevents stress. Informants used this strategy in two aspects: recreation at their house and outside their house

Recreation at their house. Most informants took a rest at their house. These strategies included; watering the plants, cooking, reading, watching television or VDO, listening to music and the radio, lying down, playing chess, and playing computer games. They chose each activity depending on the availability.

Two informants who preferred recreation by watering the plants and cooking said:

*I water a plant every morning. It helped me have a more comfortable mind when I saw green plants. Moreover, it was simultaneous exercise as well. I used to hold the bucket intermittently while pushing my wheelchair (8:36).*

*Because I have no time to look after others in details, I could put my feelings into a meal which I cooked for them. If others have it and they tell me it is very delicious, I feel better. This is my method...I felt relaxation (13:17).*

Chess is a recreation activity which is played between two people and it usually has other people sit around to provide continual players. Thus it not only provided enjoyment between the players but also created social contact. One informant who insisted that he seldom was lonely or bad-tempered talked about his recreation activity.

*I rarely have a bad-temper. Most of the time I played chess with my wife, my friends and neighbors (3:8).*

Most of the informants often chose to do two recreational activities simultaneously, such as watching television lying down or listening to music lying down. These passive activities helped to distract them from the preoccupation from their disability or work.

*When I was stressed from my job, sometimes I laid down and listened to music...I didn't think what it is (5:30).*

*If I don't go outside, I will lie down and watch television or listen to music, then I didn't think anything and I would ultimately sleep (14:51).*

Some informants might have recreation by playing computer games, VDO games, reading a book or newspaper which helped to protect themselves from loneliness and an uncomfortable mind. However, these strategies were expensive and informants also had to depend on their family member.

*I have a television for watching, have a telephone to talk with my friend. I also have a VDO and VDO games for playing. If I want to read a book, I will let my sister borrow it from the library. If I want to read a newspaper, I will let my sister buy it. Sometimes, I watched a good Hollywood movie (7:17).*

*When I felt an uncomfortable mind, I would play a VDO game. It could cure my stress (9:6).*

Recreation outside their house. Recreation outside their house was a strategy consisting of travel by wheelchair or car with or without his friends. This strategy was done every day or some days, especially by some informants who had car ownership and could drive it or those who were not restricted by inaccessible transportation and buildings, obviously had increased mobility. They could have gone outside their house whenever they wanted.

*If I travel, I will travel with my group. I didn't go alone because it wasn't enjoyable. Sometimes we went to "Hazy Toaung Thuo" (a large pond) 3-4 cars to rest. It was a good time...not thinking anything. We enjoyed together (5:43).*

The capacity for independent travelling allowed one informant to potentially participate with his neighborhood. Such social contact would undoubtedly enhance his courage, help him to forget his problem and increase his social participation.

*When I stayed at home, sometimes I felt very lonely or stressed. I kept on thinking that was why I often went outside. I went with a tricycle wheelchair to my cousin's house after having my dinner in the evening (6:11-12). Talking to*

*them made me forget my thinking. They cheered me up. Then I had a peaceful mind (6:7, 22).*

**Living with the present.** When the informants couldn't explain their life situation, they tried to focus on the present rather than the past or the future. Methods used to manage stress and action by the informants were to not let themselves think too much, try to forget or not think about what happened in the past, and let it be. These were evident from the statements below.

*I didn't think anything. I didn't think anything about my life (3:9). About future plans, I didn't know. I didn't know what to plan (3:8).*

*I thought it depended on my own self. If I think about the matter that occurred 8 years ago, I will feel bad. However, now I stand at a good point, I should go forward (13:18). It's such a waste to have that attitude, because I have to live. I just thought, live with happiness and don't trouble others (13:15). I have happiness with it, even though it couldn't meet my mind. I maybe went anywhere alone or waited for my friend. However, I have happiness with it. Now, I went to another place. I didn't attend to the old matters (13:16).*

*I didn't think about the future. I couldn't think it out, and couldn't adapt my mind. I thought that...let it be, live one day at a time (4:18). It caused an uncomfortable mind because we used to walk before and then being like this. It caused an uncomfortable mind then I didn't think about it. It will recover whenever, let it be (4:14).*

**Making their mind up (Tum Jai).** From interviewing the informants, making their mind up refers to the strategy of the mind's condition in accepting one's own physical condition (paraplegia). In this study, the informants used this strategy by trying to think, shifting their viewpoint and resignation.

The informants tried to manage their stress by shifting their viewpoint to make existence bearable; such as, their injury was not more severe, the reason of male

values, an accident may occur in anyone, not only me, and retaining capability the same as before.

With the support of family, patients with disability, and health care providers, one informant could work through the suffering situation and progress towards the stage of making their mind up in their initial phase of being paraplegic. He tried to shift his viewpoint that he was still lucky because he didn't lose more than he still had.

*Initially, I couldn't do anything. I had to do physical therapy and saw others being able to fight while I stayed in the hospital. I thought I had to get it. My mind became more normal (11:3). Nurses who worked there encouraged me, it made me realize, and the former patients also encouraged me. So I became Tum Jai (11:4)..... I have better morale later because of the assistance of people around me, family, and time. I thought I have been only this but I didn't lose more than this. So I was satisfied with it and tried to Tum Jai (11:11).*

Someone also talked about how past experience in seeking treatment made him be able to make his mind up as well as his male values encouraged him to fight for his life. Making his mind up developed in the later phases of being paraplegic.

*The things made me accept my condition and Tum Jai might be a treatment, because I went many places. I met many events causing me Tum Jai. I thought it was permanent (9:20). About 2 years ago, I have accepted my physical condition, then I have been Tum Jai continuously (9:3). I thought that being a man must mean to fight. I used to be more trouble than this in the past (9:3). Time helped me adapt as well (9:16).*

Another informant who had the experience of a car hit him while he stood on the side of the road, described the accident as a random occurrence and it could not be resolved.

*I thought it was just one accident. It was possible to occur. The person who sat eating in his house, may be hit by a bus which shot inside the house. It was an accident. If you did not perform, it was negligent of an other (13:18).*

One informant whose mother joined the discussion about why she and his son accepted his disabled condition said:

*We thought, it can't be recovered. We thought that it wasn't only us to be like this in this world (3:19).*

Another who felt self worth and happiness in his life, talked about how his current situation has the same activities from before the injury. He realized that life was not necessarily over, and he still had all these opportunities to live.

*I felt better and happy in my life. Although I can't walk in everyday life, I am not necessarily hurrying to die. I still was able to watch films, listen to music, go to have a meal, and drive anywhere (15:13). I have a chance to seek happiness. If you let me sit watching films, it won't be different from when I walked to watch by my self. It wasn't different. I could watch the same film as if I wasn't like this (15: 13,15).*

For some informants, "making their mind up" may reflect an acceptance because of their belief in karma. This kind of acceptance, resignation, refers to the acceptance of their disabled condition because they realized that they were incapable of coming to terms with life changes over basic biological functions and this way of acceptance related to Buddha's beliefs. They may use both shifting their view point and resignation to help them feel better. Resignation is a method which was used continuously because they note that the emotion generated by physical change are never completely resolved, even after living with paraplegia for a long time.

The informants were resigned through the law of karma. Half of them expressed a strong belief in the law of karma. Every cause has an effect. All of them believed that their karma such as, to kill an animal, to do bad things, or to refrain from merit making, are bound to bring about effects, their disability, in the present life. They found it useful to think of their disability as their karma, because they felt a comfortable mind and felt better.

*Because in the former time I used to kill frogs and fishes. I thought I was being like this, I can't do it continuously. I thought it was sin and karma. Now I have refrained from killing animals (10:24).*

*I realized I was being like this, it may be karma (14:32). Normally, my father preferred to shoot birds and he liked to catch fish at night. When I was injured, he ceased to do it (14:38).*

*Previously, I thought repeatedly. Why did I go that way? Why everything had to happen accidentally. Why the car had to hit me (7:8). I thought it was karma. If I think like this, I will have a much more comfortable mind (7:4).*

**Religious practice.** Following their resignation, only five informants performed religious practices. They hoped that if they accumulated meritorious acts in their life, they would get good results both in this life and in the next life. They tried to keep the following religious practices: merit making with or without family members doing it for them, praying to Buddha for help and observance of moral Buddhist precepts.

*Initially, I was making merit as I could and offerings dedicated to the Sangha. Sometimes, my cousin did it for me, sometimes I did it by myself. After making merit, I felt a more comfortable mind (4:32).*

*In the former time, I may not be making merit, it led me to be like this. I only have a meal and play. So I became like this. Therefore I had to make merit. I had to do it for the future...for rebirth. It will help me to walk like others again. I prayed for recovery before sleeping every night. Some days I offered food to the monks (5:30).*

*I became like this, I wouldn't have killed animals and have tried to make a lot of merit. If I can't go, I will leave money with others to make merit (10:24-25). My father makes a big merit every year. My mother was also making merit at the temple all the time. My mother hoped the result of making merit would restore me. If I enter to the city, I will go to worship "Kru Ba Sri Vichai" (the statue of the northern famous monk). This was a mental support (14:38). I had to pray for rapid recovery before going to sleep every day. I appealed to holy things to help me. It was mental support, speaking out has brought about a comfortable mind (14:51).*

After using the strategy of managing stress that is composed of releasing stress, recreation, living with the present, making their mind up, and religious practices, most informants described that their stress was decreased. They felt better and had a

comfortable mind. Moreover, these strategies helped distract them from thinking about their disability and they were also able to maintain social participation.

### **Protecting Dignity**

In the transition from being an independent person to being dependent on others for physical, emotional and financial support, most informants felt that they were inferior than others, were discriminated by society, and had a change in the relationships with significant others. These feelings led them to lose their dignity. As they developed physical capability and had more past experiences which promoted their ability in social skills, their independence began to increase and their daily living became secure and confident. They tried to learn to live in society with independence and dignity.

At this point, the informants began to protect their dignity by learning to avoid being a burden, maximizing their personal role function in the family, attempting to work, and using their full remaining capability to help or entertain others. Protecting dignity is a behavioral strategy in response to a situation which threatens one's sense of importance, value, and other people's respect for them. The factors that influenced the protecting dignity strategy included developmental tasks in young adults, hope for maintaining life, physical condition, recognition of one's own ability, male values, past experiences and having adequate resources such as financial resources, health information, and access to transportation / building resources. Family members and their friends can play a significant role in these strategies.

**Avoiding being a burden.** Family support was necessary during the first period of returning home and throughout all of their rest of their life. Throughout the course of their disability, the capability of most informants gradually developed. They tried to self-help and be responsible for taking care of their body in order to avoid being a burden on the family members. Male values might underlie the feelings of avoiding being a burden on others, especially with their mother.

*If I have parents staying together, they will help me better. I'm a male. If my father takes care of me, I will feel better because we are men together. If my mother takes care of me, it seems to be more distant. I wouldn't like to be a burden on her. I tried to do everything by myself. If I couldn't do it, then I will ask for assistance (2:24).*

*Previously, I couldn't transfer myself to the bed, I had to ask my mother to assist me. Now, I can do it, I try to do. If I fall down from the bed, I will try to get up by my self. Now I don't burden her because I use more self-help. Furthermore, my mother is a female and rather old. I didn't want to burden her (5:33-34). Regarding the cost of living, perhaps I help but not much because I have to keep money for the cost of treatment when I go to the hospital. I didn't trouble them (5:9).*

One informant thought being a disabled person made him a burden on his family members. To burden others less, he tried to modify his goals by downsizing his goals to correspond with his current abilities.

*Before I was like this, I had goals on one level. When I became like this, I had to change my goals to another level. This way allowed me to feel more normal, like a patient's situation. My expectation at this level is only to try to help myself more and less of a burden on others. I did not set high goals (8:14).*

Some informants talked about their activities in relation to their current state as striving toward some degree of control over assistance with activities of daily living and avoiding being a burden on others. One realized that he stayed with his brother's family whereas another recognized that he was unemployed and financially dependent on his family. Thus, they tried to avoid being a burden on their family members.



*My family has known what I could do. Instead of overprotection from family members, I have done home tasks because I would like to do it. If I have spare time, I will do it. I would end up being a burden on myself, instead of a burden on others (13:13). I have to pay the electrical costs every month. I have a responsibility to share the cost of living in our family (13:13).*

*I thought, my efficiency has not decreased. Although I couldn't walk, it was my only limitation. Now, I can do everything such as cooking, washing and hanging, cleaning house especially my room. (14:28). I tried to do everything by myself. I thought, I wasn't a burden with my family members (14:50).*

**Maximizing personal role function in the family.** One informant described how he had to depend on family members and was not responsible for anything in the family. He feared his family members would be bored of him. Another lost contact with his child because he divorced from his wife. Another thought about his function in the family. All of these issues were concerned with uncertainty or attention in performing a new role function in the family. To protect self-dignity in the family, the informants tried to maximize their personal role function as father or as the head of the household. As a result of performing family roles, they have felt meaning toward their family and were filled with purposeful activities in everyday life.

With regards to the role of father, few informants were provided a time to visit, to give food, clothes, and money, or to give a word of advice to their child.

*She didn't allow me to meet my daughter. Thus, I've to visit her at school at midday. I gave money and sweets to her. Most of all I bought clothes which I left with my aunt for her. I'm worried about her future. So, I deposit some money for her yearly. It has a total of 5,000 baht now (5:21).*

*Previously, I feared for my son and my wife was bored with me but they didn't bore me (10:23). I thought I still have a value for my family (10:24). Now, my son is a novice. I often visit him at the temple or he visited me sometimes. I feared for him about drug addiction. He was still young and didn't believe his mother but he believed me. Thus, I have to live for him (10:7).*

One informant who received good mental support from his wife, recognized his function and responsibility to his family.

*My family has only me and my wife. We help to work for our family. So, in my brain, now I only think doing the best as I can function for my family (9:3). I work in my VDO game shop everyday to increase my family's income (9:11).*

**Attempting to work.** As the informants' self help improved, they gradually increased their activities and began to consider the possibility of returning to work again. Over half returned to work but changed their previous work situation. All of the informants were self-employed. Three of them chose to work at their house by assisting his wife's business, a small grocery, and working whenever others employed him. Another three considered returning to work after they regained their strength and physical well-being, and psychological response to returning to work.

Endeavoring to live by depending on one's self and being less of a burden on others, allowed a number of informant to attempt to work again and participate in their own choice of jobs with support from family members. They experienced satisfaction and were proud of their ability in returning to work.

*I established self burden. A job reinforced my living. I would have something in my brain (pointing to his head) to think and do. I have to create work for repaying. If I achieved each repayment, I would be proud (9:30). I have a life satisfaction around eight. That is, my financial condition was adequate. My wife supported me all the time. We won't be able to speak like this, if we've to struggle. We were lucky to have a business. I thought it was our fortune. We thought and did effectively, then it led us be better (9:11).*

*Although I couldn't help other, I thought that I could still raise fighting cocks (2:10). They had a better price than chickens. If they are not a good fighter, I gave them to my mother to cook or sold for 50 baht per kilogram. If they are a good fighter, I would sell them for 1000 baht each (2:12). I thought, I had no financial problem (2:13).*

In order to get more money and have personal accommodation, the informants sought better work or expanded their business.

*I would like to borrow some money for investment. I pondered that we have to develop more business. I have to have my own house (15:15). I thought money will help me better. It means capability...potential. Money doesn't mean I get it from winning a prize in a lottery ticket or getting it in a mass. Money is money I am able to seek by myself..get more (15:14).*

*An aspect of occupation, if I wasn't like this, I would do better than this or go to work in a company (8:9). Now I think about the future, what job shall I do next (8:36). My friend persuaded me to work as a computer repairman in Chiang Mai. Tomorrow, I will look at the toilet and the bed to see whether I can live there. It was important for me (8:38).*

Although a job made them tired, one informant was still continuously working. He considered working near his own house, because transportation was limited.

*It won't tire, if I play guitar in the city. Yet it was difficult to go there by myself, I have to play music here and I felt tired because I have to play guitar and look after the shop simultaneously (13:8).*

Although there was less profit, another informant also kept the same job because he thought that the task was limited for him.

*It seemed to discourage me as well because there are many lottery ticket sellers. Sometimes, I bought expensive lottery tickets. Sometimes, I was bored. I would like to stop but I didn't know what occupation I should do (5:35).*

For one informant who had previous work as a farmer or laborer faced the difficulty of seeking a job or career. However, they have waited to work seasonally.

*I thought I would like to work. I would like to have a job. This is the most important thing (10:7). I have a job sometimes. In the season of rice planting, I wove an openwork fish cover-trap and sometimes I peeled dried longans (10: 18).*

**Using full remaining capability to help or entertain others.** The changes in function abilities and appearance following paraplegia engender the informants with uncertainties about their new identity and it caused them to feel inferior to others.

Informants built up their courage by various self-generated strategies to encourage themselves. They described the way of living in society by enhancing self-worth using their full remaining capability to help or entertain others. They did this strategy under the condition of recognizing their own ability, and past experiences. This strategy acted as self-support.

They tried to use their remaining capability to change their power and status in society by becoming an expert in business, mason, sport, using their skill, and helping others in society. One reason for using this strategy, according to the informants, was to demonstrate their value.

*I thought, I'm cool because my friends who have a business, have to consult me. They let me to plan the marketing. After I graduated, I entered a marketing system continuously. When my friends have some problem, they would consult me (15:13).*

*I was a football coach. When a child went to train, I saw them from the side of the football field and then taught them to play. Previously, I used to play football and also played sepak-takraw as well. I like all sports. I could play all sports. When other people taught them, those children rarely believed, but they believed me (14:35-36).*

*I have only an opinion to tell others. When they came to consult, I told my knowledge to them. They always consult me about building a "godown", and building a house. I went there and showed them what to do. That is a "granary" (pointing there) I told them to build it in this style. My prior job was as a mason (6:30).*

*Regarding helping another, I taught the pupils who couldn't do their homework once a week. They were children near my house. If they are my nephews, they will ask me to help with the homework everyday (8:39).*

They not only acted as consultants, but also participated in social actions such as playing music in public and assisting village activities.

*I thought I'm cool. I could have done something which many people dare not do. I was able to play music to more than hundreds in the audience (13:11). The most important thing in my life is music (13:16).*

*When my village has a fair, I would help them by driving and carrying things because my house was a place for keeping a group of housewife's things (14:17). I drove a car to help carrying things at every funeral ceremony (14:55). Sometimes a neighbor was ill, I would send them to the hospital (14:47).*

The outcome of the strategy of protecting dignity through avoiding being a burden, maximizing personal role function in the family, attempting to work, and using full remaining capability to help or entertain others was altered life goal, increased self-esteem, sustained self-worth, being more independent, satisfaction with what they have, and maintaining / decreasing social participation.

With perceiving the self as "being a disabled person", most informants tried to learn to live in society with the strategies of avoiding having a sense of inferiority, controlling negative behavior, managing stress, and protecting dignity. Consequently, the strategy of avoiding having a sense of inferiority provided evidence of "decreased social participation", whereas the strategy of controlling negative behavior, managing stress, and protecting dignity provided a chance to "maintain social participation". Lastly, in learning to live with society where options and choice are restricted for them, the informants perceived the results of these strategies including: the feeling of a comfortable mind, reducing stress, altering life goal, increasing self-esteem, sustaining self-worth, being more independent, and satisfaction with what they have. All of these results helped the informants to be able to live with value in society.

### Summary

This chapter details the characteristics of the study informants and categories generated from grounded theory analysis. Seven informants were in their early young adult age, whereas another seven informants were in their late young adult age. More than half of them have been paraplegic less than five years, and were high school and college graduates. Half of them were married and five lived in a nuclear family, while six of them were single and one was divorced. Among these people, two lived with their mother, two lived with their cousin, and three lived in an extended family. Most of them were working as self-employed and more than half earn medium to low income per year. No one was receiving a disabled pension, while one has received social insurance and four receive private insurance every three years. Traffic accident was the main cause of spinal cord injury. Most of them suffered complete paraplegia while half of them had high paraplegia. Most of them faced pressure sore, spasticity, pain, and urinary tract infection. Pressure sores created the most concern, while spasticity, pain, and urinary tract infection caused difficulty in their daily life.

From grounded theory analysis, the perception of self alteration which included the self as “being ill”, the self as “being disabled”, and the self as “being a disabled person”, was seen as a causal condition leading to the phenomenon “making the best of paraplegia”. “Making the best of paraplegia” was derived as the basic social and psychological process of managing everyday life among Thai men with paraplegia. “Making the best of paraplegia” could be divided into three phases. First, the informants perceived the self as “being ill” which was engendered by their perception of physical function alteration. This self-identity influenced an effort to manage their

situation with the strategy of learning self-care. The consequences of learning self-care were limited physical function, being dependent on others, and modifying lifestyle. The first two consequences may become a part of the following causal conditions which are the strategy of learning the system of care and support.

Second, the two consequences of first phrase added with the perception of decreasing working capability caused the informants to perceive the self as "being disabled". With this self-identity, the informants tried to manage their situation with the strategy of learning the system of care and support. The results of employing this strategy were a comfortable mind, feeling better, morale, maintaining self-worth, maintaining hope, increasing self-care capability, increasing dependence on others, being a burden on others, low self-esteem, feeling inferior, dissatisfaction with the disable support system, and perceived changes in relationships with significant others. With these consequences, some may have an intervening condition (hope), and other negative results such as an increased dependence on others, being a burden on others, low self-esteem, feeling inferior, and perceived changes in relationships with significant others may become a part of the next causal conditions of the strategy of learning to live in society.

Third, the negative results in the second phase added with the perception of discrimination from society caused the informants to perceive the self as "being a disabled person". This self-perception affects an effort to manage their situation with the strategy of learning to live in society. The outcome of using this strategy was decreased / maintained social participation, a comfortable mind, reduced stress, altering life goal, increased self-esteem, sustained self-worth, being more

independent, and satisfaction with what they have. These situations made them more able to live with others in society.

Self-interaction, and social interaction were seen as a context for the perception of self alteration and the process of managing strategies which depend on the self (personal consideration, personal attribution, physical condition, lifestyle and past experiences), and environment (setting and resources). Intervening conditions also influenced the perception of self-alteration and the process of managing strategies, including hope, norm, and sociocultural attitude. In conclusion, the person with paraplegia tried to manage their situation as well as they could follow the perception of self-alteration and depending on their context and conditions.