LIVED EXPERIENCE OF OSTOMATES: ELIMINATE SUFFERINGS OR SUFFERING FROM ELIMINATION

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ABSTRACT

The main objectives of this study are to understand lived experiences, sufferings, and coping of ostomates, to comprehend the processes of meaning construction of the ostomate's body, self and identity relating to their lived experiences and sufferings, and to grasp the ostomate's embodiment of elimination experience. Concepts of Illness Experience and Body were utilized in this qualitative study in order to clarify this phenomenon. Eight ostomates living in Bangkok and its periphery and one ostomate living in Chantaburi were purposively selected. In-depth interview and observation of each ostomate's daily life under various contexts were conducted between April 2007 and April 2008.

The results showed that sufferings of the ostomates derived from feeling loss of vital excretory organ, experiencing self loss, and dramatic change in their routine conduct. Since they were obliged to experience their sufferings alone, they chose to conceal their abnormal body parts and present only particular identities within social relations. Their real selves were kept for disclosure only to their intimate friends and relatives. Moreover, after embodying the ostomate's experience, the lay's symbolic meaning of stoma was perceived as dirty. However, repulsive feelings regarding anus and feces were not related to the connection between feces and stoma, or meaning construction of anus and feces through social history. Stoma and feces repugnance came from perception of reality through senses. While touching feces, meaning of feces as dirty and disgusting was constructed through senses. In conclusion, existence of the lived body is not for presenting merely symbolic meaning, but also for experiencing the world through senses.

Health professionals should realize meanings of the body from various perspectives, not merely from a physiological viewpoint. In addition, they should discern that the reality of feces as dirty things is constructed through senses and socio-cultural history. Thus, they should not express a repulsive manner to feces while encountering patients. Moreover, issues concerning illness experiences should be introduced in all health professionals' lessons in order to infuse their sensitive feelings to a cultural code and to increase recognition of patient's value of life rather than focusing merely on disease treatment.

KEY WORDS: OSTOMATE / LIVED EXPERIENCE / SUFFERING /SENSE

116 pages

ประสบการณ์ชีวิตของคนมีทวารเทียม: การขจัดความทุกข์หรือความทุกข์จากการขับถ่ายอุจจาระ
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บทคัดย่อ

การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อทำความเข้าใจประสบการณ์ชีวิต ความทุกข์ทรมาน และการจัดการกับความทุกข์ทรมานของคนมีทวารเทียม อาศัยแนวคิดเกี่ยวกับประสบการณ์ความเจ็บป่วยและร่างกายในการรวบรวมข้อมูลจากคนมีทวารเทียมและบุคคลใกล้ชิดที่อาศัยอยู่ในกรุงเทพมหานครและปริมณฑลจำนวน 8 ราย และจันทบุรี 1 ราย โดยใช้วิธีการวิจัยเชิงคุณภาพ สัมภาษณ์เชิงลึก และสังเกตกิจวัตรประจำวันของคนมีทวารเทียมในบริบทต่างๆ ระหว่างเมษายน 2550 ถึง เมษายน 2551

ผลการศึกษาพบว่า ความทุกข์ทรมานของคนมีทวารเทียมเป็นความรู้สึกสูญเสียอวัยวะที่ควบคุมการขับถ่ายอุจจาระ นำไปสู่ความรู้สึกสูญเสียตัวตน และการปรับเปลี่ยนกิจวัตรประจำวัน ส่งผลให้ปัจเจกต้องจัดการ โดยปกปิดสถานภาพ เปิดเผยตัวตน และเลือกแสดงอัตลักษณ์ในกระบวนการปฏิสัมพันธ์ทางสังคม เนื่องจากคนมีทวารเทียมให้ความหมายเชิงสัญลักษณ์ต่อตนเองในฐานะเรือนร่างสกปรกและน่ารังเกียจ ซึ่งไม่ได้เป็นการทำความเข้าใจผ่านการรับรู้ความสกปรกของอุจจาระผ่านการประกอบสร้างความหมายทางประวัติศาสตร์สังคมเท่านั้น แต่เกิดจากการรับรู้ความเป็นจริงผ่านประสบการณ์ทางผัสสะ

การศึกษาครั้งนี้มีเสนอแนะที่สำคัญต่อบุคคลากรทางการแพทย์ให้ตระหนักถึงความหมายของร่างกายในมิติอื่นๆ มากกว่าการเป็นเรือนร่างทางสรีรวิทยา และรับรู้ความเป็นจริงที่ว่าความสกปรกของอุจจาระเป็นการประกอบสร้างผ่านประสบการณ์ทางผัสสะและประวัติศาสตร์สังคมวัฒนธรรม ดังนั้นบุคคลากรทางการแพทย์จึงไม่ควรแสดงท่าทีรังเกียจขึ้ในขณะมีปฏิสัมพันธ์กับคนมีทวารเทียม แต่ต้องละเอียดอ่อนต่อค่านิยมทางวัฒนธรรม และตระหนักคุณค่าของชีวิตผู้อื่นมากกว่าการมุ่งรักษาโรคแต่เพียงอย่างเดียว

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CHAPTER I

INTRODUCTION

Significance of the Problem

Stoma has been used in medicine more than 200 years ago. At present there are several millions ostomates (person who had stoma) around the world. It is an incision into the colon to create an artificial opening, stoma, to the exterior of the abdomen. It is used in patients who have colon disorder such colorectal cancer, accidents involving colon and etc. in order to make an substitute anus to defecate the waste product from intestine. It is an effective and efficient treatment for colon and colorectal cancer. This type of treatment helps reducing a number of abnormalities and save life.

Although stoma can save life, it creates some impacts to the body directly. After the surgery, patients will initially feel pain around the surgical wound. They will feel uncomfortable and unable to adapt to having a stoma. (Notter J., 2006) When patients see stoma, they fear that stoma will create a bad image and suffer emotionally and mentally. They will feel nervous, fear, threatened and annoyed (embarrassment). They also feel stressed, depressed and some expressed anger, hopelessness and feeling of do not want to be alive. (Pojjana, 1983 and Bekkers M. et al;, 1996) Some are also afraid that their stools will dirty their clothes and unable to accept change. It creates social relationship problem. When others are able to see excretion from stoma, it creates anxiety that people around them will feel disgusted.

Other than that, there are effects on ostomates' daily life such showering, dressing and caring stoma while working, exercising and traveling. This includes management during sexual activities and ability to adapt from surgery to structural changes, organ's function and loss of body's function, caring stoma by oneself and changing the way one uses public toilets. (Bekkers M. et al;, 1996) These problems arise when an ostomate feels that having stoma is an embarrassing and tries to conceal others about one’s stoma, afraid that others will feel disgusted. Ostomates need to have a pouch (colostomy bag) with them all the time because they cannot control their elimination (feces, gas, and odor). When they move, they fear that pouch will leak and the smell will disturb others.

Attempts to solve those problems have inaugurated from surgical techniques development, post- operative care, development of pouch and management with post-operative care, (Banlue, 2002) training ostomates to adapt, self care and helps in decreasing risk factors and other side effects and adjust patients’ behavior into the right direction. (Loustau, 1991) There are plans to educate ostomates with stoma care, mental, emotional and social changes. These are biomedical quantitative study and have a particular objective in areas of emotional issues, adjustment and quality of life. It is aim to help ostomates to be able to live normally and to have standpoint in solving problems efficiently. From a medical professional perspective, problems and side effects can be managed by scientific methods by explaining trusted plan and scientific criterion.

However, bodies of ostomates are not ‘biological machine’ that can have discipline created, adjusted and controlled accordingly to a program. Bodies of ostomates are space that individuals can show self and identities that reflect reality of bodies and society that relates to sickness when stoma influences in self and identity changes. (Kelly M., 1992) Apart from that, bodies of ostomates are not bodies without meaning, but consist of meanings as individual bodies are where individuals feel and embodying experiences of life and are meanings for society. It helps to understand power control, power relationship and construction by various discourses, especially medical and public health discourses, which affects ideas about cleanness which is constructed in the process of interaction between people (including ostomates) in society.

Past studies about ostomates in Thailand aim to treat and explain disorders of ostomates with biomedicine knowledge and control body and life of ostomates by emphasizing side effects and abnormalities as tangible truth. It is done by professional knowledge and outsider’s perspective that it ignores experiences and suffering of ostometes and does not try to understand life and or give meaning after a colostomy. It also ignores insider's perspective which relates ostomates's experience with fundamental social culture, which consists of feelings and life in a context of particular social culture.

This study is the first qualitative study in Thailand about lived experience and perspective of ostomates and families, in order to reveal social cultural issues of ostomates' living conditions, value realization, beliefs, practice and meaning of stoma which relates to suffering and coping of ostomates experiences.

Research Questions

Main questions:

How about lived experiences of ostomate? Does stoma cause suffering? How? And what is his/her experiences in handling with his/her suffering?

Sub questions

1. How do ostomates experience their bodies and stoma? How do they suffer? What are the forms of suffering? How does it distract daily life and does it relate to society? How do they empower themselves? How do they experience management with their suffering? And after management, how do they feel and how do they express?

2. How do ostomates defined themselves and stoma?. Does such meaning effect to self and identity? How does that meaning relate to individual, society, cultural value and other power, including medical power?

3. How do ostomates construct cultural meaning of feces and body with stoma?. How do they cope with suffering and lived experience by their own constructed meaning?.

4. How do ostomates embodied their experiences in elimination through stoma? How does this process of elimination influences their attitudes, expression and clothing? How is the process and how to they learn this process?

Objectives

1. To study ostomates’ lived experience, suffering and management.

2. To study construction of body image, self and identity which relate to ostomates’ lived experience and suffering.

3. To study embodiment of elimination experience of ostomates.

Expected Results

1. To uncover socio-cultural dimensions from ostomate’s experiences which is beneficial in healing stoma person’s illness.

2. To learn from the experiences and suffering handling of ostomate and develop a guideline for taking care of them.

CHAPTER II
LITERATURE REVIEW

At the beginning, stoma occurred naturally or from injury of organ in abdominal. Later some operations such as those to cure abdominal accidents, Colorectal cancer treatments, etc. create intestine dissection and open as a hole, artificial anus, at stomach for feces excretion This make this group of people excrete via this hole. They have learnt about how to take care, prevent, and solve some complications for their quality of life.

The study of ostomates' lived experience revealed their coping in socio-cultural dimension. Moreover their value, belief, meaning and suffering to stoma, feces and dirt including their adaptation with stoma. Concepts employed in this study were studies related with stoma, body, self and identity, illness experiences, and embodiment concepts.

Studies related with stoma

Stoma is not new finding, the Old Testament recorded nature's stoma or the wound in ancient warriors' abdomen. (Peter, 2004) The surgery, post-operative care and colostomy bag were continuously developed by modern medicine. By the progressive medical technology and industry, the ostomates could live normally.

There are many definite of stoma, for example colostomy, illeostomy or stoma which are different in detail. 'Stoma' is used as general term for this study.

Stoma was the technique for curing colon and anal cancer as well as other pathology such as diverticulitis, colon obstruction, fistula of colon and rectum and Crohn's disease. Furthermore the accident wound for example, blunt trauma, gunshot or slab wound, anal trauma and loss function of constrictor muscle. (Doughty &

Jackson, 1993) Colostomy was a surgery, which removed a part of colon in order to create an opening to the outside of the abdomen. Stoma was new opening instead of rectum. The wound was round and moist in red or pink soft tissue like normal colon. It had no any constrictor muscle and sensory nerve ending. (Pratin Chaisi, 2001)

Change of stool excretion that is uncontrollable, was the result of stoma. (Loustau, 1991) purposed that the patient had to educate how to adapt and take care himself for reducing the risk and other post-operative complication. Ostomates would change their behavior properly and be promoted their ability to follow these following suggestions: cleaning stoma and surrounding skin, changing pouch (stoma bag) technique, controlling odor, adjusting food pattern and exercising.

Prevention and complication management were another concern. Most complications, which were peristomal skin irritation, obstruction of colon opening, disorder of stoma and diarrhea, were found in improper care patient. (Nilphan ruttanadilok, 1992; Alterescu, 1987; Doughty & Jackson, 1993)

All instructions for ostomates were set by medical professional perspective. The objectives were to promote patients' quality of life and able to take care of themselves. Many studies in Thailand focused on post-operative care ostomates and stoma hygiene instruction. (Pojjana Piyakornchai, 1983) studied emotional reaction of ostomates. Their knowledge and potency to care themselves after systematic stoma treatment during admission. Pojjana Piyakornchai had taught and demonstrated stoma care by herself. 4 cases were anxiety and worried about odor and feces dirty all time of admission and went out. Moreover they were ashamed their stool excretion obviously and sensitive to surrounding people's reaction and disgusting. Pojjana 's study s focused on the patient in hospital setting in the aspects of their self-care and emotion. It did not narrated the relation of patient and society anymore.

Social relation was indicated in Charinthon Somphu's (1996) study. That explained the female case by gender role as wife, mother and working woman. All roles had been adopted with permanent type colostomy. Female colostomy case could take care of her colostomy and complication well when got instruction from nurse. While she could not reject the food that causes gas and odor. By female gender role as working woman and mother, did not change too much. However her role as wife changed especially sexuality. Half of female ostomates had no sexual activities. Charinthon Somphu’s study showed social support effected to ostomates’ adaptation. Much social support caused female who lived with permanent type colostomy could adopted her role well.

That study indicated that although female ostomate took care of herself followed nurse’s instruction well, food was still major problem. Why did she cannot reject some type of food under good education? Did the food culture related to specific social context? What was the reason to accept or denied food?. Was it a tool for coping suffering from strictly control life?

Reviewed studies in Thailand are medical professional perspective. Those concentrated on the effect of body, mind and sexuality under medical instruction, demonstration. Most of them studied in post-operative cases in hospital setting by quantitative methodology.

As same as the foreign research both qualitative and quantitative research, the interesting issues were the effect of body, mind and sexuality. Bekkers M. (a) (1996)’s presented the psychosocial adaptation of ostomates in their health, occupation, sexual relation and social environment. Some cases could not accept themselves and cope with stoma due to psychosocial problem later. (Bekkers (b) 1996). They were in stress, depression, hopelessness, anxiety and worried about disgusting (Long and Phipps, 1993; Black & Gubb, 1976). Some tried to suicide. (Wade, 1990) The change of identity was the important problem because ostomate would face the stoma that effect to social, mind and sexuality. (Dalgic, 2000) Rejecting the changed identity caused ostomate saw himself negatively (Salter, 1992) and low self esteem. (Schaube & Scharf, 1996)

Ostomates had to support to accept himself and confront the problem in new condition with stoma. (Hocking, 1997) Surrounding persons such as family member, friend and medical personnel, could help and support the patients for promoting their identity and adapting with stoma well. (Maguire, 1980) .The information from medical personnel made them cope and adopt themselves efficiently. (Stewant, Hart and Mann, 1995) Everybody could take part to support them especially their family, including intimate person, friend. (Dalgic, 2000)

Most of quantitative research emphasized on the effect of body, mind and sexuality; besides medical role and social support. While those researches were the medical professional perspective and their results could be known previously. They lacked of socio-cultural dimension of ostomates' lived experience and their coping and confrontation. Furthermore they did not present ostomates' value, belief, lifestyle and meanings of stoma, stool and dirt which related to patients' suffering.

The early qualitative research was study of Kelly (1992). This study based on socio-anthropologist and explained through concept of self and identity. Kelly analyzed clearly tension between self and social identity. Stoma was the body change and effect to 'self and identity', which involved labeling, stigma and power relationship. Such were construction when social interaction did. Moreover this study explained that the individual body had related to other dimensions not only identity and sexuality. Many patients' condition was disclosed subjectivity of individual meaning, which was metaphors and image. (Janice, 1991)

The study of Manderson, L. (2004) revealed ostomates lived experience through qualitative research. Its focus was colostomy could help to save patient's life and to lower the expansion of this abnormality. While the treatment had undermined sexual relationship. Some spouses divorced; whereas, some ended sexual relationships but still took care each other by each condition. Other aspects of this study were to reflect the good view with stoma and various coping.

Another qualitative research was Notter, J.'s study (2006) lived experience of temporary type illeostomy was analyzed by phenomenology concept. Patients' lives were full of pain, fright and change of physical, body image and sexuality. Furthermore they faced their stomas problem, which was the essential point leaded to other problems such as stigma and unclean body. They saw themselves as untrained person or animal that was uncontrollable elimination. (Notter. J, 2006). As phenomenology qualitative study, this study presented general lived experience of ostomates not specific issue.

Although both studies of Manderson L. (2004) and Notter J. (2006) were medical professional work, but they were qualitative research which were different from the other studies. Data were collected by open-end question, tape record and noting, in informants' setting. The findings reflected the reaction of surrounding people when saw stoma, colostomy bag or smelt the feces or listened to releasing gas or crashing colostomy bag. Furthermore Ostomates had narrated their own stories about their suffering and coping with various social relations. Manderson L. (2004) emphasized that the medical personnel should concern with cultural issue, such as body image and sexuality

Concept about Body

Biomedicine, sociology and anthropology theory and concept of body were reviewed in order to understand the meaning of body, was the base of ostomates' live experience and suffering

Body: Perspective of Biomedicine

Modern medicine as biomedicine was based on continental rationalism of Rene Descartes' concept. He purposed that body and mind is separated and undualism. Therefore, the physical illness did not relate to mind. While Foucault disclosed medicalization to body that every part likes mapping relation. Whereas modern medicine explained human body as machine such as the cardiovascular system was the same as water pumping machine. (Samson, 1999)

The treatment in the realm of biomedicine was to diagnose each organ, a part of machine, that work or not. It needed to be repaired when it did not work. Consequently, biomedicine was discipline, which controlled human body strictly by medical professional knowledge. Medical profession had constructed new meaning of body, health, sickness and disease which all were objective. Any sickness body was measurable; accordingly, medical profession neglected subjective, symptom, whereas concentrate in objective, sign, only. Disease was the important point of body that is the measurable reality; therefore, human body was reduced in order to seek for its abnormality. (Artisuk Chungputawadee, 2548)

The ostomate 's body was a phenomenon that showed how medicine dominates body by cutting the pathological colon and replaced it with other parts of intestine liked the spare. The internal organ such as rectum, which was in hidden area, was adopt to be exposed organ, stoma. Medical personnel had controlled ostomate to follow medical standard way of life for preventing and avoiding complication. However ostomate suffering, illness and personal experience were overlooked.

Perspective of Sociology and Anthropology

While biomedicine considered body as biochemical and physical machine, its treatment pointed to manage human organ and neglected its consequence, daily life suffering. Sociologist and Anthropologist analyzed body as social, cultural and political construction through meaning and discourse of many realities of human body. (Paritta Chalermpao Kor-anantakul, et.al., 1998) Furthermore body was the social consequence and biological phenomenon; accordingly it was the individual area for presenting himself. (Mullika Muttiko, 2003)

Mary Douglas' work was *"Purity and Danger: An Analysis of Concepts of Pollution and Taboo"* (Douglas, 2003), showed the metaphor of body and social system. Body was considered as bounded system and complex structure although each organ was separated but still related each other.

"Dirty" in Douglas' work was the result of 'Pollution & Concepts of Pollution', dominated by medical knowledge. (Douglas, 2003: 35) The secretion was the symbol of body's pollution. To touch the secretion liked touch corpse, it reflected image of pollution, infection and danger. While the pollution was defined when the germ was found\. However the pollution was symbol defined as the others. Therefore, any pollution was contrast to 'the goodness' of social discipline. (Pimawan Boonmongkol, 2003)

The secretion, such as saliva and milk, was interpreted as rite and social symbol, including power and danger which effected to social structure and reproduced on human body. Especially all marginal organ are dangerous. It wound be threaten and leaded to social pollution that was harmful through 4 kinds. The first id danger pressing on external boundary; the second, danger from transgressing the internal lines of the system; the third, danger in the margins of the lines and the fourth is danger from internal contradiction. (Douglas, 2003:123)

The concepts of body in Douglas' work (Douglas, 2003), focused on body as model of social system. The purpose of several rites was to eliminate pollution, which made a conflict with social norm. If pollution was not cleared, it would be blended by adapting itself. Consequently, body had always changed for balancing social system. Durkheim analyzed body as social constructed entity. (Shillings, 1993) While Douglas viewed body only one dimension, relation of individual and society, her concepts of body do not criticized power domination. Structural and symbolic anthropologists, Margaret Lock and Nancy Scheper-Hughes, and Chris Shilling are interested in Douglas' concept about body and society relation and socio-cultural construction.

Their work, *"A Critical-Interpretive Approach in Medical Anthropology: Rituals and Routines of Discipline and Dissent"* (Lock & Scheper-Hughes, 1996) which was critical-interpretive approach. It proposed how did meaning of body constructed. Another issue was relation between 3 levels of body, which are individual body, social body and political body. Whereas body praxis was also critiqued. Individual body originates lived experience, consciousness and spiritual; moreover it showed 'self' and 'identity'. Social body was natural symbol of all stories. Explanation of socio-cultural body reflected social relation in various contents. By the view of 'Health', body was organic wholeness; therefore illness body reflected conflict and disharmony society. Body as a tool, viewed and explained society by metaphor. (Lock & Scheper-Hughes, 1996) While society had determined body part and fused all relation to indicate healthy body. Furthermore political body was regulated, controlled and surveillance by political ideology to follow politic, economic and medical policy.

Lock and Scheper-Hughes (1996) also argued body contrast to Douglas (2003). Their work pointed to social body and analyzed individual body and social body distinctly. Besides they proposed issue of hidden power in political body not power to control people into social norm only. Body praxis was raised to explain exposed power as various type of against. (Lock & Scheper-Hughes, 1996)

Lock and Scheper-Hughes (1996) suggested for further study that should consider following interesting issues. How did ostomates' lived experience be oppressed by new body? What was specific surveillance for ostomates? How could medical personnel control ostomates' body?

Power, medical dominance and lived experience were analyzed explicitly by Lupton's study, *The Body in Medicine: Medicine as culture*. It noticed that theories of sociology and anthropology were overlooked concepts of body. They concentrated on social structure and objective individual. Consequently, concepts of body were constructed by rational science and medical discourse and also neglected lived body. (Lupton, 2003)

The significant concept for analyzing body as discourse is Foucault's concept that was medical power. (Lupton, 2003) Body was considered by several discourses, which were gender and sexual body, public health and the discipline body, cleanliness, dirt and body boundaries, commodified body, food and the body and the dead body.

Body by Lupton's concept was ultimate unit to be controlled and verified. Political ideology was formed by state for controlling people in discipline and promoting healthy body as worker in economic system. There were institute of medicine, psychiatry, educational system and law. In 1800 B.C., medical institute was the main to stigma body to be deviance or health; moreover, to control body with medical instruments. Accordingly, human body was monitored and quested by medical tools and history charts. The other concepts of body and dimension of illness are neglected by medical dominance.

Vigarello (1988 cited in Lupton, 2003) revealed the change of elimination concept in France and Europe in the Middle age till to 1700 B.C. cleanliness was defined as no visible dirt on exposed complexion. Body cleansing was good manner. Only exposed organ such as hand and face would be cleaned by towel. Hot water was danger for body and leaded to illness. In 1800 B.C., the change of dirt meaning was the result of epidemic, medical science, invisible germ finding. Therefore, taking a bath became normal life style. The cleanliness was more important in 2000, when modern science had more influence. The hygiene was essential issue. A heading of woman magazine published *'for healthy family: Lysol could help you preventing.'* That reflected the necessity of cleanliness, which was the result of germ theory, cleansing product in many advertisement. (Vigarello, 1988 cited in Lupton, 2003)

Chris Shilling (2003) has analyzed body as same as both concepts of Mary Douglas and Michel Foucault. He proposed socially constructed body, which was symbol, metaphor or reflection of whole social system. Consequently, to control body was the same as to control society. While thought of body had related to society as well. His work presented many views of body. There were naturalistic body, physical capital body and civilized body. (Shilling, 1993; Paritta Chalermpao Kor-anantakul, et.al. 1998)

Naturalistic body: was the relation of body, identity and society in the early 1800 B.C. The competency and limitation of body would define individualism and originate pattern of social, political, economic relations. Body was not classified while gender difference had been divided by pattern of organ. Male and female were differentiated by biological science. Opposite sex showed personal identity and leaded to social role. Female's body was viewed as rough, odorless and dangerous other. The naturalistic body viewed the other bodies are danger, brutality and uncontrollable sex drive. Besides they were threaten to western moral and order.

Body and physical capital: By the Boudieu's concept, Body was physical capital that could be changed to be economic, cultural and social capital. Boudieu stressed on commodification. Body was essential as symbolic value and consisted of social location, habitus and taste. Consequently, individual could develop himself to get different value.

Civilized body: Body was analyzed by Norbert Elias' concept, social development. Body was the front stage of human behavior. Civilized body was directed and constructed by royal tradition. It was practiced for a long time to control and screen one's emotion before explicit acting. Especially when it interrelated to other persons. Consequently, body was not instant object. It was changeable and evolved to dynamic social context. Civilized body was treated follow tradition and concealed natural function; therefore, one's identity was different to the others obviously. The other persons could notice that one was able to controlled one's feeling and acted only social expectation. Furthermore one could plan and expect what should perform to reach desirable result.

This research studies ostomates' bodies through their experience, which acquaint to concepts of stool, its excretion, its position and body boundary as normal life. When their bodies are threatened by illness and have to alter defecation, how do ostomates, who have their own concept, react to new condition? The main issues are experience, which base on concepts of changeable body, relation of person and society, including experience of new body under medical dominance. Accordingly, ostomates' bodies should be considered in various aspects by its conditions, which are unstable, nonboundary body, both personal and social body. Personal body points direct experience and embodiment. While social body reflects sociopolitical body which reveals discourse and other power act to body? They practice through individual's narrative with several meaning system besides biomedicine.

Thai body: Cleanliness & Dirty. Body

Although body has been analyzed by various aspects, but social body was condition to determine physical body's perception and experience. Vimala Sitipong (1988) studied about thought and behavior involve to body in Thai society. Thai body was both physical and social body. Thai people defined social meaning for their bodies. Social meaning was stipulated by same thought, which effected to practice and behavior to one's body and the other's bodies. Such condition was the following practice for holding sacred body and repeating its importance. (Vimala Sitipong, 1988)

Douglas' concept of dirt and pollution was guideline for Thai researchers, who were interested in rectum; stool and its odor. Vimala Sitipong (1988) said that aperture was marginal organ and pollution. It was unclear condition between external and internal organ. Aperture was only one organ that was able to connect between external and internal organ. It consisted of 2 eyes, 2 nostrils, 2 ears, a mouth, an anus and urinary organ (Vimala Sitipong, 1988). Anus was in hidden area and full of muscle and fat; moreover, it was exit for releasing waste matter from internal organ. Aperture was representative of dirt, non-creative and bad thing; consequently, it had always been concealed. (Tanate cited in Paritta Chalermpao Kor-anantakul, et.al. 1998). Stool had the sense of bad odor, dirt and disgusting liked waste matter in body and excreted through anus.

The stool excretion, its character, color and odor were controlled by internal organ. The pollution in body due to waste matter collecting, when it released, the pollution will disappear. The defecation was privacy and individual's business. Thai people practiced personally. It was privacy and should not talk in public area. Tanate analyzed that stool was pollution because it involved to anus, marginal organ and gateway. Anus was not classified to be a part of body and it was beyond body management. (Tanate cited in Paritta Chalermpao Kor-anantakul, et.al. 1998)

The waste was not only stool, but also its odor. Thai people concerned about odor. Both male and female Thai people preferred to powder their bodies scantly. They would have a shower when they sweated. Cleanliness in Thai society had rooted into Thai daily life for a long time. Rural people liked to have a bath many times a day for cleansing bad smell, scurf and dirt (Pimawan Boonmongkol, 1993). Such performance also disclosed that our bodies were waste, our bodies liked plant, which had always produces the waste matter. Consequently, we disgusted ourselves. (Yukkati cited in Paritta Chalermpao Kor-anantakul, et.al. 1998)

Finally, anus was the symbol of disgusting and alienation because waste, which was excreted from aperture, was undesirable and polluted whatever in form of solid, liquid and gas. Feces excreted through stoma, were disgusting waste by their characteristic, color and pattern of excretion. Moreover they were unacceptable due to bad odor.

"Feces", something that is labeled as dangerous in Thai social history

In the book "Social history through the toilet" by Monrutai Chaiwiset said that the word *'kee'* (shit), according to the royal scholar means waste product that body does not want and excrete out through the anus. The word *'Uchara'* (feces), which is a bali-sankrit word, also has the same meaning. Both *'kee'* and *'uchara'* have different levels of aversion in various Thai social classes. For monks, the smell of feces may interrupt the practice, but *'kee'* does not have any other meaning than activity that needs to be preceded strictly.

For villagers, even though they feel naturally disgusted towards the smell of feces and use the phrase "going to the field, going to the woods", which meant going to excrete in the field or woods in order to be euphemistic. However, villagers still perceive that *'kee'* is a natural activity and have to live with it. *"Kee"* is a part of many food name (*keelek*, *keenoo* and etc.), idioms and proverbs. It is also used in medicine (using animal feces) and symbolizes fertility. These things reflect the relationship between men and nature and point out that *'kee'* is a natural thing and is a part of villagers' life.

However, the upper classes perceived that *'kee'* was inauspicious and disgusting. In the royal language, the word *'kee'* is removed and replaced with '*uchara, kood or moon*", which derived from bali-sankrit language. Thai upper classes considered *'kee'* as a rude word and use it to label people status. People in the upper classes were called *'moon-nai'*, while the slaves were called *'kee-ka"* and the children of the slaves were called *"kee-krok"*.

It can be concluded that the feeling of digust towards "feces" are different in each social class. Monks perceived it as a part of practice. Villagers felt some disgust, but their lives were surrounded with 'feces', while the upper class felt disgust, aversive and saw that it as something low and dirty. Other than that, *'kee'* was defined as something disgusting and dangerous as the government issued policies to stabilize hygiene and people's health.

Monrutai Chaiwiset stated that during the King Rama IV reign, a river act was passed in 1870. It was the first act that forbade people who live nearby river to litter or excrete into it, which led to a behavioral change in excreting. In 1875, 53 police act stated that people who litter in the public will be fined. Once these two laws are considered, it can be seen that they didn’t perceive excretion as a direct health issue, but the government wanted its country to become ‘civilized’, so it had to change the behavior of ‘going to the field, going to the wood’ into excreting in toilet.

In the year 116 RE (Rattanakosin Era), 116 R.E. Bangkok sanitation act was passed. It stated that it was passed for “tidiness” and to “prevent diseases for the people”. The sanitation department was inaugurated and provided staffs to clean, manage garbage, organize toilets for citizens and remove all ‘dirty matter’ from the area of sanitation control. It also controlled the construction and repair of the building.

This 116 R.E. Bangkok Sanitation act was a process to educate citizens how to use toilet. The government promoted this new habit by building public toilet in order to demonstrate toilet usage and pass the law. There were punishments for the violators, instead of persuading and educating people to excrete properly and suitably with an urban lifestyle.

The change in excretion form and a law enforcing people to excrete in the toilet embedded an idea that feces are dangerous to citizens’ well-being. In the children book, “Sanitation for self and family 2” by ChaoPhrayaThammasakMontri (1918) emphasized about contagious disease prevention such educating about cholera, telling that cholera is able to spread through water and it is greatly reduced because of tap water. In 1932, ‘health education’ was added into the national education plan. Its contents were about daily routine and hygiene such teaching children that “We should wash our hands with soaps and water many times a day; after eating, after defecating and urinating and before going to sleep”. This education subject probably made these routines seem ‘normal’ that children feel that they must excrete in toilet.

The dirtiness of feces was further emphasized in 1937. The ‘feces usage as fertilizer control’ act was passed. Although this act has a same content as the one that was passed during the reign of King Rama V, which stated that it was forbidden to use feces as fertilizers in the area of Bangkok because foreigners complaint that it was ‘dirty and disgusting’. This act had a hidden meaning that it wants to declare that Siam was a civilized country. But in this more recent act, it further forbade the use of feces in the area of Thonburi with a claim that it was done for “the safety of the citizens”.

It can be said that excretion is a basic biological activity that every race of human has to have. In an old primitive society, life was simple and uncomplicated, so the form of excretion was natural. Once feces are excreted, there will be pigs, dogs or fish to deal with it. This reflects that people used to perceive feces as a natural matter, but it was attempted to make people feel disgusted towards feces by changing their behavior of “going to the field, going to the woods” into excreting in toilet in order to prevent diseases. It is also related with the concept“being civilized” in the cultural policy, which aimed make the nation ‘civilized’. These laws and policies are social controls, which are influenced by western public health and sanitation policies. These influences have changed the cultural code of excretion, which people used to excrete in the field and rivers, but were turned into excreting in the toilet, an enclosed location. The belief on excretion was changed. Feces became forbidden, dirty, which is reflected from the used of word that consisted the word *‘kee’*. Words that consist of ‘kee’ usually have connotations of smelliness, dirtiness or wastes.

These changes have made “Kee” alienated from a people’s way of life. Accepting excretion as a natural thing is difficult. People are more alienated from their own wastes and feel ‘dirty’ when they have to touch feces in daily routine. This attitude is confirmed to be ‘real’ in the conventional medicine until today.

Concepts about Self and Identity

To study ostomates’ bodies by sociology concepts of self and identity reflected the truth of body and social related illness; moreover, they related to the change of thought, feeling, and experience and body activity. The patient, who knew and accepted his illness well, should form identity through body that other people understood his suffering clearly. (Kelly and Field, 1996)

Self is a phenomenon occurs inside, personally, (and present when one interacts with other) and construct as self. When one interacts again imaginary of his self and imaginary by other people saw this interaction will be constructed. It is experience that separated from object outside. Self can be developed from perceiving meaning in received roles by accepting other people positions into imaginary and action through expanding individual boundary. Meanwhile, self is reconstructed replace the old self. Self is both subject and object in social processes. (Mullika Muttiko, 2546)

Concepts of self are presented schematically: 1) Self is not an entity having a location in space. Self is a subjectivity cognitive phenomenon unknown to other. 2) Selfhood is about acting towards, and thinking about, self as one does towards others. Selfhood involves the recognition of self as a particular human being with a distinctive set of qualities and attributes. 3) Ideas about self tend to concrete rather than abstract. People tend to think something about themselves. 4) Selfhood is commonsensically experienced as 'the really me'. 5) Self mediates social structure and behavioral through the process role-taking. Role taking is not necessarily objectively accurate, it is a self-reflexive imaginative view both of the self enacting particular social roles, and the way others might see that enactment. 6) Self gains experience of itself in two way; a) indirectly via role-taking from the standpoint of other, and b) directly in the way that self can think and act towards self in the same way that it can act towards any external object. 7) Self has a certain amount of stability, continuity, predictability and internal consistency but also has the capacity to change. 8) Self has a number of component aspect and parts. Some aspects of self have a greater salience than other. Salience is a function both of particular biographies and particular situation. 9) Self exerts very important influences on daily life because it is the locus of interpretation and motive. 10) Internal views of self are/need to be legitimated by other in social interaction. (Kelly, 1992: 393) In summary, self may by defined as an imaginative view and being rehearsed, constructed and reconstructed. The experience of self derives from the mundane experience of everyday life.

Self connects with context and social relationship via identity, socially shaped to indicate who or where individual is in social structure. Furthermore, identity frames individual to be socially “object” which is coded or labeled on “self” that other will know. Self, then, is intermingled as a group member and social relationship. Identity is related with using of symbolic, name, age, sex, ethnicity, and occupation etc. (Apinya Fueangfoosakul, 2003; Mullika Muttiko, 2003)

Study of relationship between body, self; and identity in Kelly’s work (1992) showed that stoma which is physical event create self and identity change. It happen by loosing of normal self, attempt to preserve normal self, try to exhibit normal self-representation; which are negotiation and verbal account in interaction.

Concept of identity calling it the ‘social me’. Identity to be interlinked statements: 1) Identity are situation in social term. Identity establishes what and where the person is within the social structure. Special identity includes name, gender, age, family, occupation. 2) Identity may also be created in social situation. 3) Identity are meaning attributed to self, by others and by self. They are developed in interaction as other respond to particular presentations of self. (Kelly, 1992) In summary, identity ie the label imposed by other on self. It the public knowable aspect of the person. One has identity when one is situated and cast as a social object and acknowledged as a participant in social relation

Kelly (1992) analyze in his paper operates therefore at two level, one of identity change and the other of maintenance of self. Identity change is concerned with potential labeling, felt stigma, status passage and of experience of power relations in social institution. The subject describe experienced as a powerful, or potentially powerful definer of the situation, when the identity of person become salient and negatively salient. These process described are of identity change and identity construction. In Kelly’ paper also describe losses of normal self and the struggle to maintain a normal self and normal self-representation, in which the processes of negotiation and verbal account interaction. (Kelly, 1992)

If we consider self of ostomate as self of chronic disease patient, not only self will be changed as Charmaz’s concept (1983) but chronic disease affects to loss of self also. Self occupied by chronic disease is different from the old self since he/she has to spend remaining life with illness, live with limitation, lonely, without honour, and be burden of nearby people. (Charmaz, 1983) Self will try to escape from illness before it loose its self by construct self and identity that connect between preferred identities and identity hierarchies. **First,** preferred identities symbolize assumption, hopes, desire and plan for a future now unrealized. In short preferred identities represent identity goals. Identities develop, in part, because identity have thoughts and felling about whom they with to become and how they wish other to know them. **Second,** identity hierarchies become visible as ill people, over time, choose difference types of preferred identities, reflecting relative difficulty in archiving specific aspiration and objective. These identity levels include: 1) the supernormal social identity, and identity demanding extraordinary achievement in conventional worlds; 2) the restored self, a reconstruction of previous identities before illness; 3) contingent personal identity, a hypothetically possible, though uncertain, because of further illness; and 4) salvaged self identity, retaining a past base on a valued activity or attribute while becoming physically dependent. Experiencing progressive illness often means reducing identity goals and aiming for a lower level in the identity hierarchy. In short, reducing identity goals means aiming for a less preferred identity. (Charmaz, 1987)

Relation of body, self and identity of ostomates, leaded to interesting question. How was interpretation of ostomates' bodies? How could self and identity be changed? Both questions based on this following condition. If people lived in personal world or normal daily life, such condition were accustomed and had never raised any question. So body function worked normally by self was link between feeling and action. Then it was sent to body in order to present one's identity. One's identity was known and positioned when social interaction happened.

Concepts about Illness experience and Embodiment

Illness experience

Individual's illness experience caused suffering due to stigma, shame and loss of self. (Chamaz, 1983) It revealed that illness effect to self and identity. Loss of self caused biographical disruption. The feeling was stigma and shame, the results of negative interpretation of illness and discrimination of illness suffering person. It also related to several variables, for example age, sex, social class, etc. These variables were influence on meaning and consequence of illness and leaded to individual experience, which reflected through narratives, belief and illness explanation related to coping other condition and effects. (Pierret, 2003)

The ostomates were revealed their secret by abnormal life style such as to leave colostomy bag as infected waste. Ostomates' neighbors could notice and ostomates were stigmatized and shameful (Notter. J., 2006) While they were labeled and stigmatized in social relation. Consequently, their selves and identity had always changed. (Kelly, 1992) These experience disrupted interaction of patient and their family, including their work. It was the major problem in their daily life especially spouse's relationships. (Manderson, 2004)

Ostomates needed strategies and resource for coping such as medical practice and self help group, etc. The important strategies were medical support and instruction. (Kelly, 1992, Notter. J, 2006) However strategy's standpoint based on patient's view and experience. (Pierret, 2003)

This study of ostomates' illness experience requires disclosing subjectivity and reflecting meaning of individual's illness experience, which is the reflection of cognitive representation and image. The illness cause ostomates' suffering, it will be understood by this research as well.

Embodiment

Illness experience was studied by reflecting feeling of patients and their families. Other methods were observation and analysis for viewing the illness, which embodied and became a part of body through concepts of embodiment. It was the concept for analyzing cultural constructed body and self. (Csordas, 1990)

Embodiment was accumulating process and learning from environment through practice. The external knowledge would be fused into body. As the Bourdiue 's analysis embodiment (cited in Sunee Prasongsunti, 2005). It was the result of the outer part and practical structure were merged into the inner body and had repeated for a long time. It presented to manner of walking, eating, dresses, rite, self and identity construction. (Shilling, 2003) The actor performed intentionally or unintentionally. (Sunee Prasongsunti, 2005)

The concept of embodiment leaded to understand ostomates’ suffering and body praxis after the excretion system was changed. The researcher requires studying ‘body’ for understanding how is body invaded, shaped and classified from society? Moreover, to study how does society make body meaningful?

For the ostomates, knowledge of stool excretion in the past experience is to remember the manner when defecates normally. While stoma is happening, the stool has to be released through abdomen. The ostomates’ bodies are challenged by former knowledge. Which will knowledge use to cope the new excretion way? They have to adapt their pattern in daily life activity until they are familiar to new pattern of defecation.

Thom. J Csordas’s study, Embodiment as a Paradigm for Anthropology, gave an example of embodiment. Healing practice of Christianity as good instance for analyzing human embodiment. (Csordas, 1990) Interviewing and observation were used to reveal both intentionally and unintentionally practice. Csordas disclosed that individual would define which behavior was sinful. It would be embodied to be individual’s experience as spirit power. Individual would response to treatment by unintentional act. Csordas analyzed that it was defined by individual. Individual behavior in that rite, was physical practice based on socio-culturalized imagine and assemble as embodied image.

Following embodiment of ostomates, to clean stoma as the rite to eliminate body’s pollution. The interesting issues were the meaning of feces in Thai society is garbage. (Molruthai Chaivisate, 2002) Thai people reacted to it differently by the times. In modern society, deodorizing as daily rite by using many goods. (Pimawan Boonmongkol, 1993). The rite of deodorizing reflected expectation of each society, which individual would relate to other while one accepted one’s body as social body or ideal body, waste body. The interesting question is, how do ostomates practice under above condition?

The embodiment of ostomates had presented discourse of cleanliness, not dirt, which involved to excretion in Thai society. Furthermore, it revealed that ostomates were not passive persons, whereas they were struggle agencies and cope to their illness by several means, depended on their available capacities. Their fighting presented through their bodies objectively. Besides they disclosed their need. The embodiment reflected various dimension of body, changeable and dynamic by each condition.

Moreover, by the aspect of medical knowledge as external and relearning knowledge leaded to interesting question. How can medical knowledge shape ostomates to change the former knowledge and assimilate to their own experience? Their embodiment and practice such as changing colostomy bag and odor management also the important issues to study in this research. How do ostomates practice? How can their former experience use to cope in next time? Does assimilating experience relate to social and cultural context?

CHAPTER III
RESEARCH METHODOLOGY

No any quantitative research in Thailand revealed the meaning of ostomate's body, self, identity and lived experience. Because such illness experience is the complicated phenomenon and varied in each culture. It's impossible to understand their suffering through any group of population because ostomate's suffering, value, meaning and their daily life was unique. To reflect the sensitive experiences and suffering, from ostomate and their family (insider's) perspective, it's necessary to reduce my bias and hidden power as wound caring and enterostomal therapist. Therefore qualitative research was proper methodology for this study.

Field experiences

A day on April, 2008, it the first day to launch the field work in a government hospital, a top of state medical center in Bangkok. The out patient department (O.P.D) was so crowded liked other days. Along the way to the inner room, I walked through patients and their relatives who waited for doctor.

When I pushed opaque glass door, I smelt the strong odor blew by the air conditioner. Someone had been talking behind the green curtain on the most inside of the room and spraying perfume 2-3 times caused the strong smell disappeared.

This *'ostomy clinic'* was not only the workplace for me and other enterostomal therapists who turned around for tending ostomates everyday, but also the field for my research. There were many key informants who were nice to tell their lives with stoma.

I knew many ostomates since I had worked here last 4-5 years ago. Some patients had been under my care continuously before they were on operation. They were appointed to follow up after discharged. Some wanted only hygiene instruction. To work at this department for a long time, I could feel the various suffering of ostomate. The major problem was physical suffering, such as burning sensation around the wound, unholded or disliked the stoma pouch, etc. These problems were relieved when they changed tools and could take care of all instruments. The important point was to adapt them to live with appliances (stoma kits). I rarely met the patients who could coped well while often saw some cases who had more complication.

When strong odor was fainted, a nurse who was behind the curtain addressed me as visitor. Then she went back to work inside again and leaved me read the record file on her desk. The record showed 150-200 new ostomate patients. Although some were dead, but the number of ostomates had risen every year.

Although the ostomate record file showed several data, for example patients' name, type of pathology and treatment and etc. That information did not reveal ostomate's lived experience for selecting the key informants; therefore I had to find them by other methods.

"Good morning Mr……., could I bother you for learning about your daily life and stoma problem while you were home ?" That question was raised in 'ostomy clinic' when I, who worked as Enterostomal therapist, was caring the stoma. When they accepted my request, their personal contacts were noted for interview later.

18 ostomate key informants were found within 2 weeks. They were selected by variation of age, sex, marital status, period of being ostomate. The essential criterion was all of them were informative- rich cases.

Although 18 cases were willing to share their experience, but some cases were cancelled by several reasons. Some informants missed an appointment while they confirmed. Some refused to answer the telephone and hurriedly go out after treatment in clinic and had never went back to see me anymore.

Another case was 72 years old woman who was willing to share her experience. She allowed me to interview her at her home near the hospital. I met hers and her son twice at home. Her son told me that she was the fourth stage of colon cancer and had to live with stoma throughout her life. He concealed his mother about her colon cancer and did not let her met the truth. He wanted to keep this secret firmly. His mother knew only she was colon obstruction and hope to live without stoma by surgery finally. I realized that the secret had to be disclosed during our interview and I did not want to violate her son's intention; then I stopped to ask her anymore.

Above conditions implied to key informants' difficulties. It was too risk to make them sympathy. Consequently I could not collect any data from some informants.

To be medical personnel gained advantage to know key informants but not to collect data easily. I had to realize their consent and research ethic as well.

Finally there were 8 key informants merely. Uncle Winai, Auntie Nee, Nuan, Chan, Moh, Kung and Duaen were in Bangkok and and its periphery. However I was so stress and considerate in hospital context. It might be our relationships between me who was medical personnel and the key informants. I desired to learn more about their lives in their own context.

The ethic of human research

I started to collect data as researcher, so I would introduce myself

> *"…I was student of Mahidol University and studied in master degree program. I had been studying the lived experience of ostomates: the suffering of elimination. I desired to learn about ostomy case through sharing the long term experience with stoma. I hoped these data were useful to ostomates directly. …."*

I introduced myself and explained this research's objectives, methodology and expected values with friendly. If the key informants were worried about sharing their data or they did not allow to interview, I would not ask and record anything without their permission. I had to conceal their personal data and use 'assumed name' in this study. Furthermore I had not to offend their privacy and deceived them for any my benefit. The findings did not be distorted also. All key informants would sign in consent form after they knew research's condition.

The consent form became the problem not a tool to promote ethic of human research. When each informant accepted to share experience while refused to sign in the consent form. Many cases told me that although their real name would be disclosed, it had no any problem. However I always realized to respect their right and privacy. Before every data collection, I would read content of consent form to informants and asked for their allowance verbally although they denied signing in consent form.

Key informants knew me as enterostomal therapist not only a student. Consequently I would played therapist role during interview and always reminded researcher role as well. To reduce the power relationships in social relation between key informants and me, both enterostomal therapist and researcher roles were presented with friendly, respectfully and sincerely. I hoped it would lead them relied on me as researcher more than therapist in finally.

Data collecting and analyzing

I had planned to collect data in 2 phases within 12 months. The first phase started on January to April, 2007 and the last phase was during June to December. The key informant's history, way of life, experience of stoma and illness experience and other issues in the guideline were set to ask in the first phase. The further information and verifying data would be done in another phase.

However the data collecting had launched on April 2007 to April 2008, after the committee of human right in human research of Mahidol University had approved.

The plan for 2 phases had adopted to be the one complete step. I collected and verified data in the same time.

I let the key informants to make appointment and chose the time and place they wanted to relax themselves. I always observed their feelings and checked sensitive question; besides verified data in each interview.

The first period of data collecting, most of informants were the patients in hospital where I had practiced. Then they wanted to be interviewed at hospital or the restaurant was near the hospital. Uncle Winai and his wife made appointment to see me at ‘ostomy clinic’ after x-ray examination was finished. His reason was it’s convenient and privacy. Moreover many cases were satisfied to share their experience at hospital. During the interview, I had observed their dress, verbal and non verbal performance and etc. Tape recording and jot noting were done as well.

The collected data had been analyzed for a time; almost data were front stage stories which key informants wanted to please me as nurse and researcher. Social desirability bias should be reduced and back stage data had to been disclosed. Those were important issues that I tried to balance hierarchy power with cases.

A technique was to build up friendship between key informants and me. The participatory observation method could reduce my bias and medical dominant power. Those findings pressed me to look for new research fieldwork which supports me to know their daily lives contexts. Finally I should understand them as ostomate and their family (insider’s) perspective.

Until a senior nurse gave me an idea, Chantaburi province was chose as new fieldwork finally. Chantaburi was rural area and not far from my birthplace, Cholburi where was far from fieldwork about 200 kilometers. Furthermore its local language was similar to my mother tongue language; consequently, it was not hardly to understand key informants’ worldview through the familiar language. My relatives and mother were support me all facilities such as vehicle for using in the fieldwork; moreover, my mother took care of me contentedly.

Besides ‘myself’ as a tool, the others were taken tape recorder, camera, notebook and pens as well as my dresses also look liked local people.

I had planned to work in fieldwork for 3 periods. The first period, I would introduce myself to the informants and talk about general illness. The second period, I had stayed in the fieldwork for 10 days to habituate and observe their routine lives including participate their activities. All daily data and my feeling were written every evening for analyzing and checking to complete them on next days.

When I had visited elder Somjai frequently, her neighbors suspected who I was. While Somjai and I had came back from market fair, we went to oil station. A local people asked her who I was. She replied that I was her eldest daughter who worked as doctor in Bangkok. Her answer made me smile; I had closed to be inner person of their world.

The findings were analyzed by research question and theory. The issues of “self” and “identity” were not cleared, including “sense of smell”. I decided to be in the fieldwork as third period for 5 days to verify data and complete the miss issues especially ‘feces disgust’

During collecting and verifying data, I tried to interview Somjai not too formal. I had been stress and anxious cause me to face an accident on a day morning. I was scared by a truck would crash my motorcycle on the way home. Somjai noticed my fear and asked me what was happened and why my face looked so pale. I had been relieved after told her both the accident and my worry about thesis. She persuaded me friendly to stay with her family while I worked in this fieldwork. Her kindness made me relax and warm. When I had finished my work in this area, my mother and I went to thank for Somjai and her family’s kindness.

The rural context relieved the stress and consideration between key informants and I. Ostomate’s world in rural context had been revealed while in urban context had not been cleared.

I decided to back to the first fieldwork again. Sister Duean was the first ostomate whom I thought of. She was under my care since September, 2006 and I had always perceived her suffering. I asked her consent first and told her the truth that her life would be shared to the other ostomates and intimate persons as ostomate’s experience. She accepted to be the informant.

Data collecting was done by informal interview. Tape recorder and notebook were tools for recording the important point during dressing the wound and dining. I had a chance to visit her family in Chiangrai. This case’s findings were checked by research question and theory as well as the others.

However theory was only the guide for analyzing and reflecting phenomenon. This research would present ostomates' experience through narrative method with theory analysis. Moreover this study would show ostomates's perspective and their coping with the new identity and suffering.

Data from the field

Summary, in this study, there were 9 key informants; they have experience with stoma in various durations, ages, sexes, marital statuses and various experiences of appliances. The characteristics of key informants in this table.

Table 1: Number and General Characteristics of Ostomate

Characteristics		**Number**
Gender	Male	2
	Female	7
Age	Less than 30 years	0
	30-40 years	2
	41-50 years	5
	More than50 years	2
Occupation	personal business	1
	public health personnel	1
	semi-government employee	1
	jobless	4
	Government teachers	1
Period of living with stoma	Less than 1 years	2
	2 years	2
	More than 2 years	5

The experience of appliance

In the present, stoma pouch (ostomy bags) has various forms and sizes for different needs. The important point is how to select properly for each patient regarding to their economic status, career, skin irritation, convenience of buying, and so on. The bags can enhance the patients' quality of life and reassure for their living. Most patients may prefer the most effective one that can prevent from the leak of feces and smell, while some may choose the light or cheap bag. The types of stoma pouch are: 1) close-end pouch (for hard feces, convenient for travel), 2) drainable pouch (for liquid feces, necessary for post-operation), 3) 1-piece pouch (for disposable use, convenient for the elderly) and 4) 2-piece pouch (for recycle use, cleanable). As following, some ostomates selected ostomy bag in different ways.

Uncle Winai used to try 'a new image floating flank' that has 'two pieces with open ended top' and also it is expensive for approximately 300 Baht. This kind of floating flank is composed of 'base plate' (a plate have skin barrier) and 'pouch' (plastic bag). The base plate can be called '*Pan'* that made of artificial leather with 10 centimeters diameter and it is not cut to open for covering a center stoma. Additionally, there is a strong plastic periphery attached two pouches together. The pouch is one piece with open ended top without adhesive strip. The diameter of its plastic edge is for 44 meters adjoined base plate. Whenever there are feces flowing out, the used pouch can be detached for cleaning and then another pouch is applied in place without changing base plate.

Miss Kung and Mr. Winai have used 'Coloplast 5930' valued 60 Baht. This kind of stoma is 'one piece with open ended bag'. Its figure is a transparent plastic along with rounded circle top; its bottom is concave to narrow the stoma in order to be a channel for releasing feces or air. When this kind of stoma is not used, it should be rolled up with plastic glazed wire to protect the flowing out of feces. Inside stoma touching a body made of artificial leather that can absorb some feces. There is the adhesive strip sized 2 cm in outside part of stoma. The center of stoma has a hole used to cover the ostomy that is already cut for this usage sized 38 millimeters.

Miss Duean has used 'Alcare D-5' valued 130 Baht. This kind of stoma is 'one piece with open ended top' like the one of Mr. Winai. Their figures are alike to each other. However, this kind of stoma has two tiers; the first inside tier is plastic and the second outside tier is a thin paper like mulberry paper. It helps conceal a vision of feces inside pouch. In addition, there is carbon sheet sized 10-baht coin inside stoma for soaking gas and smell. The bag can be adapted its size and shape suitably for intestine.

Miss Ong has used 'one piece with open ended top' named 'M-NILES®' in the price of 13-16 Baht. It is a curbid white plastic bag. Both top and bottom are close ended. The side touching skin is adhesive strip with circle shape sized diametrically for 38 millimeters that can cover emerging stoma.

Mrs Somjai has used 'one piece with open ended top' named 'M-NILES®' like Ong. Later she used a *'tung anamai 200 pi'* (200-year healthy bag), it designed by ostomate. This kind of stoma costs 180 Baht and composed of three parts. The first part is a strong plastic periphery with 60 millimeters diameter; its inside and outside part overlap each other. Two small buttons in outside part are for suspending stretching hose. The second part is stretching hose is used for pulling circle edge to fit well for the body. The last part is the plastic shape like food bag. Whenever the bag is used up, instead the food bag can be applied. The stretching hose is changeable when it is inoperable.

CHAPTER IV
THE SUFFERING OF OSTOMATES

“Stoma” is a structural modification of organs that usually function in elimination. Today, this physical event happens in a context of medical treatment and is not known by the public. Thus, being an ostomates are like “hidden people”. When they put on clothes, they do not differ from normal people. No other people would ever know that they are ostomates. The stories of ostomates are kept hidden, not only about the history of ostomy treatments; the chronicles of the suffering of ostomates are also unknown.

When we attempt to understand “the world of ostomates”, we have to learn from their lived experiences rather as hospitalized patients. As a basic understanding of their suffering when they return to society, this chapter will describe daily life of ostomates from illness experience and problem management in stoma care and adaptation with physical event that has changed.

Although some part of following stories are unable to be inspected, these stories were from patients that were delighted to tell me their suffering experiences. These speeches and stories were collected from full periods of illness. Their voices reflect suffering and individual life experiences that were related with social context, which were created from change in daily life after having stoma.

The life world of ostomate

In the first month of collecting fieldwork’s data, I appointed with an ostomate as a primary informant and he was free to choose location and the length of talk. The informant chose the day that he came to my hospital to do a computer x-ray in order to keep track of the disease.

On that day, I chose to wear casual clothes in order to create a friendly environment during the talk. I walked to a computer x-ray room, where I appointed "Uncle Winai" at nine o'clock.

The computer x-ray room was divided into three parts, a lobby part and a diagnosis part inside and the area in the middle were placed with aqua-colored sofa for patient's relatives to sit. The sofas were filled with people.

Although the air condition inside made the temperature inside the room comfortable, it didn't help me become more patient. The appointed time went by about two hours. I decided to ask a female staff at "information" counter in the lobby. She replied that Uncle Winai is still being diagnosed in the room. I was little relieved, but my I began to feel anxious again after half an hour. The clock showed me that it was already eleven o'clock, so I decided to call Uncle Winai.

A large tall old man, wearing light blue jeans, T-shirt and yellow polo, with shirt untagged lift up his mobile phone at the same time I pressed call and walked to an old woman who was sitting on a sofa in front of mine. He looked at me and smiled. I went to introduce myself.

Uncle Winai introduced me Aunt Manee, his wife and said *"Let's go to Ostomy clinic, I usually go there every month anyway."* We went in elevator to go to the third floor of the same building.

Today 'ostomy clinic' didn't have a rancid smell like a day before, but was filled with a light perfume instead. Green curtains were tied up next to the wall. The nurse at the desk was talking with patients. I greeted with the room owner and asked her permission to use the room for the interview, while I was pulling a chair to make a circle in the corner of the room.

If I didn't look after Uncle Winai as an anal cancer patient since 5 years ago, I would never know that he has an ostomate and a stoma under that t-shirt. When I looked at his body and clothes, I cannot see any difference around his abdomen from normal people.

As we were talking, Uncle Winai lifted up his shirt. A stoma pouch was placed on the left side of his abdomen. It was a plastic bag. It was probably transparent, but now it is now muddy yellow-colored. The top of the bag was circular and the bottom was concave in order to make its end smaller. This part is used as a path way for eliminating feces and gases. If it is not in used, it must be folded, otherwise feces will leak out. There was a little bit of air inside, but I could not smell anything from that bag.

Uncle Winai's illness started in 2003. He was approximately 60 years old. At that time, "Aunt Manee" looked after him both at hospital and home. Uncle Winai had 5 children before and another son after he was married with Aunt Manee, which stays together in the same house, while his other children have moved out. However, they still visit and send money for his father.

After he was retired from the police force, his spending and most of hospital treatment cost are relied on his pension. Although he was retired, he was not vacant. He bred gamecocks, birds, gardening and participated in a village committee. His involvement in these activities helped him to have time to observe abnormalities in his feces.

Uncle Winai's house is located in Ayudthaya province. There two toilets in his house's area. The one inside his house is a modern toilet, which you can sit on. The one outside is an old-fashioned toilet, which one has to squat.

> *"After I was retired, I didn't have much to do, so I usually went to the toilet outside. Before I go, I have to take a cigarette with me to smoke inside. Because I was squatting, I observed that my feces were red like there was bleeding. I was not so sure at first because there was only little blood. I thought that it might be dysentery, which I had when I was young, but I didn't think too much about it."*

The next day Uncle Winai went to toilet outside the house as usual. However, the bleeding didn't go away. Uncle Winai began to worry, so he decided to seek some advices from a doctor. He received some medication from doctor without getting further diagnosis, but the bleeding was gone.

During that time, Aunt Manee was feeling not so well, so she had to go to provincial hospital. Uncle Winai felt lucky that he brought medications from first diagnosis with him. As his wife was getting diagnosed, he told the doctor about abnormalities in his feces and showed him his medications, so the doctor performed a primary anus check.

"There is a tubercle in the large intestine, a size of a pea. It is shiny, slippery and ready to bleed. If the feces come through, it must bleed." Aunt Manee described what she saw when the doctor was looking through the microscope.

After the check is performed, the doctor advised Uncle Winai to continue his treatments in a bigger hospital. So the couple decided to come to Siriraj hospital. Doctor performed ultrasound check in the abdomen area (checking the metastasis of the disease – author), large intestine and anus were checked by colonoscopy and the tumor was cut out to be inspected. The result stated that it was obviously a cancer, so Uncle Winai was advised to go to the radiation therapy department in order to make the tumor smaller before a surgery is performed.

When Uncle Winai met the radiation therapist for the first time, the doctor told him *"Please don't escape from me"*. Uncle Winai told that the therapist met many patients who avoided radiation because they believed that radiation will make them die. Uncle Winai smiled as he saw the good will of the doctor and received the treatment with medications at the same time. While Uncle Winai was receiving radiation treatment, he showed neither sign of allergy, nausea nor pain around the anus. After he received 25 radiation treatments, he was on chemotherapy for six months; 5 days per month, 5 hours each day.

'Stoma' an organ with several meaning:

The story of the illness experience of Uncle Winai is not that much different from others. Many said that they bleed while eliminating and thought that they had hemorrhoids, but they were diagnosed with cancer and had to have surgery and intestine modification. They usually hear words with hidden agenda such

> *"The doctor said that there is a tumor in the intestine and it has to be checked whether it is a cancer. If it is a cancer and surgery has to be*

performed, maybe the intestine cannot stay at the same place, perhaps it has to place it outside the abdominal."

"…. Granny, we have to perform a surgery, it will give you five more years"

"tumor, it has to be treated immediately, otherwise the intestine will explode"

These doctors' explanation made an image of a stoma in Uncle Winai's thoughts and it lead to the lost of anus. It is an organ that controls excretion of feces, smell and gas. Anus is replaced by a stoma as "a pathway in excreting feces, gas and smell in place of anus" with bio-medical perspective; it does not only reflect medical professions' perception of stoma, but it also indicate that they perceive human's body as machine, erasing thoughts, feelings, values and other meanings of ostomates, which is actually complicated and delicate from various perspective.

Saving lives and avoiding death: the same meaning and medicine

Uncle Winai has perceived this meaning of stoma from medical professions during the time of his treatment until it was preoperative period. While Uncle Winai was staying in the hospital to prepare for surgery in a next day, his wife and children came to visit. Uncle Winai and Aunt Manee told me about their children's perspective. *"If the surgery is not done, it would not be good. Losing an organ is better than losing a life."*

The couples reflect their children's perspective that they thought if the tomor is not removed because fear of losing anus and ability of eliminating, their father will die from cancer, but if the anus and cancer are removed, the disease will be treated and Uncle Winai will continue living.

If we look at Uncle Winai and his family perspective, we can see that they are normal people that have realized the importance of stoma for cancer treatment, but for "Ong" the stoma was performed in order to reduce the pain from intestinal obstruction since eight months ago (20 April 2007). Later, he is diagnosed with colon cancer.

Ong is a public health personnel at public health centre in Nakorn Pratom province. He is married and has one daughter, who is 21 years old and studying post-graduate at Silapakorn University.

Normally, Ong would defecate every day. But somehow, he started to have constipation. There was no obvious pain. He thought that it might be dysentery because he just went to the northeast part of Thailand, which he ate some uncooked food. Once he returned home, he had felt that he had to defecate, but he was unable to. However, he was able to go outside normally; there was no pain and only little flatulence. He went to hospital and wanted to receive enema. He thought that he would be relieved, but after he received enema, medications and laxative for 9 days, the situation did not get better. So the doctor decided to do an x-ray and found that feces are stuck on the top part of the intestine because there was a tumor obstructing an intestine. The doctor decided to perform an emergency surgery.

> *"When I learnt that I had an intestinal obstruction, the doctor told me to get treatment immediately, otherwise the intestine will explode. On the day, the doctors performed a colonoscopy, so I had to fast anyway. Once I came out of the colonoscopy room, I went immediately into the surgery room. The doctor said that he would cut a part of the tumor out to get inspected. He told me back then that I had a high chance of having a cancer. I didn't worry that much because there are a lot of people with colon cancer nowadays. Some of them can continue living for ten years and nothing happened to them. I only thought that whatever happen, I will accept it."*

Ong thought in his mind that he must have colon cancer, but he recalled about a woman of 25 years old who had a stoma for about 20 years and is still alive and he had changed a stoma pouch for her once. Ong thought that if he has a cancer like her, he would not be afraid because the medical profession had advanced drastically compared to the twenty years ago.

However, when thinking of having a stoma, Ong thought that he would let fate take its place. Although he felt uncomfortable to change stoma pouch frequently during the first period, two months later he started to get use to it and learnt that he can have a surgery to close the stoma down in several months, which lightened his hope up.

Ugly and strange: negative values

All the time of having a stoma for 5 years, Uncle Winai has perceived the meaning of a stoma in the same way as medical professions that saved his life and accepted changes in the body. A stoma has become a part of his life that he does not worry about using public toilets anymore. Uncle Winai said that during the first two years he still didn't know when the feces were going to be eliminated. If he had diarrhea and excreted a lot of water of all time, which he had to drain feces from the bad frequently, going outside is difficult because of toilet issue. But after having a stoma for a while, Uncle Winai can use toilet in gas station or department store conveniently.

The feeling that a stoma has become a part of body is reflected from "living a normal life" like a life before having a stoma. An import issue of an ostomate is that one have to protect the stoma pouch from water, so the adhesive would not be degenerated, which make the bag will disengage from the abdomen. However, Uncle Winai does not think about this issue because he perceives that a stoma and the pouch have become a part of his body.

Uncle Winai told that, around his house in Ayudthaya, there is a water earthen jar for storing water. One day, he was at his house and it suddenly rained. He wanted to store rain water, so he ran out and was soaked with rain. When he returned to his house and was removing his shirt, he saw his abdomen and just realized that there is a stoma pouch in front of his abdomen. Uncle Winai has felt like this for several times. Sometimes he goes into a pond and once he come out he will inspect the bag. If he sees that the bag is wet, he will dry it. If the bag is not leak or disengaged, he does not change the stoma pouch.

Although Uncle Winai has realized the change of the body that a stoma has become a part of his life, after having a stoma for five years, Uncle Winai still realize the “ugliness” of the stoma’s exterior, which is “disgusted” and undesirable for other people to it.

> *“At first, I felt uncomfortable. I was not used to it and felt stressful frequently. If other people see it, it would be ugly. If not, it won’t be. I felt embarrassed… well it’s a special ass. It is disgusted by others”* Uncle Winai said.

Uncle Winai’s feeling that a stoma is ugly and disgusted by others is the same feeling that Ong has, a person who had a stoma for 8 months and has to accept that he has to excrete through a stoma, not to treat a colon cancer, but to ease the pain of intestinal obstruction.

I remembered the day that Ong came out from surgery room and came back to recover in the patient’s ward that I work in. The first question Ong asked me before he is fully conscious from chloroform is *“Is it close?”* It makes me curious how Ong would think of living a life with a stoma. A week later, Ong described his feeling before the closing stoma surgery.

> *“I had it for a long time, I want to close it down, so I can go anywhere like normal people. Having a pouch with you all the time is tiring. Even other people don’t know that I have a pouch, but it smells and my shirt becomes baggy (the area that is attached by a stoma pouch)”*

When Ong’s body is normal again, he described his feeling that *“feels good, doesn’t have to carry the bag around, it is such a burden. I feel that I have an excess, unlike normal people”*

The feeling of having an excess is a feeling that a stoma has an alienated status in a body and life, no place in the body and no concrete definition. It can be said that meanings and values of a stoma that are given by people are negative.

Wound, anus, special anus: transformation of meaning

A person must construct new values and meanings for stoma, which is a new part of the body in order to live a normal life. For Uncle Winai, when he perceive his body which has a stoma on the left side of the abdomen. He expresses his feeling that *“Aren’t I afraid or feel disgust when I see a stoma?”* and thinks that he is not different from others and realized the significance of the stoma as the mean of survival because he needs it for excretion.

Once Uncle Winai went to the international botanical fair at Chiang Mai with friends, it was well-organized with convenient facilities including toilets around the fair. However, there are still not enough toilets to meet the number of the people who came to the fair. Apart from giving out unpleasant smell, the waiting line is very long. Uncle Winai did not have to wait in a line like other people. He gave an example of a stoma when he didn’t have to face a toilet-usage problem like others.

> *“It’s a special anus, when I travel, I don’t have to go to toilet. When only need to go to toilet when I need to excrete (taking out feces from the bag). When I’m on the bus, I don’t have to go toilet to the business.”*

Apart from seeing it as a need for treatment and survival, Uncle Winai’s wife thinks that having a stoma is normal. It is not different from “anus” of normal people. It is just “anus in different places” Stoma has a duty in excreting like others’ anus, but her husband’s anus is only “moved” from the bottom to the abdomen.

> *“We must not feel disgusted towards him because we do feel disgusted… and we have to give courage that it is a normal thing, have to think that it is also a buttock, but only in different places, it is the same as others’. Other people have to excrete like us, just from different places” Aunt Manee said.*

Uncle’s Winai and his wife attitude in perceiving benefits and meanings of a stoma demonstrates changes in meaning and other significance of a stoma other than excretion. It is also a self-empowering, not to feel alienated and unwanted from others.

Uncle Winai and his wife’s realization of values and meanings of a stoma can be divided into three forms; medical profession’s meaning, negative meaning and transformed meaning. These three meanings all reflect values and meaning of a stoma in various forms that are unable to be separated or reduced to only one meaning.

Various definitions of stoma are always changing according to different contexts and are embodied in daily life. It does not decrease the value of one's life and it expresses the reality of the body. When one has become a stoma, it is related with life and illness rather than just the value of excreting, like medical profession's meaning.

Daily life: eliminating in front of an abdomen

After surgery, Uncle Winai had to stay at the hospital for about 10 days. He learnt how to clean a stoma and peristomal skin, change stoma pouch, how to empty pouch (pour feces out of the bag), how to prevent and treat side effects, choosing the right bag and how to live with a stoma. *"At the hospital, they told me before surgery, how to live and what to do"* he said.

From medical professions' perspective, these learning processes are crucial issues that help all patients to adapt and accept the situations and diseases that they are facing, see the importance of self-care and are ready to look after their stoma by themselves because when living with a stoma, one cannot controls their elimination, so one must use a stoma pouch in order to keep feces in the bag.

Although using a stoma pouch is not that uncomfortable, one must adapt how it fits oneself. Uncle Winai has used different types of stoma pouch. He used two-pieces and drainable pouch before, but didn't use them more than ten sets because they weren't very comfortable. They had hard thick plastic edges and strained his abdomen. They also have space on both sides, which make gases push outward and the smell come out.

So in the end, he chose to use one-piece and drainable pouch because he feels that it does not strain his abdomina and is able to stay on the abdomen for 4-5 days without having to change. However, Uncle Winai's stoma pouch usage has changed his daily routine.

A routine that is a 'burden'

During the period of recovery at home, Uncle Winai still had pain from surgery. He cannot sit comfortably. So, Aunt Menee was a person who took care of a stoma such draining out feces, cleaning the stoma and changing the pouch for months. When Uncle Winai was strong enough to go outside, Aunt Manee reduce her duty to only changing the stoma pouch. Uncle Winai is able to discharge gases and drain feces from the bag by himself.

Aunt Manee learnt how to look after Uncle Winai at the hospital, but it took about 2-3 months to get skillful at it and continuously for five years that it has become her daily routine.

> *"First step, you have to remove the pouch out and put it into a plastic bag, wipe it with cotton ball and dried it with a fan. When it is dry, you sprinkle the powder and glue (skin barrier paste-author) it around the stoma, close and fold the bag. At first, it seems like a big business. When I saw how it's done, I thought that I would not be able to that! I had never done it before. It didn't take too long, about two or three months because in the beginning I was afraid that he will feel too much pain, feared that when I pull or apply medication for him, it would hurt. I was used to it after about a year."*

As one cannot control excretion, one has lost the old form of elimination and the use of stoma pouch and other appliances become a daily routine that has to be applied according to an individual life. One also has to control one's body in the plan in order to prevent side effects. These changes in daily routines have created various types of discomfort and suffering for stomas.

Some ostomates express the feeling of excreting through a stoma as "a burden" such Kung, a police's wife, 48 years old, diagnosed with colon cancer 2-3 years ago. Before the surgery, the doctor told her "If is severe, we have to cut the intestine", but a stoma has never been in her life. She has never seen a stoma before. After having a stoma for a year, even though she realizes that she has a stoma on her abdomen and has to excrete through that, but she still avoids talking about it. She tries not to even think about it, doesn't want anyone to see it, even her husband and children, who are closest to her.

Everyday she has to sell pork at Bang Kae market. The air inside the market is hot and humid, which makes her sweat all day. She tries to act normally, so others would not know her body's change. Living with a stoma makes her suffer and miserable and feels that it is a burden to excrete out of an abdomen.

> *"I very sad and regret that I decided to get a surgery. It is something that makes my mind suffers. It is a burden. At the beginning, it was very hard, but I tried not to feel stress about it. I have to worry about it all the time. If it does not stick, it will get dirty. The problem is that when our skin is glued for many years, it will start to rot and will not stick well. When I am working in the market, it is very humid, sometimes I sweat and the glue won't stick and sometimes I have diarrhea and it will come out. It is a torture."*

Apart from feeling that excreting is a burden, changing stoma pouch frequently creates scar and rashes around the stoma, which is a side effect from changing the stoma pouch every before taking shower. But Kung's suffering is not from physical side effect, but living a life with a stoma pouch.

After Kung has a stoma, she always uses a stoma pouch with a commercial name "Coloplast 5930", one-piece drainable pouch. Although she is able to take care of herself, but she feel troubled because of her conflict with hospital staff who told her not to change a stoma pouch everyday. Normally, if she doesn't shower, she has to clean the stoma pouch with water and wipe peristomal skin before she put on a new bag. In the first year, she had to use a cotton ball to clean the stoma, but now she has changed to using tissue and flushes it down the toilet after using it. If she has to take a shower, after removing the old bag, she cleans the stoma first then attaches a new bag. The hospital staff sees that removing bags frequently creates rashes and scar around the stoma, which makes the bag unable to stick well.

Although she feels that changing bags frequently is a burden that happens everyday, but Kung still tenacious to change the stoma pouch every time she showers.

> *"Some people said that why I don't use a bag for several days and have to change it everyday. This is a real problem that they don't see changing frequently is a torture for me. Sometimes it is dirty and I am feel*

> *very stress that if the bag is attached I don't get to shower. If I shower and clean it, I feel comfortable and normal. I don't have to worry. If we change the bag and shower, it feels more comfortable, sometimes it is dirty, and it is a torture."*

If we consider that showering and not changing the bag is Kung's suffering, it may be too superficial to perceive it that way. When we look further, her suffering is caused by the feeling of "dirtiness, not hygienic" after showering. If she showers without removing out the old bag, the area around the stoma would not be cleaned, which makes her feel uncomfortable.

Shower… a routine that needs to be modified

Although Kung has to change the bag everyday after shower, but Uncle Winai will only change the bag when it leaks or the period of 4-5 days. When he needs to change the bag he will take a chance to take a full shower. Before taking shower, he needs to remove an old bag out and wipes feces that remain peristomal. The day that he doesn't have to change the pouch, he cleans himself by using a wet cloth to wipe his body and clean with soap. After that he would wipe the top part of his body with wet cloth again and the part below a stoma is cleaned by pouring down water. Uncle Winai called this method of shower *"half body shower",* which helps Uncle Winai to use a pouch for 5 days and shower everyday without needing to change the bag every time.

Smell and See: new routine

Before the surgery, when Uncle Winai woke up in the morning, the first thing he had to do is to go to toilet with a cigarette. But after he had a stoma, first thing that he has to do is observing himself whether he has 'feces' smell' is leaking out of the pouch, if there is no smell, he has to see around the edge of the pouch that is attached to the pouch, if the adhesive tab around the bag is turning yellow, then he has to change the stoma pouch. If he leaves it too long, the pouch will leak. The feces that leak out will irritate the skin and create wound (excoriation or partial thickness skin loss-author) and there would be a burning pain while applying medicine (skin barrier cream-author) on.

> *"Sometimes I don't realize that it leaks, so I feel itchy"* Uncle Winai said.

> *"Sometimes there will be smell, we have to be careful. If it seeps out, we have to change it quickly."* His wife adds.

Other than that, when it comes near the fifth day, which the skin barrier starts to degenerate, Uncle Winai has to be careful of his movement and avoids food that creates smell and gas such garlic, beans, cabbage, onion, soda drinks and etc in order not to create excessive gas and smell from the stoma pouch.

> *"I have to be careful, because if there is a lot of gas, I don't bend down, otherwise it will push the air out. I also have to walk and sit carefully. If there is too much gas, then I have to take it out, if there are feces then I have to take it out."*

Uncle Winai use 'smell' as a warning sign, which enables him to put on the pouch in the right time. The experience in using the stoma pouch made Uncle Winai and Aunt Manai observe feelings such "wet", "itchy" or "smelly". In the morning, if it is only a little itchy, he has to check anyway. Sometimes the bag has not come out yet, but there will be some leakage of gas and smell. *"If it doesn't leak, then there will be no smell"* So "smell" is a warning for Uncle Winai that the colostomy is "leaking".

Experience of pouch disengagement and feces leakage

Apart from changing stoma pouch, cleaning and showering while having a pouch (bag) on an abdomen, the experiences that make many ostomates suffer are when the pouches come off or when they leak, which can happen all the time, especially in the first stage of having a stoma.

Normally, Uncle Winai's stoma won't have too much problems, but if he has diarrhea, the pouch will usually leak.

> *"If I have a diarrhea and the bag (pouch-author) breaks. The feces are acidic right? If it comes off and I can feel it right away that it hurts. Skin is around this area is very weak. If the faces came out, it's quite problematic, rashes come up immediately. Well, I never have any allergy. If I have a wound, it heals quickly. Gee, if someone is diabetic and excrete this way and have rashes like this, it would be very difficult."*

Experience of pouch disengagement and feces leakage happened a lot with Ong. Working as a public health officer, he has to meet a lot of people. Sometimes he has to have a conference in an air-conditioned room. If the feces came out in a large amount, the smell would be obvious. The person next to him would be able to smell it, too. Ong has to go out of the conference room in order to change a stoma pouch in the toilet.

A close friend of Ong who usually travels with him in a car said that on a day when the car's air-conditioner is turned on and windows are closed, he could always smell it. Even Ong is gone from the car, the smell is still there. However, he does not feel disgust. Once they went to a dinner during the New Year, while he was talking to his friends, Ong just disappeared for about half an hour. He was anxious about Ong, but could not find him. Finally, Ong walked back and said "I went to toilet."

> *"On that day, I excreted a lot. When I was standing or sitting, I feel that it is going to break, so I have to go and change it. It was leaking out around the edge. The bag was having a vacuum, too, so the feces leak out. Ong talks about the situation of that day.*

Ong still travels with this friend frequently. One day, while they were driving to funeral, feces leaked out from the pouch. So Ong had to drive back home to change his cloth, which is about 10 kilometers in distance. Because of the uncertainty of feces' quantity and inability to feel the excretion through a stoma, he is unaware and put his hand under his shirt to untug it, a lot of time his hand is dirtied by "feces". If he can smell and feel "wet", he is able to prevent this mishap.

Embarrassment and fear of being disgusted

Uncle Winai has changed physically. Although, people would not know that he is an ostomate, but a leakage experience is something that tells him that he has a different way of excreting. Many have accepted the change of the body, which are the results of illness and caretaking with feeling of compassion such feeling of Aunt Manee.

> *"I don't feel disgust. I only think that a normal person has to become like is quite pitiful because no one wants to belike this. It is something inevitable; nobody wants to be this way…. But once you have to live like this, you can only accept it."*

However, while they are having social interaction, many perceive that a stoma is "ugly" and "disgusted" by others such one of Uncle Winai's experience.

On that day, Uncle Winai was sitting in front of his house. A long time neighbor, who has known him for ten years, came to talk to him about his well-being and ask whether he can have a look at the stoma. As an open-minded person and not thinking that having a stoma is absurd, Uncle Winai pulls his shirt up in order for his neighbor to see the stoma and stoma pouch. Uncle was able to see that his neighbor was 'shocked in surprise". This event made him feel very embarrassed that he never shows them to anyone anymore, except for his wife and medical professionals.

In social interactions such social activities such, going to work, funerals or outside and etc makes ostomates feel alienated, anxious and confident because they cannot control their excretion at anytime and are unable to expect other's reaction when the bag is leaking.

> *"I'm afraid that I would be disgusted by my presence. If I were them I would not want to sit near ostomate. I don't know how they would react, maybe they don't react, but if it they're not close friends, I don't anyone to see it….. Once the bag was leaking so I had to drive back home. During the New Year, I was having dinner with friends, but then I had to go into toilet for half an hour. There was a lot feces and had to sit and get up a lot, so I could feel*

> *that it was going to leak, so I went to a toilet to change the bag. On that day, it leaked fair bit. It leaked out on the corner that I put plaster on." (Ong)*

This feeling will always emerge when they are outside and interact with people who are not within the family.

> *"Although, others don't know that I have a bag, but it smell and shirt becomes baggy. So I have to put on safari shirt when I go to work. If I tug my shirt in, it will be ugly and annoy. If I unhook my pants, it will smell instantly. And if I have some food and my stomach is not well. Digestive system will work very quickly, sometimes excreting very quickly; it would fill up in a short moment. Once I was going to get chemotherapy, I had to park in front of my partner's office, lie down and got her to change the bag for me. The thing is that it is never certain. It depends on food, if it (feces) is watery, it would be filled up very quickly."* (Ong)

The following actions and thoughts demonstrate the feeling of disgust for feces, which make ostomates take in those thoughts automatically. It makes one interpret oneself as "dirty, unclean and disgusted by others" Fear of being disgusted from others impact ostomates to change their lifestyle, especially diet, clothing and etc. These experiences are continuous, dynamic and one must always be adaptable.

Apart from being afraid of other's reaction, ostomates still perceive that feces are "dirty, waste."

> *"Feces by itself are dirty because it is waste. But if we treat it correctly, then it is dirty. When I have clean, I use cotton ball and I wash my hands…. Feces anybody feels disgusted by it, not only human's, dog's and cat's and these types of things are all disgusting by nature." Uncle Winai*

> *"Of course, they all disgusting. They are feces, if there emits smell too, it is even more disgusting... right? The smell that comes out from an stoma is not like fart. The smell is stronger, more rotten like something stale…" Uncle Winai's wife said.*

Apart from a stoma and feces, smell of feces is also disgusting, but these feeling of disgust are results of sensing "feces and feces' smell", which are reflected from Uncle Winai's thought that realized that having a stoma is about illness. He does not feel disgust towards feces and the stoma because he can take care of it without touch feces.

> *"If you are used to it, you won't feel disgust about it because they are not disgusting because you don't have to touch it," Uncle Winai said.*
>
> *"Because I don't have to touch it and when I take it out, it does not stain me. I am careful enough." Aunt Manee adds.*

The suffering from body's change made ostomates lose their old self and are not able to accept differences. The perception of these changes is from seeing, which is a sense that people normally emphasize. Others usually react in some way when see a stoma such as "sign of shock and surprise" of Uncle Winai's neighbor. This type of reaction make one realized the feeling of disgust of others when one can see it. Other than that, touching by hand is a sense that construct thought immediately that "feces are dirty and waste", which is reflected from "Thoughts and actions" of cleaning a stoma.

The feeling of ugliness and disgust that are emerged from the sense of seeing and touching do not create the same level of suffering as "smelling feces", which is an issue that ostomates signify. Uncle Winai and his wife gave their opinion that smelling other's feces are more disgusting than the feces itself because the smell communicates with oneself and others that there are feces coming out of the body.

Ostomates' social interactions reflect their suffering that are derived from feeling of being alienated and perceiving that feces and a stoma are dirty, disgusting and are undesirable by others. It makes many ostomates worry that they will lost their social interactions with others, especially fearing that close friends and family members will feel disgusted. In Uncle Winai's case, he shows his status to people who are close to him in order to let them realize and accept these changes, which are from illness. Surprisingly, no one expresses the feeling of disgust. So the feeling of self stigmatization is something that emerged from interacting with others.

Chronic illness: Cancer is aiming

The Uncle Winai' realization of illness as an ostomate is related with cancer that creates feeling of "death" and mental reaction. Although living with a stoma for the last 5-6 years did not create many problems for Uncle Winai and his wife as the feeling of torture that derived from colon cancer. There is a feeling of conflict inside that this disease can be cured, but the feeling of "death" still harming them all the time.

> *"If I was treated early according to the doctor, it would be cured… I'm not afraid of it while it is aiming, I'm afraid that it will shoot. If it only aims, I won't die for sure. I'm not afraid. At first, I fear a little because I don't know it well, but now I know it. But cancer is not to be feared. If you know early, it can be treated…. Now I'm fine." Uncle Winai said.*
>
> *"Nonetheless, I still worry, I don't what will happen. I don't know whether I fear him or me dying because for sick people, it is a natural thing. Everybody has to die someday. I only hope that if it is worse, we don't have to suffer too long. Whatever happens, I have to take care of it anyway" Uncle Winai's wife adds.*

The image of "death" is always disturbing feelings and thoughts of every cancer patients, even a public health officer who knows about treatment and the course of the disease. So, it's a problem for Ong. He assumes that if colon cancer is cured, but he still has a stoma, he will be able to accept it. After living with a stoma for 8 months, he started to get use to changing the colostomy.

The conflict and negotiation of thoughts that one has to die from cancer of Uncle Winai and Aunt Somjai are struggles with an image of cancer, which dominates thoughts of people in the society to manage with bio-medical thinking process, especially body's management with various treatments, including ostomy surgery.

As Uncle Winai recalls the day that he was diagnosed with colon cancer, going through treatments and experiences of various symptoms, it makes Uncle Winai understand deeply with the phrase *"A life without illness is the luckiest thing."* As he had to struggle both physically and mentally while his body was down. Although he was very depressed, he had to fight with death. The illness's experiences of Uncle Winai and other ostomates made me learn about thoughts about being an ostomate, adaptation and perception while sick and being an ostomate, which makes my perspective get closer into the world of ostomates.

Marriage relationship: Changes after having a stoma

An experience of becoming an ostomate is an obvious body's change. Apart from oneself that sees one's body is married couples. Changes in sexual intercourse make ostomates suffer, especially the story of Mor, a muslim woman, 47 years old.

Care after well, but have an affair

Mor had colon cancer and received ostomy surgery. She stayed at hospital for two months for recovery and returned home and was look after by her husband, Bung Ju, who helps her changing stoma pouch with compassion and does not feel disgusted.

During twenty years of marriage, Bung Ju has never thought of leaving his wife and children. Although he was a philanderer and had many women when he was young, he let go of those relationship because he realized Mor's benevolence. She works hard both in household and outside and never a fussy person.

When Mor became an ostomate, Bung Ju realized that his wife was afraid that *"He will have an affair, afraid that he won't love her anymore"*, but for him, he is still able to love and continue a relationship, without feeling disgusted about a stoma. Although before Mor was ill, normally she would sleep with her husband everyday or at least once in 2-3 days, but it had to be stopped for a while as Mor had to get radiation therapy in the area of anus and perineum. It is Bung Ju again, who cleaned and looked after the wound. After three months, they returned to having sexual intercourse again. Bung Ju said that he was afraid that the wound was not healed totally and his wife would feel hurt, but if it is unavoidable, he just has to be softer about it and let his wife use less effort.

While Bung Ju said that *“there has been no change in the family”,* his wife told me that *“My body is fine, but my mind isn’t”.* After surgery, her husband has an affair with a woman in Bangkok. When they go to hospital for radiation therapy, he always goes to her house and if he had to work in Bangkok, he won’t come back home in Ayudthaya, but will stay at his mistress’s house, it makes Mor anxious.

Although, Bang Ju has a mistress, but he still come back home, take Mor to hospital and change stoma pouch for her. When his daughter learnt about her father’s mistress, she didn’t talk to him for months, but she thought that without her father, who would look after her mother. *“Now, dad is still looking after mum, take her to hospital, looking after wounds.”* Mor children told her to accept it.

Mor just tries to think it as *“kama”* (destiny). When her husband was younger, he had some affair, but once she told him to stop and he stopped, but now she is ill, if her husband will have an affair, she has to accept. Sometimes she muses a lot about this issue. All the neighbors gossip that *“If my husband does this to me, it’s worse than being ill”*

Good relationship, but there must be a cloth on an abdomen

Kung’s husband is a philanderer, they separated once, but they continued their relationship before she fell ill. Kung feels that her husband loves her and understand her condition. *“He knows that I am in this condition, but he doesn’t show any sign of aversion.”* The doctor asks her every time she comes for a check *“He asks how is my relationship, afraid that there will be problems because my partner is a police.”*

She never shows a stoma pouch to her husband, even during sexual intercourse. *“He knows, he never touch it and never ask and wonder about the pouch and he is able to accept it.”* She asserts that after having a stoma, their sexual relationship has not change, but *“there must be a cloth to conceal my abdomen, I have never shown it…”* She would use towel or any cloth she can use to “conceal” the bag every time.

While Ong stopped his sexual relationship after having a stoma, but Mor and Kung still have good relationships and are looked after well by their husbands. In those three cases, they have lived family lives for a while. Some people said that is because of "pity and concern", but for people that have started family lives in the same time, how would the stories go if someone get sick.

Recovering family relationship

Normally, Ong would go out at night and come back very late. Sometimes he comes back around 4-5 o'clock. At half past six, he has to get dressed and drive his wife and children and then return home to sleep. His wife has moved to sleep with her daughter. The couples don't see each other much in a day. Their daughter is studying a post graduate at Silpakorn University and his wife is very busy with work that she would sleep with him once in a long time.

After he has a stoma, even with pants on, there are still some smell and it even smell worse when he unzip his pants, so he stopped sexual intercourse with his wife because he thinks that his wife understand his situation and he is old. *"I know it is a natural thing, but I have cancer and with bag like this, why would I try that hard"*.

However, because of illness and ostomate, Ong is closer to his daughter. When he comes home late, his wife will call him. Now, both his wife and daughter take turns to look after him and change the stoma pouch for him. His close friend said that *"seems that he loves his wife more and his family is now much warmer"*.

As his relationship in family is improving, his friends don't want to ask him to go out anymore and postpone his travels until he will get better. Ong's case demonstrates that when one fell ill, it can recover relationship within the family; even the sexual relationship is ended.

Although many previous researches show that sexual relationship is changed when one has a stoma, this work founded that, while someone is decreasing sexual activity, but still caring after, some have to cover a stoma (and pouch) with a cloth while engaging in sexual activity. But the impressive thing is that someone abstains from sexual activity but recover family's relationship, while some people have better sexual intercourses after having a stoma.

Conclusion

After trying to comprehend and connect the world of ostomates from their conversation and stories, it reflects their suffering from daily life changes. Each person realized the importance, values and meaning of stoma in different forms, which is body's realization that relates with life and illness, rather than just having a value in excretion only.

Other than that, when an ostomate lost an ability to control their waste product and have to use plastic bags to restrict the area of feces, each person has to live with a stoma pouch, excreting through a stoma has become a new routine, which is a burden in daily life. One must change the way one showers in order not to wet the stoma pouch. One also has to face disengagement of the pouch, pouch's leakage, which makes one feels embarrassed and fears that others will feel disgusted while having a social interaction because they interpret themselves as dirty and disgusted.

CHAPTER V
DIRTY BODY

From bio-medicine viewpoint, a body is composed from elements, matters and organs. However, anthropology perceives human's body differently. It is because human lives with a body and society, so the body is an important medium in having lived experiences. To understand ostomates, it has to be done through body, which is a medium to the world and ostomates' action.

If we consider the body of an ostomate as a body that is culturally constructed body, has a negotiation and is dynamic. So a body is a material for studying a life experience of an ostomate. Thus, I have to question "How is an ostomate's body used? What is the condition of the body in life's experience? How is it used as a symbol as the society brings its code to label ostomates' bodies?

Body in a daily life

Before I started to collect fieldwork's data, I had a chance to care after this "patient" in the end of September, 2006. At that time, she just moved out from an Intensive Care Unit (ICU) to general patients building. On the first day that we met, she was wearing a hospital's light blue dress. She was lying still on the bed, gloomy face, bald head; her head was big when compared to her body, which is scrawny. Her legs were not able to move by themselves. There were only a pair of eyes that were looking around, following movement and sounds of others.

Two weeks later, I met "Duaen" again. Her condition is no different from the day I met her for the first time. Only her clothing was different, she was wearing a red-black pajama with trousers. She was sitting on a wheel chair, looked exhausted. I brought her to clean the wound (middle of abdominal) and change the stoma pouch (left side of abdominal) at the clinic. I moved her wheelchair as close as it can be to the diagnosis bed. The bed was only waist-high and there were small step, but Duaen was unable to get off the wheelchair herself. I tried to support her, but it didn't succeed. Tee, her husband had to lift her up from the wheel chair. I had to support her to step up onto the bed.

When I undid the dressing and tried to remove the stoma pouch, Duaen brought her hand up to hold my wrist and screaming *"Ouch, it hurts…."* I was shocked and stopped what I was doing immediately and waited until she stopped crying. I picked up a soaked water cotton ball and dripped water onto the adhesive tab, so it would be easier to take out, which took about 10 minutes. After that, I realized why Duaen was screaming all the time, the surgery wound are separated and did not look like it was going to healing soon. There were 3-4 wounds around the stoma, which were macerate and infected with feces. The skin was red and bruised. It was as thin as a paper, which was ready to come off with adhesive of stoma pouch. On the other part that is not red, even it is thicker,

> *"We went to a private hospital, but they didn't clean the feces. They only wiped the surface and put the pouch back on. They are not professionals. Some of them shown sign of disgust, some did quite well and some did it carelessly, although we pay two or three hundred baht each time." Duaen's husband said.*
>
> *"They treated me like I have a stigmatized contagious disease." Duaen adds.*

After listening to their stories, I asked Duaen to come to clinic for a period of time in order to follow the healing of wounds and peristomal skins. They accepted and were delight to come to the ostomy clinic, rather than going back to the old private hospital.

Cleaning the wound takes about 1-2 hours, each time and was done for the period of five months. While I was nursing her, I asked about her illness and family. She is the second daughter of "Grandpa Nan", which was 60 years old in the year of 2008. Her elder brother is 40 years old, married and have three children. She also has a younger sister, "May", 34 years old, living in the same condominium in

Rachadapisek area. Her mother died at the age of 35, when she was only 17 years old. Her step mother "Nak" is now 53 years old, living with her father and look after her brother during time of sickness. Now Duaen is 38 years old, living with Tee (44 years old). They are owners of a laundry shop and have a business on internet.

After her mother died, Duaen moved to study in Bangkok and got a husband who is from Surin, who is a cook in a restaurant in Japan. Duaen had to pay a Japanese to do a fake marriage and migrated to Japan for about 8 years. When she came back to Thailand, she had a new husband, but finally separated. After that, she had many more partners until she fell ill. Although there were men to flirt her, but she didn't think of having a new husband. During that time, Tee was living in the same condominium and saw her condition of all time, so he came to look after her and decided to marry in Chiang Rai, less than one year before she received a surgery.

Duaen's illness started from mouth inflammation and an abscess in her perianal. In year 2005, she started to receive treatment from a state's hospital and had to move to 2-3 more private hospitals. She had abscess removal surgeries twice, but the wound in her perianal did not get better. She was unable to eat. Sometimes she defecated with blood. She had to go to the hospital often to receive saline solution. Her parents had to look after her for three months. The doctor told her that she had Crohn's Disease and it was beyond his ability. She changed the doctor and was treated with a gastro-intestine system specialist, but her condition was not better.

Having an stoma for the first time

When one fell ill with cancer, a surgery seems to be reasonable to remove a part of an organ to slow down the growth of the cancer, but for Duaen, who had an intestine's inflammatory disease, doctors didn't plan in advance that she require an stoma, but a diagnosis indicated that she had to have one.

The beginning of September, 2006, Duaen defecate out blood, so the doctor appointed her to have a digestive system check in another hospital one week later. In the day of colonoscopy, Duaen, Tee and May came to hospital together. Once they sent Duaen to the checking room, everyone separated to do their own business. One hour later, Duaen went out from digestive system microscopy room, she had a very painful abdomen. She thought of two previous colonoscopy but they weren't this painful. She felt that her abdomen was about to explode. May came back to hospital ten minutes earlier than Tee and talked to the doctor to decide about the surgery.

> *"The colonoscopy went in and the intestine is perforated, we have to perform a stoma … it has to be done today. We are preparing the surgery room and will out best." The doctor explained.*

After she heard the explanation, Duaen felt that scared and was unable to accept the condition. She thought that it must be ugly. While the doctor was explaining, Duaen was lying in pain on the bed. As May saw Duaen's condition, she thought that if she left her sister like this, she will die because of pain. So she gave permission to the doctors to perform the surgery.

Tee and May didn't know what happened in the surgery room. As Duaen woke up, she saw numbers of life saving instruments and she didn't know anyone. She still felt some pain, but it wasn't like before the surgery. She looked down upon her abdomen and saw a bandage in the middle with a plastic bag. She was shocked and thought of what the doctor said before the surgery. She cried when she met her sister and husband. *"If I have to be like this, I rather die. Why is it this ugly and scary!"*

Duaen's word made Tee feel very sorry, but he only thought at that time that *"What has to be done now has to be done. Life has to be saved first and other problems can be fixed later."*

After having stoma, showering and cleaning bodies after excreting are routines that had to be changed. From excreting 1-2 times a day turned into emptying a stoma pouch 2-3 times.

Cleaning after excreting also includes removing the smell of feces. Duaen remove the smell of feces by fan, Aroma candles and ….spray, which she has to have them every time she goes outside. Every time she empties the stoma pouch, she has to hose water into the pouch in order to clean feces out. This action is inconvenient for her when she travels to other provinces.

Once, she went to a trip with her husband and cousin. During the drive, she said that she really needed to go to toilet. *"I can't hold this anymore, I have to go to a toilet, but it must be a disabled toilet"* but there weren't any disabled toilets in gas stations they drove in.

Apart from "emptying" feces many times a day. Another routine that has to be changed is "showering". Everyday Duaen has to shower warm water twice, but having a warm shower made her stoma pouch humid and the adhesive degenerated before its expected life. She has to change her stoma pouch more often, thus she needs to change her method of showering.

She has to change the pouch in every three day. Before taking a shower, she will cover the pouch with a large plastic bag and put a cloth on the bed. After she took a shower, she detaches the old pouch and put it in a plastic bag and ties it very tight. After coming out of a bathroom, she lies down on the bed and has pillows supporting her so she is able to bend down to see her abdomen. She uses cotton balls to clean and after the skin is dry, she applies skin barrier cream around the stoma, attaches a pouch on and lies down for half an hour to an hour in order for the pouch to stay for three days.

Duaen's suffering is not only from the disease and excreting through an stoma without having thought before that she would not be in this condition, but she also suffer from physical and mental pain, which are derived from a surgery wound and inflamed wound with feces under skin.

Once she has treated the wound, but it came up again. The scar of the inflamed wound is around 5 centimeter around a stoma. While dressing the wound, she feels great pain. Sometimes I see she cries or went unconscious. On a day that the wound is heavily inflamed, she will ask for a pain killer. Wound dressing around the stoma takes about 1-2 hour each time and it was done in the period of 5 months. This chronic illness discourages her because she doesn't know when it is going to be cured.

> *"I don't want to have a wound like this forever, I don't know if it is going to be cured. I don't want to come to hospital this often." Duaen said.*

Although, now she is able to do some activities that she did before she fell ill such partying (playing cards for 6-10 hours), getting out from a bedroom and work at the laundry shop, but she has become a burden for her husband, especially payment in medication and tools, which they never know when it is going to end. Her suffering made her husband comfort her by carrying her and tell her, *"If we cannot be with anyone else, we just live together in this room"*.

Tee started a marriage life with Duaen when she her condition was not well. Although Tee liked Duaen for a long time, but Duaen still had a partner. After she separated from her ex-husband in the time of her sickness, Tee had an opportunity to look after her until they married. During that period, Duaen did not have any money, apart from her father; Tee helped her financially and paid for treatment in a total of nearly a million baht.

I thought of a question that researchers usually interests about sexual relationship after having a stoma. Many researches show that having a stoma is undermining for the relationship. So I asked this question with Duaen *"How would Tee think if he sees a stoma while sleeping together?"*

"What would he think? Now I can't even get up, he helps me to urinate and excrete." Duaen said that her husband wipes her every time she excretes or urinate. During that period, she couldn't even feed herself and she stayed in bed of all time because couldn't get up. Sometime she has to dress her wound and change the stoma pouch while "lying naked" on the bed, without feeling embarrassed in the eyes of her husband. Other than that, her sexual organ has a stitch and she felt great pain in the anus, so she was not able to sleep with her husband. Once a stoma is treated for a while, the wound at the anus and vagina are healed, so they are able to continue their sexual relationship. While having sexual intercourse, she takes off her clothes normally, her husband didn't show any sign of discomfort when seeing the stoma pouch.

Sensory experience in daily life

The adaptation of Duaen's daily life is related to the use of stoma pouch, which she had limited option in choosing and had to use a pouch that is suitable to the wound treatment.

Once Duaen called and said that her pouch ran out and had to used a pouch with little amount of glue (Coloplast 5930), but she could only use it for a night because once she woke up it smell was very strong. Normally the pouch has to be leaked to have a smell, but she saw no leakage.

"It smelled very awful, I didn't go anywhere." Duaen wanted to buy a brown pouch and will have her husband to pick it up, but this type of pouches are not in the market anymore, so I recommended another type of pouch for her.

"Does this type of pouch make noise….The brown pouch is good, but when I move around, it makes noise like plastic bag." She still negotiated with me.

Her husband could also hear when she moves around, even in the distance of two meters. However, she could not find a pouch that she wants, so I recommend another type of pouch name Alcare D-50, which is a two layer bag, inside is plastic and the outside is a thin paper, so feces are unable to be seen. I called Duaen and she said that she was quite satisfied, but she said there is still smell coming out of the gas inhibitor, but she put a plaster on it.

Duaen's changes in types of pouches demonstrate that the transparent plastic bag made her feel uncomfortable because feces inside are quite clearly seen, while the brown pouch makes it unclear to see. However, some types of plastic are hard and every type of pouches all have 'plastic bag' noise, but a type that she will never use again is the pouch with "feces smell coming out."

Duaen's frequent changes of stoma pouch made me doubt why does she do it and how? I realized this when I went to sleep over in her condominium. While I was sleeping in a bed comfortably with cool air-conditioning. I had to wake up when I scented a nauseous smell. I went to the toilet and saw that Duaen was still watching her favorite television show and her husband was still using the computer.

There was a ventilator attached on the ceiling of Duaen's toilet like any condominium's room. The difference was that there were air freshener, aroma stove and unused plastic bags.

I thought about Duaen's unpleasant experience about a year ago. While she had to receive antibiotics for about a week after she came out of the emergency room. Her body's condition was like a living corpse. She had skinny arms and legs. Her weight was about 28-30 kilograms. She was unable to help herself; even lifting her hands were nearly impossible.

While she was in the hospital, it was doctors who had to change the stoma pouch and the nurses' duties were to empty her pouch. Duaen observed nurses that *"some came to empty my pouch carelessly, they didn't do it wholeheartedly."* It was not that all the nurses were like that. Sometimes she looked around for a kind nurse and waited for that nurse to come for work shift.

When she went back home, her sister helped emptying the feces into a plastic bag, but she felt that this procedure was inconvenient, messy and the smell stayed in the room. Her husband wanted her to be able to help herself as much as she could. He carried her to the toilet seat, told her to separate her legs and opens the stoma pouch's end to be emptied. She used the shower to wash the pouch and stoma, while her husband was helping her.

The Body in theory

Body of an ostomate is a body that constructs definition and structurally complicated. It can be considered in three levels; individual body, social body and political boy according to Lock & Schepper-Hughes' idea.

An individual body constructs lived experience, which is a part that has thoughts, spirits and self. It is able to communicate self and identity of oneself. A social body is symbolic for natural description or social and cultural characteristics, which reflects the condition and social relationships in different contexts, while the society itself dictates values of body's organs differently. Political body is a body that is regulated and controlled by political ideals to follow the policies of politics, economics and medicine. From this viewpoint, a consideration of an ostomate has a following issue.

A body in the hospital... learning how to excrete through a stoma

Throughout the treatment process, the body of an ostomate reflects the action of medical profession's and control objectively, especially in persuading people to have a stoma by relying on the legitimacy of knowledge and specialization of medical professions.

I was recommended by a nurse in the ostomy department to care "Aunt Jan", a female ostomate, which only had the surgery for seven days.

I went to the hospital too met 'Aunt Jan'. She was lying on the bed and reading "how to prepare before a colostomy surgery". She smiled at me and tried to put the book on the table. One side of her hand was holding her abdomen and her face was wry, so I had to take the book from her and put it down for her. She was a small person, about 150 centimeters tall and was about 50 years old. She still looked very young.

In 2005, Aunt Jan started to fall ill from an anal cancer, but she thought that she had hemorrhoid, so she came to the hospital for the diagnosis and the doctor told her that she had to have a stoma. She couldn't accept it, so she went to another hospital, but they told her the same thing. The handbook that she was reading had a kangaroo on the cover. After she saw the images of ostomates in the book and from patients that the hospital staff took her to see, she thought,

> *"If I get surgery and it is not cured….If I do it and have a stoma and pouch, it must be disgusting. I don't know what to do. If I'm going to die, just let me die anyway."*

But she has been looking after a nephew, a son of her eldest daughter for three months from birth. She decided to have a surgery. She said, *"The reason I do it is only because of my nephew"*.

Before I came in, Aunt Jan just went to empty the pouch in the toilet. After the surgery, there was a nurse coming to help her change the pouch when the pouch leaked and she came to release the air out, but she started to empty the pouch herself because she felt that her feces are very disgusting and smelly. She didn't want anyone to do it for her, because she fears that the nurse would feel disgusted.

> *"It's ours, I fear that they can't stand it, fear that they will throw up. If it's baby's feces, it's ok. But this is an adult's. I prefer to do it myself". Aunt Jan said.*

I talked to her for about an hour. Before ending the conversation, she planned *"When I go to work, I have to take a plastic bag with me. When feces are excreted, I will go in to the toilet. It will look just like a normal person going to the toilet"*.

After Aunt Jan is diagnosed with cancer, she is persuaded by medical professionals to look at images of ostomates from the handbook before the surgery. She had conversations with doctors; saw the conditions of ostomates and their stoma pouches in order to persuade her under the total control of medicine. From a medical professional's viewpoint, a body with disease is considered to be in danger, so it is the doctor's legitimacy to dictate the treatment with knowledge.

After having a stoma, no one is able to control excretion. Even after the surgery, medical power is still controlling the body by giving knowledge and demonstrate the significance of using different types of pouch to cover the stoma, in order to receive the feces while one is aware of it or not. The learning of a new excretion form needs to be relied on a person with knowledge about tools, so the medical professionals use their legitimacy in managing the learning of excreting through an stoma. Even choosing the pouch and appliances are still under the control of medical knowledge until one is able to attach the pouch by oneself. Apart from this, every step of medical professional treatment demands ostomates to expose their bodies during diagnosis, being stared, touched and questioned about their stories involving their bodies and ostomates in order to benefit the treatment.

From this viewpoint, a body of an ostomate is controlled and managed by the specialized knowledge of medical professionals. A body of an ostomate reflects medical control as an action of objective power during the process of treatment. From a political body's viewpoint, a body of an ostomate is controlled by the medical authority of all time during the treatment. However, this action is done in order to treat the illness and support one to have a good life quality and is able to excrete through a stoma.

Nevertheless, these actions are done to make ostomates' bodies to be used to the new form of excretion and realized the importance of learning how to use the stoma pouch. It creates plan of how to be a good ostomate and is able to attach a pouch by oneself without the pouch leaking in order to prevent side effects.

An Individual body…. Change of self and identity

Experiences that happened through the body of ostomates change the set of thinking about excretion, the boundary of a body when it is attacked by diseases. Ostomates as human who experience through bodies; show values and definition in different viewpoints, not only in bio-medical definition. Defining such way demonstrates realization and appreciation of a stoma as something related with life and disease and is a process of body's reality awareness through the interaction within oneself that one is conscious of oneself, leading to understanding oneself and one's body that has changed and differs clearly from others.

Struggle of self

When there is a physical change, which can be seen objectively, that is an opening of an intestine to make a pathway to excrete through an abdomen. Ostomates talk about the characteristics of the new composition of the body in the same direction. *"Something red", "Red, slimy, oily like blood", "This area usually turns red and swell"* and etc.

The realization of a stoma as an organ that excretes happens simultaneously with the realization of a new eliminating form that is related with the pouch usage. For Duaen, even though she realizes that she has a stoma, but the difficulty in attaching a pouch on the wound around a stoma, she was unable to change the stoma pouch herself when she just came out of the hospital. After she had a stoma for 5 months, Duaen came to change the pouch and had her wound dressed by me at the hospital. While I was busy with cleaning her stoma and the peristomal skin.

"It doesn't look that bad while I'm lying down, but when I look it in a mirror, it is very ugly". Duaen spoke in high pitch voice to emphasize that her stoma and wound are not pleasant to be seen.

After that she talked about her feeling while she was changing her pouch and cleaning her wound by herself for the first time three days ago. She needed to look at the surgery wound on the abdomen, which was about 2x10 centimeters in size. She had a rotten wound on the peristomal skin, which is caused by the thread that stitched the wound came off, so wounds emerged between skin and intestine. Some feces are unable to escape out to the skin surface. There is enzyme in feces, which creates irritation. Apart from that, the wound also took a long time to heal because of the bacteria in the feces.

On that day, she put all the tools she needed in pouch and placed it next to her body before she lied on the bed. She uses a mirror to help her see her wound. She injects salted water into a surgery wound on an abdomen. After that, she sprinkled powdered skin barrier and put a pouch on and lied down for an hour, so the pouch will stay on for three more days. Now, Duaen always carry a small pouch with her. It contains stoma pouch repairing tools; skin barrier paste, small scissor and a plasters.

After having a stoma for about a year, the wound and the pain are getting better. She starts to eat more and help herself in putting on a pouch and is able to manage time in changing the stoma pouch and emptying the feces, which allows her to travel more, especially playing card. She said that if she can play cards, it means that she is fine. So I asked her *"How would your life be now, if you didn't have a colostomy surgery"*.

> *"I don't know how would it be, but she wouldn't be this healthy perhaps." Tee answered for his wife.*
>
> *"If she didn't get a surgery, the wound in the anus would still be there." May added.*

Duaen stayed quiet. As I didn't get an answer on that day, I asked her again while she was in her hometown in Mae Sai.

> *"Before, I couldn't accept it, but now I'm used to it. I don't think about it too much nowadays. I am able to travel, play cards and party like I used to before. It's fine." She replied.*

Duaen's story demonstrates the realization of physical change and an attempt to accept her body's condition. It staggered Duaen's self as "she is an ostomate", which is different from the old self because she has to live with a stoma, pouch with more limitation in life. It leads to the feeling that she has lost her old self and replaced by the new ostomate's self.

However, Duaen still kept asking me and the doctor *"when I will be able to close my stoma?"* This struggle to preserve the old self emerged from a feeling that her body is not like normal people, which makes her lose dignity and values in herself. But as time passed by, Duaen was able to help herself and didn't have to be others' burden and accepted herself as an ostomate. It shows that the old lost self is able to be replaced by the new 'self-reliable' ostomate self. Finally, she is able to live with dignity and values.

As an ostomate, one does not only face various changes and problems, but one also has to change the status of a normal person into the new one. Living with a stoma causes one to have them as significant characteristics of self. It leads to the understanding of self and one's body that has changed from the old structure and differs from others' clearly.

The self acceptance of an ostomate is a physical reality realization and reflects with the image that stoma has become a part of the body. This reflection of thought is a "self interaction". It is a conversation with oneself that it searches the explanation for the real situation that happens in life. This interaction is person and self's imagination that needed to be practice frequently from daily life's experience, which observes and matches with one's thought.

However, the process of reality awareness is not received from self interaction, but it is also awareness through social interaction as the 'exterior world.', therefore a self of an ostomate is an interpretation and definition that were created from interactions with self and others.

Concealing abnormal body parts and status

Beliefs concerned with feces and fear of other's reactions while having a social interaction, other than making an ostomate feels that one is "dirty and disgusting", they stress one to feel that one has lose self and values, which makes one feel inferior compared to others. Labeling an ostomate to feel about oneself pessimistically. It is an obstacle for one to face others in the society while one is unable control noise, gas and unwanted smell. This social labeling makes some chooses to conceal their bodies and status, keeping the status ambiguous, when they are not sure of other's reactions.

Many times when I travel with Duaen, I observe that she uses her hand to feel her abdomen frequently; even her cloth is already baggy. It can be seen that another side of an abdomen that has a stoma is baggier. However, if it not carefully looked at, one would not see any difference, but when Duaen uses her hand to touch it, it becomes more obvious.

I observed clothes that Duaen's wear when she go outside are usually loose. She said that she normally wears a modern above-knee skirt, it does not make her feel uncomfortable and others are unable to see a pouch. She has many well fitting t-shirts in her closets, but she doesn't wear them anymore because these clothes are too tight on her abdomen, which will make the colostomy quite visible. Apart from Duaen's adjustment in clothing, which is comfortable and not tight fitting, they are also modern in order to make her feel "normal" like others in the society.

The status concealing also includes actions. For example, in a pouch leakage situation that people complain, Ong acted like there's nothing happening and she just leave from the group of people or sometimes she has to lie that she has a "stomachache" in order to go to change her stoma pouch.

Although close friends and family are aware and do not express feeling of disgust towards ostomates, they still perceive their bodies as abnormalities, which should not be exposed to anyone, even a sexual partner. In a sexual intercourse, which is a time a body should be exposed the most, some still conceal their abdomens.

> *"I conceal it; I don't want him to see it. I don't want anybody to see it, except for doctors and nurses. … It can be any kind of cloth or towel. I need it because I have never shown it before."*

Choosing clothes and actions are internalized change from an identity that makes one feels abnormal and embarrassed. When there is a publicly visible situation such pouch disengagement, pouch leakage, feces smell or external characteristic that indicates that one is different to others, these are negative experiences which makes one feel labeled and change in one's thoughts about self. It influences one's awareness and refines one in interaction with oneself and others. Therefore, identity is reconstructed dynamically and leads to self defining.

Self disclosed

Self disclosed is usually found in among the people that define stoma positively, which expose their selves with intimates and others, such Duaen, who expose an ostomate's identity in front of her husband, relatives and neighbors by telling others that she has a stoma. She does not feel embarrassed at all.

When Duaen was very ill, it seemed that she was going to die. While she was receiving treatment sin the emergency room, her relatives were discussing *"where should we have funeral for her?"* Once she survived from near death experience, people's conversations about her were surrounding the topics of illness and her being as an ostomate. Some gossip that she was infected with HIV. When she and I went back to her home during the '*Songkran festival*' (Thai New Year), relatives who came to pay respect her father all asked the same question *"Are you cured yet? Did you put your intestine back inside?"* or other questions about a stoma. I observed that Duaen answered all those questions with smile and did not hesitate to answer *"Not yet, doctors said to wait for five more years"*.

Other than that, I was surprised when I was eating with Duaen's relatives, a number of around 20. During the conversation, I observed that the noise of chatter was frequently interrupted with laughter, belching and fart through Duaen's stoma. However, the people in the circle didn't show any sign or reaction of aversion.

Duaen's exposition of self and identity in her village is a different story when compared to her life in Bangkok, which she chose to conceal her status with employees or neighbors that live in the same condominium.

Present only particular identities

As it has been stated before that, having a stoma happens simultaneously with other diseases such cancer, intestine, thus this made an ostomate to have an identity, which is related with illness and ostomate's identity. For example, Uncle Winai chooses to tell his friends and neighbors that he had a colon cancer and already had a surgery. He would only tell very close people about his stoma. Aunt Somjai is a person who chooses to expose her ostomate's identity only with siblings and relatives, but choose to expose her "a cervical cancer patient" identity with neighbors.

However, social interaction will affect ostomates in term of realization of having a stoma, learning about having stoma, the tracking of the disease and limitation in buying tools that are used in attaching the stoma pouch, which can be bought only in hospitals or pharmacies. These things had emphasized the relationship between ostomates and medical professionals. It makes them feel that they are ill all the time and choose to expose their identities as chronic diseases patients, in order to conceal ostomate's identity. This decision making in choosing identities is an issue that emphasize clearly that an individual has different identities that are chosen according to the social relationship.

Therefore, an individual body of an ostomate is where it experiences and constructs definition. Once there is physical change, but it is unknown by the public, one choose to conceal one's body and status, expose self and identity and choose particular identity that is related to sickness rather an ostomate's identity, which is a tactic in dealing with suffering and social relationship in different social contexts. Individual body also demonstrates the change of self and identity, by losing an 'old self' in the process of social interaction, making an individual interprets oneself as dirty and disgusted by others.

Dirty body: the social body of ostomate

According to Douglas that considers the symbolical meaning of body as a symbol of bounded system. Body's orifices (including anus) are in marginal state of being in between being internal and external organs. They are parts that are vulnerable to dangers and are the exits for the pollution inside the boundary and conflicted matters in those areas. From this viewpoint, these orifices are defined symbolically as 'polluted organ' by itself and the pollution that is excreted out.

Using this idea to explain the social definition of "feces" or "waste" in Thai society as pollution that a body is unable to control, it is waste that is composed of smell, dirtiness and aversion. It is also categorized between 'waste products' and 'excreta' which are eliminated from the body. It is considered as a contaminated matter like germs and bacteria. By the connotation of 'feces', it is a matter that goes in and comes out without becoming a part of the body and is beyond the body's control in the form of excretion, color and smell. As it came out of the body through an anus, it demonstrates that feces is waste that interrupts the balance inside, preserving waste inside the body will create pollution and once wastes come out, the pollution is exterminated. From this viewpoint, feces in Thai society are defined as body's wastes, something low, dirty and ugly.

"Stoma" acts as an exit for waste, relates with feces and is placed on the body's boundary. Therefore a stoma has the same meaning as an 'anus', but does not have all the same features like an 'anus'. The important feature of a stoma is that it is a part of a dissected intestine, which is brought out to the outer surface of an abdomen. A stoma is an organ that relates to 'blood' and 'colon', which are internal compositions, which are unable to seen, except in accidents such getting stabbed in the abdomen that the intestine comes out of the body. Uncle Winai describes when he talks to others about stoma.

> *"When others ask about my illness, I will say that I have a colon cancer and already had a surgery. If some continue to ask about it, I will say that my intestine is taken outside the body. People usually comprehend this better rather than saying stoma. When someone heard the word 'stoma', it doesn't sound scary and they understand that it acts like a 'fake ass'. But if I*

> *speak of 'intestine', it sounds a bit scary because it feels like getting stabbed." Winai said.*

Therefore, a stoma is 'out of place' and is unable to be classified to be assimilated with compositions that the body used to have, so having an stoma is a conflict with original body's structure and is an experience that is mutated from the original thought about one's structure. It turns into a chaotic condition when it is unable to place orders in the organ's relationship.

Other than that, many ostomates use euphemistic term in stoma care (such wiping a stoma with a wet cotton ball and covering an stoma with a plastic bag). The cleaning process is usually called "wound dressing" The management with a stoma demonstrates the process that ostomates deal the body and reflect the idea that ostomates feel disgusted towards stoma, feces and smell, which are excreted from the body.

Once a stoma's definition is considered, the feeling of dirtiness and ugliness are not only related with organs that are on the abdomen's surface. But are also related with feces, intestine and blood, which are compositions of the body. Seeing feces and blood, which are internal organs that cover the stoma's surface, so it further creates the feeling of dirtiness, which is an interpretation symbolical structure that is dictated in the thoughts of people in the society.

Conclusion

Although the physical body of an ostomate reflects the medical profession's control, which refines an ostomate into a concrete object throughout the treatment, but this action is done in order to treat illness and support ostomates to have a good life quality, are able to continue living and excrete through a stoma. But ostomates' bodies aren't recognized by normal people, so they choose to conceal their bodies and status, expose and change selves and identities by one's self is affected that an individual interpret oneself as "dirty and disgusted by others". Each ostomate chose to expose their social identities that are related to the disease and illness rather than identities of ostomates being. Once we considered the meaning of a stoma, the feeling of ‘dirtiness’ is not only related with organs that are in the area of abdomen, but are also related to feces, intestines and blood. Sight of feces and blood, which cover a stoma, also creates the feeling of symbolic dirtiness.

CHAPTER VI

SENSORIAL-CONSTRUCTED DIRTY BODY

The realization of the physical event happens simultaneously with the realization of new form of elimination. Although normal people would not know that they are ostomates, but fear of being disgusted by others in social interaction affect them to change their daily routines. Thus, ostomates have to manage their physical problem and social relationship by various methods. It demonstrates that a stoma, other than being a conflict with the body, the life experience that is related to a stoma is also differed from one's thought that used to be managed clearly. However, their daily lives have to be suffering because of management involving stoma and feces that are unable to be controlled. "Feces" are still right on their abdomen and are able to be seen. Some feel disgust and dirty, fear that it will leak and loss of ability to control excretion. These feelings reflect thoughts that consider suffering through the reality of the body.

Although the body's change of ostomates are materialistic truth, which bio-medicine describes a stoma as an anus of the end of the digestive system, which has a duty to excrete fibers and wastes that are left in the process of digestion. But the human's reality doesn't only have one side. Human have abilities in interpreting various experiences around them. As ostomates have social relationship with others, the most significant interpretation that creates self-stigmatization is the feeling of "disgust for one's own feces and a stoma."

Why do ostomates repulse their bodies? As they all accepted stoma as means to save their life and to reduce their illness. We can further question that do these stigmatization relate to the feeling of disgust and fear of feces' dirtiness and Thai social definition of feces or not? How? So in order to answer these questions, we have to understand the definition construction of feces, which is a part of socio-cultural phenomena.

Smelling: the perception of reality

Although the life experience of an ostomates are perceived through five senses such seeing, smelling, touching, hearing and tasting, each of them is used to experiencing excreting through the abdomen. But according to a fieldwork data, a type of sense that is used to detect abnormalities of one's health, this sense is also used to dominate life experience and explain the reality of an ostomate at the same time, that sense is smell.

Aunt Somjai, a villager who had a stoma for three years, she used smell with seeing as perceive to detect 'abnormalities' in herself, from smelling blood that came out of her uterus and anus that she had to wear tampon for the period of two years. The blood was normally red, but on a day it turned black. She tried to detect abnormalities by "smelling", but there was no smell until feces came out through her vagina and anus that she was sent to have a stoma at the provincial hospital.

I went to Aunt Somjai's village in Chantaburi in August 2007. It is approximately 200 kilometers away from Chonburi (my birthplace). Once I arrived at her house, I could smell spilled petrol from the ground near the house and petrol from a rusted motorcycle.

Aunt Somjai was a middle age woman who was diagnosed with cervical cancer, at the age of 35. She received radiation therapy, chemotherapy and surgery and had to receive stoma because there was a fistula between uterus and anus from the previous three years.

At the moment, Aunt Somjai is 41 years old, a widow with two children. 'Gap' youngest daughter is now 18 years old and just married and went to live with her husband. 'Golf', her eldest son, 21 years old, lives with his mother. Golf had a high school education. He doesn't have a certain job, only do some small jobs and helps his mum with the shop.

Her first husband 'Somkiat', Golf's father worked as a civil servant in the nearby province and separated from Somjai when 'Gap' was about two months old. Somjai had a new husband, but didn't have any children. He was a truck driver and later became a drug addict and psychopath that sometimes he chased after Somjai with knife. Once he beated Golf up and that was the end of their relationship. After that she did not get married again.

Somjai talked about her illness from cancer that began in 2003, after separating from the second husband for two years. She observed that her period was not the same.

> *"Before I wrapped tampon in newspaper for 2-3 days, then I would burn it. But on the last three months, the blood in the tampon did not dry, but turn rotten and there were worms coming out…"*

Aunt Somjai decided to receive a conventional cervical cancer treatment, by receiving radiation and chemotherapy at the same time, before a surgery was performed. While she was receiving chemo and radiation therapy, she was allergic to the therapy and had chronic nausea.

First time experience of having a stoma

While she returned to shop keeping in order to afford her two children's education after leaving these duties for her parents for nearly 2 years. During that period, her body was still recovering from radiation therapy.

One day, she was looking after her shop. She felt that she had to excrete, but she held it in. She walked to the toilet at the back of her house. Her tampon that used to absorb red blood, it turned into black red color and there was no smell. The next day, she went to see a doctor and receive medications. Two days later, there were blood and feces coming out through her vagina and anus. She brought her experience of seeing ostomates at the cancer center in Chonburi to negotiate with the doctor to have a stoma. She recalled her feelings of that time.

> *"The reason I asked the doctor to perform a stoma is because I had seen a patient at the cancer center. I don't know what type of bag he used, but I know that he had something to do with the intestine"*

After Aunt Somjai had seen an ostomate at the cancer center, she persuaded the doctor to perform a surgery for her. *"I asked them whether they could do it"* but the answer that she received from a nurse was *"You could just stay like this."* Somjai thought in her mind *"How could I keep living like this…please… just do whatever you need to do… just get this pain away"* (laughing with tears)

> *"I felt wrong about my self. Things got their own path of excreting. Why didn't it come out the way it supposed to? I felt very anxious and worried, so I asked the doctor to do a stoma for me."*

Later, she was diagnosed and sent to the provincial hospital to have surgery. She was taught how to use the adhesive pouch (a colostomy pouch "one piece with close ended" called M-NILES).

Although Aunt Somjai intended and begged the doctor to perform to a stoma without any condition, but she still feels that

> *"….I feel like it is not good. Well, the first thing I did when I became conscious was touching my abdomen. I couldn't still bear it, but I was the one who told them to do it. I just have to accept the truth."*

Aunt Somjai tested herself that she actually had a surgery by going to the toilet to see her body.

> *"I didn't know how long I slept, but once I got up, I went straight to the toilet. I just wanted to know how my body has changed. Some people asked me whether I can accept this change. I answered that Yes, if not, I still have to".*

Although Aunt Somjai said that she was able to accept her condition, but she was still in shocked *"well, I have to use this path, not others."* She tried to live with a stoma, but she tried to get a stoma closing surgery anyway and she asked the staff at the hospital about it and the staff replied, *"Don't do it… if you do it, the same conditions will return."*

> *"…After I recovered for six months, I went back to the cancer center* and *asked the doctor that do I still have a potential to get my stoma closed?"* Aunt Somjai was still determined.

> *"Don't do it… the tissues are dead. If you close it down, the intestine will leak again."* the doctor said.

So I asked Aunt Somjai whether she could accept it right now, she replied *"Of course, I'm comfortable about it."*

Smell – the staggering of self

After Aunt Somjai just came out from the hospital, she was very thin and weighed only 42 kilograms. Once Aunt Somjai was wearing a loose t-shirt and sarong and asked her parents to drive to a market in the town, which is about 10 kilometers from her house. On the way, they went to petrol station, Aunt Somjai only walked for three steps from the car.

> *"… I was so embarrassed at the gas station. I didn't realize that it came off. I didn't know what to do with the feces. I just told my mum that we should just leave."*

Once she came back home, she went straight to the toilet. The feces' stain that came leaked out from the adhesive tab was still there. She removed the pouch, cleans her sarong, showered and put a new pouch on. When she sits, this type of pouch usually detaches from the skin and when feces come out, there is nothing to hold it.

After that mishap, she had to keep using this type of pouch. When she went outside, her mother would keep asking *"Would you like to eat or go to toilet?"* While her mother was asking, she would use her hands to feel the pouch. After she felt the pouch for a while, she would say to her mum *"I will go to the toilet for a sec"*.

> *"I keep touching my bag all the time. It feels like there's something blocking here. It feels like there's something foreign inside my body. I keep touching my bag wherever I go…."*

These things always happen in her daily life, so smell is used as a sign when feces is being excreted *"Sometimes there's smell, sometimes not, but the air came out* *straight away"* Smell is also used to indicate that there is leakage, while in the public before anyone else knows.

Even the day she went to Bangkok, the car was running on the Bangna-Trad road. She drank some milk on the way, only after a half an hour, she had flatulence and she felt that she was going have a diarrhea.

> *"On that day, there were about four people coming with me. They didn't smell it, but I was worried all the time. I felt very comfortable and was not able to sleep because I smelt it all the time."*

The car was going to go on the highway, but she decided to tell the driver *"If you see a gas station, please stop by immediately"*. Once the car stopped at the gas station, she hurried down from a car and went straight to the toilet. She cleaned her underwear and put on a new pouch.

"What happened?" people asked her after she was gone for nearly half an hour.

"I went to the toilet, I had a diarrhea." Somjai answered.

In addition, One day Aunt Somjai' son said *"What's the smell, it smell like a broken toilet"* This event made her felt "bad". She was afraid and worried that people in her family will feel disgust about her 'dirty' and always smelling body.

Her house is about 70 kilometers from the provincial hospital. She has to use the same type of pouch until the doctor appointed her and Somjai negotiated with the doctor to change her type of pouch. The new type of pouch has a commercial name *'thung ar-na-mai 200 pi'* (200 years hygienic bag). She hoped that this new bag will be better than the last one in the area of leakage and smell.

The '*thung ar-na-mai 200 pi*' has a plastic cover the stoma and a strap around the body. It feels more secured and doesn't worry that feces will leak out like the adhesive pouch.

However, Aunt Somjai still feels that she "stinks" all the time whether there is feces in the plastic bag or not. Although showering makes she feel 'clean' from feces and its smell, but she cannot take a shower at all time because she has to look after her shop.

> *"If I don't excrete or only excrete one or two drops, I don't change the bag, but only washes it and put it back on. I'm afraid if I didn't wash it, other people will smell it. After having a stoma, I'm the only one who smells it"*.

The issue of feces' smell still makes her worry all the time. If there are a lot of feces in the bag, she has to change the bag frequently, if she only excretes one or two drops she has to wash it anyway and put it back on. It is an anxious feeling that feces will leak out and dirty her cloth without knowing. Whether she excretes or not, she has to shower and change her clothes many times a day to ensure there's no smell in her and clothes, but after she used the '*thung ar-na-mai 200 pi*', no one has said anything about the smell. She understands that she is the only one who can smell it because she worries and realize that she excretes all the time.

The awareness of the smell that happened after having a stoma shows that individual senses are tools to realize the reality of the body and creating an analogy between body and sickness, by perceiving "dirty smell" from feces as dirtiness and abnormalities that one has never experienced before.

After three hours of conversation, Aunt Somjai didn't show any sign of tiredness, apart her eyes and nose were getting red. She told the story with half-laughter, half-blubbering. Sometimes she had to lift her t-shirt's collar to wipe her tears. It was getting dark and the rain was falling lightly. The clock on the wall showed that it was already 5 o'clock. Fortunately, it was a weekend. If it was a school day, she had to stay at school from three o'clock, busying selling snacks to children. The conversation had to stop before the rain would be heavier. Aunt Somjai walked me to my care and gave me a wave. She smiled while her eyes are still red and one of hand is holding her abdomen, while I was driving from her house.

Dirty and disgusting: Construction of dirtiness in daily life

Labeling definition of an ostomate as a body that is “dirty and disgusting” is a labeling in term of symbol, which is structural interpretation of symbol that is embodied in the thoughts of people in the society. I argued those interpretations of these bodies are derived from Berger and Luckmann’s social cultural construction of reality and phenomenology thought “Truth is something that is constructed”, to understand ways of ostomates’ daily lives.

This idea is initiated from a proposal that stated “Human’s knowledge that are transferred from others and society are knowledge that are not received directly, thus human should realize the world and society by themselves and remove experiences that are received from others.” It basically said that one should only be aware of experiences, values and perspective that came directly from an individual experience. If human is able to experience directly, human will be able to construct a social world by oneself. Knowledge will be derived from a social world, which is constructed from defining ones and other’s actions. The truth that is constructed from individual consciousness, connecting with thoughts and actions, and the important of human is social interaction.

Thus, connecting social construction of reality with the idea of dirty, it makes me wonder whether the dirtiness of a stoma is “real” or “constructed” and how does society embody and turn a symbolic world into reality.

Once we connect various experiences that happened with bodies of ostomates, which are defined symbolically as dirty and disgusting. We are able to describe that dirtiness of a stoma is not “real”, but is a “construction” symbolic world into reality, through process of history, which made people disgust of feces and changed their way of excreting, which is a basic biological activity into “doing business in the toilet”. The attempt to relate excretion with being civilized, enforcing laws and policies to control society. Feces became something forbidden and was given a connotation of dirtiness. Apart from that, people are aware of “danger” of a stoma when they see intestine and blood, which are parts of body. This attitude is confirmed as “real” in the life experience of an ostomate.

The awareness of body's reality through social interaction does not only demonstrates that "physical" illness must only relate with "mind", but it also create awareness that of "outer" reality and inner "reality" through an individual body that acts as a medium of change, while the mind acts as a centre of self and merge in order to aware the social reality. Therefore reality is culturally constructed.

Although, reality is social culturally constructed, but it does not mean that people in the society will have an only absolute set of reality. Apart from being constructed from life experience and social culture construction, it is dictated by relative senses and perception.

Embodiment: Sensory construction of dirtiness

Although an ostomate does not lose any sense after the surgery, but being unable to control excretion, makes controlling "feces smell" impossible. In this situation, they are aware of reality with "feces and its smell", which turns suffering into "being used to" living with "feces and smell" in the world of an ostomate.

Once one cannot control their elimination after having a stoma, which makes one unable to rely on oneself, one has to receive help from medical professionals. The important skill that an ostomate needs to learn is not how one excretes through the pouch like excreting into the toilet, but it is the management of the pouch, a plastic bag that covers a stoma.

For Aunt Somjai, the adhesive pouch that she is able to take from the hospital are limited in varieties. The learning process and the usage of the pouch have created suffering for her. She still remembered the first day that she had to learn to attach the colostomy bag from the nurse.

> *"She teaches me to cut is first, but I didn't, I just put it on, so it sticks both inside and outside. I told them that I don't want to use that type of pouch and asked whether there was an easier pouch to use. They gave me a new pouch, but it didn't fit, so I had to remove it and put on a new one. There were only three pouches left. So what did I do? I delay the use of it for three days*

> *and go to hospital. Sometimes I didn't excrete at all, didn't eat, and didn't drink".*

In the first stage of having a stoma, one is still not skillful so one adhesive a pouch over a stoma, which creates gap and feces will leak out that way. Sometimes the glue tab sticks itself, so it was unable to be use. Sometimes an ostomate is afraid that there will be not enough pouches for use, that they even fast in order not to change the pouch.

A closed end pouch is unable to release feces out from the pouch, when there is feces or gas in the pouch, it will make the pouch becomes heavy and leaks. Therefore, the pouch needs to be changed every time there is large amount of feces or when the pouch is leaking. The adhesive tab of this type of pouch is unable to absorb feces at all, especially when the person has a diarrhea, it will make the pouch leaks in this area easily. It is also inflexible with skin, which is the cause for skin around the stoma to become bruised and it is more difficult to attach the pouch next time.

However, Aunt Somjai didn't use this type of pouch for long. She changed to use a new type of pouch called *'thung ar-na-mai 200 pi'* . Once she uses this type of pouch, if she excretes only small amount of feces, she only needs to bring the pouch out to clean. If she excretes a lot, she would empty it into the toilet and change the pouch. She is able to shower all the time.

> *"I only need to clean the bag and throw it away. I don't have to feel embarrassed. I never make anyone feels disgusted or looks down upon me. Every time before I throw the bag away, I always wash it first and put it in the bin properly."*

Aunt Somjai's fear and anxiety are reduced by using a new type of pouch, but she still worries with the deterioration of the tools. Somjai used this set of pouches for 6 months. A button is broken on one side, but Golf repaired it for her. It is still able to be used for a while. Aunt Somjai was thinking of buying a new one from the provincial hospital. When I went to see her a month later, I bought some for her.

Excreting feces from an abdomen and emptying feces from the colostomy pouch have challenged the knowledge set of how to excrete that were learnt from birth. By excreting normally, body has memorized that one has to squat or sit in order for feces to be pushed out of the body and fall into the toilet. But the learning of new way excretion, which restrict feces in the area of plastic bag that acts like a toilet. With this new way of excretion, one has to change method, form and pattern of body placement, both in attaching the colostomy pouch and emptying the pouch from the colostomy pouch. Some might sit or lie down, some might change in the toilet, some have to empty feces into another plastic pouch before putting it in the bin. Some empty feces from the pouch while standing and some do it while they sit on the toilet.

These different forms and patterns of postures are creativity that changes according to the experiences of ostomates, which are controlled by senses.

Getting used to the suffering

> *“During the first period after the surgery, I excreted irregularly. I have to hide in the toilet…. When I go to toilet, I feel embarrassed. I was not used to it yet… I was afraid that people would feel disgusted. Sometimes I feel very uncomfortable, I don’t know where to go? At that time, I was unable to realize when the feces are coming out. I always have to feel the bag. After a while, I will tell mum that I will go to toilet for while to clean the bag, but others don’t know, just think I go to toilet normally.*
>
> *“But after a while, it started to have a regular pattern. It is expectable, so if it is the time, I just excuse myself for half an hour or an hour… it is kind of comfortable, because you don’t have to mess with the bottom, you just deal with the top part”* Aunt Somjai said.

The change of the body led to the change of life experience and self, which are part of an individual body, by relying on senses as the tools to realize reality. For an ostomate, senses are used as tools to differentiate illness from normal body status and influence one to have self interaction and accept oneself as an ostomate. Each sense has an equal significance, that perceives different importance and describe with various forms.

Sensibility to feces

Perceiving feces as a disgusting object is what people realize as a social code, so one has to learn and control the smell in the social space such a story of Aunt Nee.

Once, just before the lunchtime, I was organizing my notebooks at my work desk in the clinic. I had to lift my face up when I heard the noise “Bang”. The door was pushed so hard. A fat woman was walking in and complaining “Doctor, it is so itchy under the pouch. I don’t know what’s going on.”

I read her record quickly. She was 61 years old and a widow. She was diagnosed with uterus cancer. Once she lied down on the bed and lifts her shirt up and takes a transparent plastic bag that is tied with the pants out next to her. There was urine in that pouch, amount of about 200 cc. When she walked in, I didn’t realize she had this pouch.

There was air inside the colostomy pouch. The plastic that used to be clear turned into muddy yellow. There was no leakage of feces and smell. I peeled the plaster and remove the pouch. The smell came out immediately. Aunt Nee closed her nose with her shirt and I grabbed a spray to spray twice on an abdomen and once on a colostomy pouch and I put the colostomy in the bin. The smell is gone suddenly. Under the moist plaster, there were red rashes. She brought her hand up to scratch it, but I had to stop her because the rash would be further exacerbated. While I was helping her with rashes, I had a chance to talk about her illness and being as ostomate.

She said that she had calculi, so the doctor took out the intestine. She used to have a business, but after surgery, she only does some small housework.

> *“Before this, I used to sell ice cream and food, but after falling ill, I cannot do anything. If I didn’t have my intestine out, I would still be able to work. Now I don’t’ have much energy. However, I’m still living, that’s good enough.”*

One day, while Aunt Nee came to hospital by air-conditioned bus. The bus started to smell like fart, but it’s much more rotten. Aunt Nee started to feel something cool on her right side of the body. She thought that it was urine which was leaking from the tube that is connected from her bladder.

The cool liquid that wet her shirt didn't have a smell of urine. She put her hand to touch her shirt and bring it up to her face to smell it. It was feces and her hand was dirty.

"What's the smell?" people in the bus complained, but there was no answer. She tried to cover the pouch with a cloth, but it was too late.

> *"It smelled very bad in the bus, they were complaining, but I didn't answer. I came off the bus. I'm afraid that they will kick me off. Not only people in bus are unable to bear the smell, I cannot too."*

After Aunt Manee finished telling the "broken pouch" story, I finished my job and record it into the clinic's book. I asked her permission to take her a photo of a full body with colostomy pouch. She was delight and smiled at me before she was leaving.

When Aunt Manee stayed still while being aware of the smell, without showing that she was the cause of the smell. There was procedure that she followed. From trying to control the smell, going off the bus and controlling the leakage of the pouch. These situations in ostomates' life are sensibility to feces smell, when they have to deal with pouch's leakage in the public.

Ostomates have to always observe the smell around them because smell indicates whether the pouch is leaking or full. Although the pouch is not leaking, there will be smell because air inside will push outward. One has to always be careful, especially while walking. Therefore one has to release the air out of the pouch.

Although the smell that are originated from feces are from food that one ate, but people feel disgust once food went through the digestive process. "People feel disgusted because of the smell"

Some are able to get used to their own smell and does not feel disgust about it, but if others are able to smell it, one would feel embarrassed and fear that others would feel disgusted, even medical professionals who were taught not to express aversion to patients.

From what has been said, the relearning of new method of excreting, the body memorized form and pattern according to different experiences of an individual. At the same time, they have memorized the feeling while the feces are being excreted out of the body. In this situation, senses are important tools in perceiving reality, especially the sense of smelling, which is a natural tool to detect one's own abnormalities and pouch's leakage. They learned that feces' smell is disgusting and has to be controlled in the public. However, a feeling that feces' smell is disgusting is insensitive, it demonstrates that feeling disgust towards feces are collective social feelings. The "smell" has become a social controlling tool and dictates feeling and actions of people in the society.

Butterfly and a cockatoo: A daily reality explanation

The real world is not only constructed by social cultural history, but they have to be constructed and must be able to make sense in daily life because of the suffering that is caused from an awareness of contort body. Although it does not have a characteristic of immoral action or stepping over a line of moral boundary, but this suffering emphasize one's life experience to agonize with the feeling of hatred for one's own body, which sometimes one has to question oneself "Why does it happen to me?" Some relates their suffering with the belief of karmic.

Aunt Somjai knew a shaman called 'Sister Noi' who was about 10 kilometers from her house. Her neighbor persuaded her to see Sister Noi to explain about her dream. Aunt Somjai already intended to ask about the placing of the shrine. While Somjai was about to start telling about the shrine, the shaman interrupted that *"you place the shrine improperly, someone put a spell on that area, it makes your living unwell, you must move the shrine to another side"*.

Aunt Somjai agreed because the shrine in front of her house, although it is in the boundary of her house, but it is also on the school's boundary, which makes her life unwell, always having worries. Once she collected enough money, Aunt Somjai invited the shaman to adjust the place of her shrine.

From that day, Aunt Somjai came to the shaman's place more and more often, that the villagers gossip that the shaman's place is "a crazy people's residence", especially her parents, when they know that their daughter were going to the shaman's place, they will express their discontent. If Aunt Somjai was going to see the shaman, she had to do it secretly, but if she was able to go there, she would stay there until dark.

During the first period of seeing the shaman, there were only conversations and questions such placement of the shrine, dream interpretation and etc. Once Aunt Somjai went there more often, she saw that some of her neighbors came for cure. Some had rotten wound on the neck and failed with hospital treatment and herbal remedies, but once the person was applied with the medicine given by the shaman for three days, the wound was cured. There were many that were cured at the shaman place.

The shaman's renowned made Aunt Somjai brought Gap, her daughter to see her. After Gap gave birth to a son for about three months, she had a frequent abdominal pain, her skin turned yellow. "A new mother, there's not enough blood in her." She went to hospital, but did not succeed. She went to see a massager, but it made her even sorer in her legs. Aunt Somjai thought of the shaman and brought her daughter for a cure. After the shaman blew areca-nut water onto Gap and told her to apply hot compress massage for three days, she was cured. *"At first I didn't believe it, but she was right about everything…"* Gap said.

After Somjai took her daughter with her several times, she started to think about her illness, which she received treatment from hospital for the past five years.

> *"I feel that taking hospital's medication for a long time is not good. They are chemicals. I feel that if I take it for longer, my body would be weaker. I fear that I will have kidney disorder or something, I want to try herbal remedies."*

On one day, when there was not much people to see the shaman, she had a chance to ask her about her illness. The shaman told her to turn around and touched her on the back.

"… You have a broken intestine, right?" The shaman said, while using her hands to fumble on Aunt Somjai's back.

With surprise, Aunt Somjai told her about her sickness over the course of 5 years and showed her abdomen to the shaman. The shaman then blew the areca-nut water onto her back and said. *"…It is burnt inside, your kidneys and liver are burnt too…. I only see a butterfly, a big butterfly, the size of a palm with eyes on its wing"*.

After listening to the shaman's word, Aunt Somjai recalled that she had this type of butterfly flying in her house. She said that Somjai's condition is the result of a cockatoo biting a butterfly.

> *"…. It is an old karma. In the last life, Somjai was a cockatoo, which liked to eat grass for food like this butterfly. While the cockatoo was eating grasses, it bit the butterfly's end. Its intestine turned rotten. Once this butterfly is reincarnated, it has an upturn body, while normal butterflies have a closed end. It tries to say to you that its illness has gone." The shaman said.*

Before seeing the shaman, Somjai took medications that were given by the hospital. Once she stopped the medication, blood would come out of her vagina. If she takes an anti-inflammatory drug, she would get better, but if she does not take the medication for three or four days, the same would happen.

The shaman told her to pick a type of grass and boil it and drink it like tea. Her vaginal bleeding was gone after half a month of drinking this remedy.

> *"Now it is all dry, there is no more blood coming out. I think it's actually healed. Hospital's medication immediately stops the symptom, but these remedies have to take time."*

Because of talking with the shaman, it made Aunt Somjai accepted and understood that all people with cervical cancer that received radiation therapy are all in the same situation *"….It is a karmic disease. It is a consequence of the last life. If we caused someone to suffer, we will suffer, too."*

When Somjai initially went to the shaman's place, her parents were complaining "Why would she go there?".

> *"When I go to that place, I feel comfortable. I am able to sleep much better now. I don't think too much. When I go, we exchange thoughts. When I talk to her, she always listens. If I go to talk to someone else, I don't know how to talk. I don't like it."*
>
> *"People that went to the shaman's place are friendly. Everyone is ill and knows each other's sickness. They keep asking whether I still take the remedy. I think there is nothing to lose. I drank that grass and didn't die. Before I had never think of going to see her, but everyone was cured. And how does she know about my karma? How could she know it so clearly? The remedy I take is not so hard to drink and to find. I feel better now." Somjai said.*

Aunt Somjai' s story reflects the ambiguity between nature of "truth" and "reality" that construct reality on an individual. Aunt Somjai was made to believe in something that is beyond her senses. Although she is aware of some truth about a stoma in medicine, her daily life is influenced into believing the story of "A cockatoo and a butterfly", which is unable to be proved. It demonstrates that Aunt Somjai is able to interpret her ostomy and suffering into the story of "karma", which is an idea that is embedded deeply in Thai culture.

If we analyze and interpret Aunt Somjai's body as a consequence from old karma, which is impure and related to religious system, her body is unclean and is ritually unclean. Therefore, to remove her uncleanness, it must go through the process of merit making.

Conclusion

The symbolic labeling of a body as something dirty and disgusting is social construction of reality, which constructs symbolic world into reality through historical process, which makes feces as something dirty and disgusting to be touched. Other than that, the world is able to be interpreted as a result of *'karma'*, which is an idea that is embedded deeply in Thai culture.

The reality is social culturally constructed and is controlled by senses, therefore an inability to control excretion makes controlling smell of feces impossible. In this ostomates' situation, it is an awareness of reality by turning suffering into being used to living with the feces' smell, which everyone has to learn how to control, remember the pattern of the body in various forms. The sense that emerged when the feces is excreting from the body, which led to sensibility of one's own feces' smell, so everyone has learnt how to suppress the smell in the public space or turning it into an admiring issue. "Smell" has become a tool of social control and dictates feelings and actions of people in the society.

The relationship between senses and awareness of excreting through a stoma, as a daily routine that does not only respond physically, but it embedded in life and is continuous, changing and creative under the sensory body, which is a lived and sentient body and is the essence of experiences. By analyzing the idea of embodiment, it points out that ostomates' experience which is embodying through the human's body. It is a new self continuous construction through a sentient body in telling stories.

CHAPTER VII

CONCLUSION, DISCUSSION AND RECOMMENDATIONS

I got a chance to do research on life of ostomates when I noticed that previous studies about ostomates in Thailand focused on medical treatment. With biomedical knowledge, those studies explained diseases of ostomates, controlled body and life of that patients, and concerned complications and symptoms as a truth that is touchable by professionals. As a result, the narration on lived experience and suffering existing in everyday life of ostomates has been neglected by previous studies.

This could be the first research in Thailand that used anthropological methods in understanding lived experience of ostomates. Since I put a high value of insider's perspective, my work adopted illness narrative to present experience and view of ostomates and their families. By this way, the research can illustrate sufferings existed in daily life of ostomates, including giving the meaning on body, and coping with problems.

Throughout the study, I adopted qualitative research methods and the concept of illness experience and the body to collect data from 9 key informants, who were ostomates and their intimates, in Bangkok (8 informants) and Chantaburi province (1 informant). During April 2007 – April 2008, in-depth interview and observation of daily activities of ostomates in different contexts were used as the main data collecting methods of the study.

This inquiry makes my view move out to get more into the world of ostomates. At the first step of getting into their world, I had conversations with them in order to learn their illness narrative and coping with problems of having stoma. I perceived their torments that were severer than physical pains and complications. Later on I got a chance to live with ostomates and learnt three more issues; their lived experience and suffering, meaning construction of the body and changing of self/identity, and experience absorption of practicing on abdominal elimination.

Conclusion

Lived experience and suffering of ostomates

From my work experience of working as an enterostomal therapist all over a decade, covering stoma with a pouch or plastic bag is the only way to control elimination for ostomates. This research also restates that ostomates must wear pouch. Those ostomates who came to the hospital I am working for used opened-end drainable pouch, which can drainage feces many times a day. In contrast, many ostomates in community level hospitals used closed-end pouch, so they needed changing pouch if they had feces. Still, some ostomates used *'thung ar-na-mai 200 pi'* (200 years hygienic bag), which can make "feces and its smell" leak because it has no skin barrier or adhesive (glue tape) to stick with the skin.

Living with the stoma and the pouch made many ostomates to be troubled, suffered and worried since their regular ways of living were hampered. Some ostomates gazed at themselves by observing feces smell or being aware of the feces leak. They had to "count for the day" to change the bag and needed to adjust the way of cleaning the body. Having stoma caused them to feel shame and to fear of being disgusted when other people knew from the leak of feces. This status made ostomates suffered and were anxious as they could face unsure experiences in every situations or places.

Dirtiness and revulsion are the important issues leading to the loss of "social relation". Many researches revealed that having stoma undermines intimacy between husband and wife. However, this work found that sexual relationship of ostomates could be different from one to another. Covering stoma area during having sex was one way for some ostomates to cope with the problem. While some partners reduced having sex and cared ostomates with sympathy, some had sex as usual without making uncomfortable feeling when they saw the pouch at abdomen. The study found that those ostomates who had less sexual relation could improve relationship in their families. This because the ostomates considered that having sex was not important and they thought that the intimates could understand them. Additionally, some ostomates thought that they were old and wanted caring from their family to make warmer and better relationship.

Besides suffering related to having stoma, the world of ostomates was overflowed with suffering from chronic illness. The cause of becoming ostomates for most patients related to cancer and chronic illness. These illnesses led suffering of “fear of death” as well as becoming “chronic patient”. Having stoma could not be cured, existed for a long time and brought about extra expense of high cost pouch.

Lived experience of ostomates, therefore, was not only the loss of controlling bowel movement organ, but also suffering of changing daily activities (the forms of elimination and cleaning the body), including changing social relation. Internal feelings of ostomates, existing in interaction process between ostomates and other people in society, led ostomates to explain what they really faced.

Meaning construction of the body and the change of self/identity

Although becoming ostomates was concretely physical phenomenon, objectification of stoma was difficult. To communicate with other people in society about stoma, ostomates avoided to call the name by making some gestures or used other indirect words without clear definition. However, individuals perceived and gave meaning to stoma variously. It shows that ostomates perceived the fact of body in relation to life and illness rather than valued defecation function as what medical definition does.

Regarding to the thought of Marry Douglas (2003) and Wimala Siripong (1988), stoma is a part of internal organ but come out of the body to be seeable. Stoma functions as anus that usually was at undercover area. It can be said that stoma is matter out of place and cannot be classified within regular formation and relation of organs. Having stoma opposes to normal structure of the body, therefore it is deviate from thinking structure in their mind. Ostomate’s body is “dirty body” that is far away from the ideal body because of the disorder of some organ. In this case, the operation for closing stoma and back to defecate by anus as usual can be a project that can finally make wanted body.

Perception and recognition of “dirty body” were to accept self and identity of ostomates occurred during both self and social interaction. Even though having stoma was not realized by other people, the fear of being disgusted and the perception of stool as that dirtiness and filth caused ostomates to define themselves as "dirty, unclean and disgusted person". Each of them, thus, created strategies of presenting social identity. In case of other people, ostomates concealed body and status. They would show only identity selected for indicating their illness to neighbor or others. On the contrary, they could express identity of person with stoma with their intimates or relatives. These strategies were to be as normal as others in order to protect themselves from stigmatization.

Personal body of ostomates also embodied ideas, getting from medical personnel, that how they should clean the body and wound. Society regulates cultural code concerning to cleanliness-dirtiness onto the body of ostomates by considering the ways they thought and acted when they cleaned the body after defecation. The code reflected social value about stool and the way of thinking about dirty and disgusting body. This is symbolic view according to the aspect of ostomates and their intimates.

In addition, the body of ostomates can reflect the control power of biomedicine for the whole process of treatment and becoming ostomates through relearning about defecation by stoma. Since this power used by those professions who are expertise in medicine, it is legitimate when it controls and gazes ostomates. Medical personnel can request ostomates to uncover the body as well as can touch and penetrate into ostomates' body. Also, they can make ostomates to discover personal information by asking the questions during giving treatment.

Experience embodiment of practicing on abdominal defecation

Defining ostomates is a symbolic view towards the body according to experience of having stoma as dirty and disgusting body. This is the social construction of reality that analyzes and interprets through symbolic structure in which the thought of people in society has controlled throughout socio-cultural history and medical cleanliness discourse. When ostomates perceived the world and society, they perceived the phenomena of consciousness, value, and worldview from touching and defining feces and stoma according to their perception. The feeling of their disgust at dirty body was existed by constructing the meaning of feces and stoma on the basis of ideas of individuals and others, including their personal consciousness that linked with what they thought and did during social interaction. Importantly, such consciousness should make sense based on the concept of *'karma'*. When uncleanness was linked with religion system and the world sacred, the distorted body was also stigmatized. Cleaning up "ritual uncleanness", therefore, needed "making a merit" as spiritual operation.

Nevertheless, the feeling towards dirtiness and revulsion at feces was not derived from understanding through perceiving that feces is relevant to stoma as well as not even from constructing historical and social meaning. It was actually occurred when ostomates experienced "touching" (by hands), "seeing" (by eyes), and "smelling" (by nose) and thought immediately that "feces was dirty and disgusting." At the time feces leaked from the pouch, the meaning of dirty could be constructed through sensory experience. In this regard, senses construction of dirty is beyond social, cultural, and symbolic construction in which, according to Douglas, feces and stoma are defined as dirty thing that out of place. So, the body we are living does not only has symbolic meanings, but also use for perceiving the world through sensory.

Even though I finally can answer the research questions, some unexplored facts are still in my mind. It is the life of a lay woman that I think about. The lady has lived with stoma for more than 30 years and can do all daily activities, including abdominal elimination. She did not get use to at the beginning, but she is now familiar with having that stoma. I may need to find out more by using other perspectives.

The Last Story

While I was on duty as a nurse in ostomy clinic, two ladies in different ages came to me. The old one was the mother, suppose that her name is "Grand ma Nuan". The other one was a middle age woman who was Grand ma Nuan's daughter.

Grand ma Nuan told me her story of last 30 years that she began to defecate with fresh blood after getting the sixth son. She thought that she got hemorrhoid and took many kinds of drug. Self care did not work and she became worst and worst. She was quite skinny and weak after having bloody feces 20 times a day for a long time. She did not go to hospital because she had to look after her children. After almost a year that she fed her children breast milk, she went to see doctor and was told that *"you need surgery! And you can live 5 years more"*. The surgeon's words were in her memory even today.

Other ostomates may use modern pouch that can cover both figure and smell. But, Grand ma Nuan used dry cotton piece to cover on the stoma after cleaning. She also covered the dry cotton again with a piece of cloth wrapping around abdomen in order to prevent the leak of feces.

> *"I always do like this. Cover with a piece of cotton. Use a lot of cotton rolls. Always have cotton rolls at home. I buy 4-5 rolls each time. I have closed it like this for more than 30 years… I can [go out]." Grand ma Nuan said.*

She was a lay woman living in Bangramad subdistrict, Bangkoknoi district in Bangkok with 6 children and husband. Her husband often got drunk and used to move to other woman after she got surgery. At that time, she stood on her legs by working as a boat driver. During she was working, if she had bowel movement, she had to go back home to remove the cloth and put a big piece of cotton to place under feces. After that she cleaned abdomen and stoma by using water and wet cotton. She then covered the stoma with dry cotton and wrapped abdomen with a piece of cloth as usual. If the cloth was dirty with feces, she would clean it with soap and water. It went the same everyday.

If she worked outside and sometime did not stay home at night, she usually took a laxative one day before hand. If she took it, she needed to use a chamber pot instead of absorbent cotton since feces was watery.

> *"I take a laxative. If it comes out, we can go everywhere, not dirty. When I take it, I can defecate and feel clear. The bowel will be smooth.. I can go out comfortably. I won't make dirtiness when I stay outside. When I go out and come back both are clean, not dirty at all. If we clean it, it will be clean*

> *and we can go out with cleanliness. If we don't clean it, it will be dirty. Other people will smell. I know when I will go out. I will take a laxative and I can go 2-3 day without feces".*

She always managed her self in this way. Until one day, she fainted and lost conscious. Her children took her to the hospital that I worked for. That time she just knew 'Ostomy Clinic' that she could get advice about stoma pouch. One of her daughter was a teacher in government school took her to get treatment here.

The first image I saw Grand ma Nuan was as that old lady. When she removed her shirt, I saw a gray cloth on her abdomen. I removed the cloth and saw a big piece of absorbent cotton. Under that cotton was clean and had no smell. I was surprised when I heard a story of abdominal elimination.

> *"…My children told me that it will be comfortable when I travel. "Mom do like this", they told me. If I get diarrhea, they will be shamed. So I use when I go with them…"*

Grand ma Nuan told about what made her to come to learn the use of stoma pouch on that day. The cause was her children's need. According to her voice explaining the reason to me, I interpreted that she disagreed with her children.

> *"If you wear this bag, feces will come in it. Would you accept that?"*

I asked Autn Nuan during giving advice and demonstrating the use of stoma pouch because I realized that Grand ma Nuan did not have feces on her stoma.

> *"I don't know, if I can't accept, I won't use it. If it bothers me too much, I am not going to use it. Although my daughter can refund, I don't want to have it. It sounds strange. I've never used, so I don't want to try."*

Grand ma Nuan answered me. She waited for her daughter for a while and left home.

Two months later, the answers of Grand ma Nuan were clearer when I called her niece. I was told that Grand ma Nuan used stoma pouch got from the hospital only 2 times. The first time was the day she tried at Ostomy Clinic of the hospital. The last time was the day she was dead since she could not do thing anymore.

The story of Grand ma Nuan pulls my thinking which had long been filled with the idea that "elimination of ostomates needs only ostomy bag". Grand ma Nuan make me know that having stoma can have other ways to manage. Moreover, ostomates have power as agency that are not passive or comply with knowledge of medical personnel without resistance and they have eliminated the suffering by themselves in daily life.

Discussions and recommendations

Although these stories are interpreted and presented by me since I got a chance to see and to participate in the situation of ostomates, I realize that medical personnel cause ostomates to be stigmatized so that make I have sympathy for those patients.

The stories of ostomates make me realize the meaning of body in the views other than being physical body. The body of ostomates is as the body of individuals that has creativity and symbolic meanings. It is also a social body that presents practices against medical power. Importantly, it is the body being in the world, which can perceive the fact that stool is dirty through sensory and historical, social, and cultural construction. Medical personnel should learn such important stories to be more sensitive towards cultural code and not express the feeling of being dirtiness and disgusted during social interaction with patients.

Therefore, I would like to call medical personnel to learn into the world of ostomates and illness experiences of other kinds of patient. Medical personnel should practice in realizing and hearing the suffering voices in which the patients reflect through language by speaking, gestures and toughing. These things are concerned as they are sensitive in symbolic view. There should be these guidelines added in training course for medical personnel in order to stimulate the professionals to realize humankind and value of life of people rather than medial treatment.

At last, I want to tell a little bit about the shortcomings of this work. I started at seeing the changes of ostomates, who admitted in the hospital for only 7 – 10 days. In my view as a professional, it is suffering. So, I focused on problems and sufferings associated with ostomy, while the voices of other sufferings were lost from this study. However, I learnt from doing this research that still there are many issues that should be explored in further researches, such as creativity in daily life other than medical knowledge or the feeling of touch resulting in sufferings that are similar to social and cultural construction.

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APPENDIX

APPENDIX A

INFORM CONSENT SHEET

My name is Miss Kanchana Rungsangjun, the master's degree student of the Faculty of Social Sciences and Humanities, Mahidol University. I am interested in doing a research on the topic "The lived experience of ostomates: the suffering of defecation". In this study, I would like to request…………………………………………………… and his/her relatives to participate in the study.

This research aims to study the lived experiences of the ostomates. Data will be collected by conversation, interview, and audio tape record that based on life history, life style, illness problem, and their experiences about stoma, meaning and management. Total time of data collection is about 45 minutes. I will make an appointment whenever you and your relatives set as you want. To do this is for relaxing yourself and familiarizing each other.

The thesis is expected to benefit the interviewee and other people according to uncover socio-cultural dimensions from the ostomate's experiences which are beneficial in healing stoma person's illness, and are the guidelines for taking care of other ostomates.

This study may be sensitive for your mind and your society. If you are involuntary, I will not collect your data. During data collection, I will not violate your privacy for any personal benefit or will not distort the findings.

This study is only the research of interview, conversation and audio tape record; it is not an intervention or a treatment or a diagnosis.

You can participate in this study as well as you have the right to withdrawn at anytime without prejudice to you. Your answer is not assessed for its true or wrong.

The data will be concealed and I will use 'assumed name' for reporting and publishing the study. The findings will be used and concluded for an educational result only.

CONSENT FORM

Title of project: THE LIVED EXPERIENCE OF OSTOMATES: THE SUFFERING OF DEFECATION

Approval date: date .... month ....year.................

Before signing on this consent form, I am explained by the researcher about the purposes, methods and benefits of this research. I understand all clearly.

The researcher reassures me that if I have any question, I will be answered without concealment until I am completely satisfied.

I have the right to withdrawn from the project at any time without getting effects. I voluntarily participate in this project. If I am involuntary, the withdrawal will not affect any medical care that I supposed to be provided.

The researcher reassures me that the information can be published only after the permission and can be discovered only in the form of research with academic reason. If there is any more information that may affect the research, I will be informed without concealment.

I have already red and understood all mentioned above. I am willing to sign this consent form.

Signature ……………………………..interviewee
Signature …………………………………witness
Signature …………………………………witness

In case of illiterates, they must give consent with full consciousness and state that “I cannot read but the research has red this consent form for me and I totally understood. I am willing to sign or put the finger print of right thumb in this consent form.

Signature ……………………………..interviewee
Signature …………………………………witness
Signature …………………………………witness

APPENDIX B

INTERVIEW GUIDLINE

1. Question guidelines on life history: To ask about general information, such as age, sex, marital status, income and occupation. Request the interviewee to tell his/her life to reflect their experiences.

2. Question guidelines on experiences, ideas and feelings towards the body with stoma

2.1 Did you remember the first day after the surgery? How did you feel and what did you think about it? Who did you stay with?

2.2 After the surgery, is there any 'story' that you can remember? Could you tell me, please! Which story is the clearest?

2.3 Apart from these stories, do you have one more 'good story' that you want to tell me?

2.4 According to the story you told me, can you remember where did the story happen? Who did you participate with and what were their reactions?

3. Question guidelines on meaning construction of the body, self and identity that links his/her lived experiences

3.1 When you look in the mirror, could you tell me what you see! How do you feel about yourself in the mirror? In your opinion, how do people think if they see you?

3.2 Do you remember the first time you saw the stoma, what was it in you mind? How did you feel about it?

3.3 If it's necessary to tell others about your illness, will you tell them? How will you tell them indirectly? Do you have any good thing to tell others instead of telling them your illness?

3.4 Do people know about you that who you are and what you do? Do you think they change their attitudes after they know about your illness?

3.5 After you have the stoma for 1-2 year, do you and people have different attitudes/feelings about yourself, and how?

3.6 Do you think children, elder, and younger have different attitudes/feelings? Please describe your answer!

3.7 When you hear someone talks about 'stoma', do you know what it is? How do you call 'stoma'? What do you think when you talk about 'stoma'?

3.8 How important does the stoma mean for you? What will you be if you do not have it since it helps your bowel movement?

3.9 Have there been anyone see your stoma? Why did you allow them to see? What did they think?

3.10 What do you think and how do you feel about the feces on abdomen? What do you respond?

3.11 How are 'feces, cleanliness and dirtiness' related from one to another? Do they associate with you? How do you clean it and how do you feel after cleaning?

3.12 How do you feel when you heard about 'throwing feces', like when people threw feces to politicians or T.V. actors? What do you think that they are the reasons and feelings of doing so?

3.13 How could you know that the feces leak? Do you smell, see, touch or do something else?

4. Guideline of questions about experience absorption and coping with problems of ostomates

4.1 How do you feel when you care stoma? Do you think you can take care of others' stoma, if it needs?

4.2 After the surgery, do you have any problem about stoma care? How did you experience?

4.3 How did you manage the problems? Who could help you?

4.4 How to make people understand ostomates?

4.5 Before the surgery, how did you eliminate?

4.6 When you have stoma, how do you eliminate? When do you change the bag and how? Who can help you if you can't change it by yourself? How do they change?

4.7 How does abdominal defecation affect your gesture, dressing and elimination's practice? Do you realize that changes? If you do, how dose the change process? How do you learn that?

BIOGRAPHY

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